



ACROMEGALY
community

Voice of the Patient: *Living with Acromegaly*

Report from the Acromegaly Virtual Externally-Led Patient-Focused Drug Development Meeting

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Voice of the Patient Report: *Living with Acromegaly*

Acromegaly Community, Inc., is a patient advocacy organization representing those who care for, suffer from, or are at risk of Acromegaly. This Voice of the Patient report was prepared by Acromegaly Community, Inc. as a summary of the input shared by patients living with Acromegaly during an Externally-Led Patient Focused Drug Development Meeting (EL-PFDD). This meeting was hosted virtually on January 21, 2021.

Authors and Collaborators

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Introduction

In recognition that Acromegaly patients and caregivers are the experts on their disease, Acromegaly Community, Inc. conducted an Externally Led Patient Focused Drug Development (EL-PFDD) meeting on January 21, 2021. The purpose of the meeting was to hear directly from individuals living with Acromegaly and their caregivers about their lived experience of Acromegaly symptoms and subsequent daily impacts, their experiences with available treatments and outcomes, and to hear their preferences for future therapies. We shared these perspectives directly with the FDA, academic investigators, clinicians, healthcare providers, industry partners and medical product developers.

This EL-PFDD meeting was modeled after the work of the U.S. Food and Drug Administration (FDA) Patient-Focused Drug Development (PFDD) initiative. While this meeting was held virtually for participant's health and safety due to the COVID-19 pandemic, the virtual platform allowed increased participation across the United States and the world. The information gathered at the meeting is presented in this Voice of the Patient report. It will inform and impact decisions regarding the development and review of drugs to ultimately catalyze significant improvements for the health and quality of life for those living with Acromegaly.

Acromegaly Overview¹

Acromegaly is a chronic and rare disease that varies by severity, age of onset, and gender. Globally, three or four new cases per million per year were reported in the 1980s and 1990s, but this is likely closer to ten new cases per million per year.^{2,3} Although an estimated 25,000 individuals are currently living with Acromegaly in the U.S., many more patients remain undiagnosed.³

The primary cause of Acromegaly is the growth of a benign tumor in the pituitary gland, called an adenoma, which produces excess growth hormone (GH). The excess GH stimulates the production of insulin growth factor 1 (IGF-1), mostly from the liver. The high levels of circulating GH and IGF-1 act dependently and independently, manifesting in increased somatic growth and metabolic dysfunction throughout the body.

Individuals living with Acromegaly experience a wide range of physical symptoms. This can include changes to their appearance including a coarsening of the features which include bone growth in the jaw and forehead, soft tissue growth including enlarged nose and lips, widely spaced teeth and enlarged hands and feet. Individuals with Acromegaly often experience painful arthritis requiring multiple joint replacements, fatigue, headaches, excessive sweating, sleep apnea and snoring, vision loss, carpal tunnel syndrome, spinal cord compression and respiratory complications. Acromegaly impacts mood, causing depression, anxiety, and excessive anger. Also, the growth of the pituitary tumor can compress normal pituitary tissues,

¹ Modified version of Drs Melmed and Harris's presentations.

² Acromegaly. *Nat Rev Dis Primers*. 2019 Mar 21;5(1):21. doi: 10.1038/s41572-019-0076-1. PMID: 30899021.

³ Broder MS, Chang E, Cherepanov D, Neary MP, Ludlam WH. INCIDENCE AND PREVALENCE OF ACROMEGALY IN THE UNITED STATES: A CLAIMS-BASED ANALYSIS. *Endocr Pract*. 2016 Nov;22(11):1327-1335. doi: 10.4158/EP161397.OR. Epub 2016 Aug 19. PMID: 27540880.

altering the production of other hormones leading to gonadal dysfunction and other secondary effects. Because of these symptoms, individuals living with Acromegaly experience negative quality of life impacts in addition to suffering from the psychological impacts of the disease on an individual's self-image.⁴

Due to long diagnostic delays and the impact of chronic, slow high levels of GH and IGF-1 exposure, most patients already exhibit advanced disease at the time of diagnosis. The persistent high hormone levels lead to hypertension, cardiomyopathy, valve disease and diabetes mellitus. These comorbidities can become life threatening, resulting in premature morbidity and poor quality of life for the patients, decreased productivity, and increased costs of medical care. Most of the excess mortality is due to cerebrovascular dysfunction, especially heart failure and hypertension.

Once diagnosed, individuals living with Acromegaly face life-long treatment regimens. Acromegaly is managed through the normalization of GH and IGF-1 levels. Current Acromegaly treatment strategies feature an integrated, multi-modal approach of surgery, radiation, and medical therapies. For most patients, the first treatment is transsphenoidal surgery to remove the tumor from the pituitary gland located at the base of the brain. For many patients, surgery is not curative and may require additional surgery to resect residual or regrowing tumor. For patients with disease activity after surgery, medical therapies include: first- and second-generation somatostatin analogs (octreotide acetate [Sandostatin], lanreotide [Somatuline] and pasireotide [Signifor LAR]); GH receptor antagonists (pegvisomant [Somavert]); dopamine agonists (bromocriptine mesylate [Parlodel] and cabergoline [Dostinex]). Radiotherapy is generally regarded as optional after surgery and medical treatments but can sometimes shrink large tumors before surgery. Several methods including gamma knife are used to administer radiation to the tumor. Each treatment option has benefits and can reduce the long-term disease-related complications, but all treatments have limitations and potential risks.

The therapeutic effectiveness of these interventions is evaluated by measuring whether GH and IGF-1 levels are within normal range. Unfortunately, the biochemical levels of hormones do not necessarily correlate with clinical burden and Acromegaly symptoms often persist despite "normal" levels of GH and IGF-1. Most patients continue to experience persistent, debilitating symptoms of the disease described by the patient community as "breakthrough" and "wear-off" symptoms, which profoundly impact quality of life.

In addition to the surgery, medical therapy and radiation approaches described, aggressive interventions are needed to manage Acromegaly symptoms and comorbidities. These include the treatment of very severe headaches by endocrinologists, aggressive therapy for joint pain, arthritis, and spinal fractures that may occur, diagnosis and treatment of sleep apnea and diabetes control. Reproductive and sexual concerns need to be addressed. Maxillofacial surgery can be used to improve jaw overbite and improve cosmetic self-image if appropriate.

⁴ Fleseriu, M., Fogelfeld, L., Gordon, M.B. *et al.* An evaluation of the Acromegaly Treatment Satisfaction Questionnaire (Acro-TSQ) in adult patients with acromegaly, including correlations with other patient-reported outcome measures: data from two large multicenter international studies. *Pituitary* **23**, 347–358 (2020). <https://doi.org/10.1007/s11102-020-01038-y>

Hypertension is sometimes extremely resistant in these patients and needs to be treated aggressively to prevent further complications such as heart failure or stroke. Endocrine replacement may be necessary for pituitary hormones which may be deficient because of the expanding, compressing pituitary mass. The aggressive approach to addressing comorbidities can reduce mortality, enable patients to return to work, and enhance their quality of life.

Meeting Overview

The January 21st meeting was attended by 304 registered attendees, including 128 individuals living with Acromegaly and their family members, caregivers and friends, industry members, representatives from advocacy groups, scientists, healthcare providers and FDA representatives. Online polling was used to determine demographics, specifically of the meeting attendees living with Acromegaly: 79% of respondents were from the continental US, 74% were female and 92% were over 30. While 35% of respondents experienced their first Acromegaly symptoms between the ages of 19-30 years respondents, just over half (51%) reported experiencing their first symptoms between 31- 50 years. The age of Acromegaly diagnosis was older, with only 16% of respondents diagnosed between the ages of 19- 30 years, 56% diagnosed with Acromegaly between 31- 50 years, and 34% diagnosed between 51-60 years. The full demographic polling data is in **Appendix 1**. The virtual format enabled increased participation, promoted interactive conversations, and allowed moderators to ask in-depth questions as the conversation unfolded. According to the Acromegaly Community Inc. YouTube statistics, the meeting has been streamed 948 times (as of October 20, 2021).

The January 21, 2021 meeting was structured around two main topics. The morning session was structured around Topic 1, *Living with Acromegaly: Symptoms and Daily Impacts*, and aimed to explore the patient and caregiver experience of living with Acromegaly, the symptoms that are most significant to individuals living with Acromegaly and the impact that these symptoms have on their daily lives. The afternoon session addressed Topic 2, *Perspectives on Current and Future Approaches to Treatment*, and explored the most important treatments and modalities used to manage Acromegaly, treatment trade-offs and effectiveness and preferences for future treatments. The meeting agenda is in **Appendix 2**, and the questions provided for meeting discussion are in **Appendix 3**.

The meeting was opened by Jill Sisco, President of Acromegaly Community, Inc., who welcomed and thanked all attendees for their participation. Dr. Theresa Kehoe, the Director of the Division of General Endocrinology with the FDA Center for Drug Evaluation and Research, welcomed meeting participants and defined the FDA's role in facilitating the development of safe and effective medical products for Acromegaly. Dr. Shlomo Melmed, MD, MB Cedars-Sinai Medical, who has made major contributions to understanding pituitary disease, provided a clinical overview of the biology of Acromegaly.

To initiate discussion, participants listened to pre-recorded panel sessions. In the morning session, five patients shared their experiences regarding the symptoms of Acromegaly, the impacts that these symptoms have had on their daily life, and their fears and worries of living

with the disease. Patients described their long diagnostic journeys and shared their struggles with Acromegaly symptoms. To broaden the discussion, all patients living with Acromegaly and caregivers were invited to respond to online polling, call in by phone to speak live, or to submit written comments through the online portal. James Valentine moderated a discussion between several community members who served on a live zoom panel, patients who dialed in by phone, with additional relevant comments read by Larry Bauer. The first names of patients and caregivers who served on panels or were online callers are listed in **Appendix 4**.

The afternoon session opened with a presentation on the current and future treatments for Acromegaly, by Dr. Alan Harris, MD, PhD, NYU-Langone Medical Centre, an endocrinologist and physician scientist who led the development of octreotide. A live zoom panel of five patients living with Acromegaly and caregivers described the different medical interventions they used to treat their disease and other approaches they used for symptom management. Patients described lengthy treatment journeys, treatment successes as well as the many challenges of unmet treatment needs. Again, all patients living with Acromegaly and their caregivers were encouraged to respond to online polling, call in by phone to speak live, submit written comments through the online portal, and their voices were added to the moderated discussion by James Valentine and Larry Bauer. The meeting concluded with a summary of the key meeting points by Larry Bauer and was closed by Jill Sisco of Acromegaly Community Inc, who thanked all the participants and attendees.

A recording of this meeting can be found at: <https://www.acromegalycommunity.org/events>. Meeting-related information are in the Appendices, including Topics 1 and 2 polling results (**Appendices 5** and **6**, respectively). To include as many voices from the community as possible, an online comment submission form was open for 30 days before and after the meeting. A total of 145 comments from 104 unique individuals were submitted and are included in **Appendix 7**, edited slightly for grammar, spelling, and punctuation. The online comments represented a spectrum of Acromegaly experiences and reflected the experiences and perspectives shared at the January 2021 meeting.

Report Overview and Key Themes

Acromegaly Community Inc. has provided this report to the FDA, and it is publicly available for the many stakeholders in the Acromegaly disease community, including governmental agencies, regulatory agencies, medical product developers, researchers, and healthcare professionals. This report provides a high-level summary of the perspectives generously shared by patients living with Acromegaly and caregivers who participated in the January 21st, 2021 meeting, and includes the comments submitted through the online portal.

The input received from the January meeting reflects a range of experiences with, and perspectives on Acromegaly and Acromegaly management approaches. Participants at this meeting may not fully represent the overall population of individuals living with Acromegaly and there may be symptoms, impacts, treatments, or other aspects of Acromegaly that are not

included in this document. The terms used in this report to describe specific symptoms and treatment experiences reflect the words and language used by meeting participants during the meeting and in submitted comments. The patient quotes that appear in this report were selected to represent the common experiences of many individuals with Acromegaly, as well as some of the less common symptoms and experiences. All quotes in this report are attributed to patients living with Acromegaly unless otherwise indicated.

This report intends to identify themes that emerged directly from individuals with Acromegaly and their caregivers to create a better understanding of (a) the symptoms and burdens of Acromegaly in daily life, both the common experiences in addition to the heterogeneity that exists in this disease, and (b) the challenges and trade-offs in selecting an appropriate treatment which highlights a massive unmet medical need for effective treatments for people living with Acromegaly.

Key themes that emerged from the January 21, 2021 Acromegaly meeting.

- 1. Due to the profound mismatch between biological control determined based on GH and IGF-1 measurements and symptom control, individuals with Acromegaly live with a high disease burden despite optimal disease management.** Meeting participants with Acromegaly experience a high number of significant symptoms affecting many body systems. The symptoms with the most impact were fatigue, arthritis and joint pain, anxiety and depression, and headaches. The disease is heterogeneous, and not every patient living with Acromegaly experiences the same symptoms.
- 2. Uncontrolled Acromegaly symptoms negatively affect all activities of daily living and quality of life.** Patients living with Acromegaly described damaged relationships, loss of self, isolation, loneliness, missed opportunities, unfulfilled potential, discontinued careers, disappointment, the loss of activities and hobbies, and poor quality of life. Acromegaly has almost a progressive nature, and many patients fear that their tumors will regrow and their symptoms will return or intensify.
- 3. Most patients living with Acromegaly are diagnosed many years after first experiencing symptoms, increasing the potential for adverse outcomes.** Patients described how they were misdiagnosed, their symptoms misattributed to other causes, or their symptoms and suffering simply dismissed. A delayed Acromegaly diagnosis means that cumulative, persistently high levels of GH and IGF-1 irreversibly damage bones and other tissues in the body. A challenge is that many medical professionals, even specialists do not know much about the disease.
- 4. Patients living with Acromegaly described lengthy and complicated treatment journeys and many unmet treatment needs.** Despite extraordinary treatment efforts, most patients living with Acromegaly reported that their disease symptoms were not effectively controlled even with the multimodal and combination therapies currently available. For some, Acromegaly treatments addressed only a limited number of their symptoms,

breakthrough symptoms were common, and many reported that their treatments stopped working after a period of time. Many patients reported that their therapies included side effects that were hard to distinguish from Acromegaly disease symptoms.

5. Patients living with Acromegaly identified priorities that were important to them.

● **Therapeutic Priorities**

- For future drug therapy priorities, patients living with Acromegaly selected treatments for fatigue/muscle weakness, joint problems, and arthritis and biochemical/IGF control as their top polling responses.
- During meeting discussion, patients requested treatment to shrink or control tumor growth, therapies that restore or preserve pituitary function, and therapies to address hunger and weight gain. They also requested improvements in medication efficacy and administration.
- Patients requested a lowering of the recommended GH/IGF-1 ranges, hormone monitors to evaluate IGF-1 and GH in real time, drug implants for consistent delivery.

● **Research Priorities.** Patients living with Acromegaly asked for more research into the root cause of their disease itself, and more research into symptoms.

- Research to understand the contribution of ghrelin.
- More information is needed about how Acromegaly affects fertility and the health of the unborn child and the safety and efficacy of Acromegaly medications during pregnancy and breastfeeding.
- Patients recommended establishing a patient registry or a national data base of information.

● **Education & Resource priorities with a focus on earlier diagnosis.** Patients living with Acromegaly recommend education initiatives aimed at greater disease awareness and ultimately earlier disease diagnosis.

- More public awareness is required so that patients recognize their own symptoms and there is more understanding and support for patients living with Acromegaly.
- Acromegaly needs to be more widely covered in the medical school curriculums.
- Additional resources needed for patients with Acromegaly include education resources, mental health resources, and supportive therapies; information and support for patients with Gigantism, especially when transitioning from childhood to adolescence to adult care.

Topic 1: Patient Perspectives on Acromegaly Symptoms and Daily Impacts

Acromegaly patients experience a broad range of disease symptoms, often severe. During the meeting, patients with Acromegaly used online polling to first select all the Acromegaly-related health concerns they currently experience and then chose the top three most troublesome Acromegaly-related health concerns. Fatigue/muscle weakness and joint problems/arthritis were the most frequently experienced and the most troublesome health concerns. The polling results are in **Appendix 5, Q1 & Q2** and summarized below. The symptoms are described with comments from the meeting panelists, moderated discussion and submitted online.

Joint problems/arthritis

Ninety percent of poll respondents reported experiencing joint problems/arthritis and 65% reported this as their most troublesome Acromegaly-related health concern. Many individuals described how arthritis affects their entire body, impacting mobility and some individuals reported joint-related issues including, locking joints, carpal tunnel syndrome and de Quervain's tenosynovitis. One patient described, *"As a result of excess bone growth due to Acromegaly, I have osteoarthritis in my spine, hips, hands, knees, and shoulders. The arthritis means I have chronic pain and limited mobility. ...Now when I move, my joints feel stiff, and they crackle and I have pain even while sitting still."*

Joint issues/arthritis are accompanied by constant pain. A panelist described his pain: *"because I went many years with very high levels of growth hormone untreated, I've developed chronic pain. I have pain in my hands. There is a constant aching and sharp pain all day long that makes doing everything with my hands difficult and painful. ...In my back, I have multiple crushed, compressed, and bulging discs, and this makes things such as sitting, laying down and standing, painful. Even the most basic activities can cause intense pain such as walking, sitting, laying down, bending over and lifting light items. I also have a hard time sleeping and end up waking in pain, ... I toss and turn all night while trying to shift my pain from one side to the other."*

Many participants required multiple joint replacements because of arthritis. One panelist who *"underwent [a] total hip replacement at the age of 46"*, described how she *"was in constant excruciating pain, and used a cane for almost two years in order to walk because, 'The cartilage was completely worn out like that of a 90-year-old,' the doctor said."* Another panelist described how *"both with my cervical and my back, my whole spine has had multiple surgeries. So, I'm fused front and back in different areas. And that was [due to] deterioration of my bones and I have bad knees and bad shoulders."* A caller added, *"I'm 50 years old, so okay, but I've had now five joint replacements. I don't have a lot of joints left to replace and the pain that I have sometimes the mobility issues that I have, it can be unbearable."*

Fatigue/muscle weakness

Fatigue/muscle weakness was reported by 92% of attendees/participants and was selected by 63% of attendees as one of their top three most troublesome Acromegaly-related health concerns.

A patient described her fatigue, *“The most significant symptom I experience is extreme fatigue. Normal activities like just walking to the car to go somewhere or from the shower to my bedroom can exhaust [me and take me] 10-15 minutes to recover from. ... I was so bad at one point my family was scared to let me drive.”* One panelist described how her unexplainable fatigue *“feels like a perpetual hangover.”* One said she was *“overwhelmed with fatigue to a point of major, major, major depression.”* Another patient said, *“I couldn't make it through the day without having a nap in the middle of the day. You can't even understand what it's like. When you have excess growth hormone, every single cell in your body is working harder than what it needs to.”*

Many participants described the unpredictability of fatigue. One patient asked, *“What's next? ... Every day is an unknown. I may wake up fine, energetic, and two hours later it's changed. I'm down to zero again. ...You don't know what's coming.”* Another patient described her fatigue, *“It's transient. And so sometimes you feel good, sometimes you don't, so you have to limit your time. Sometimes you have four hours and it varies, it's just not ideal especially for a work environment. ...So, that fatigue is a problem.”* Another said, *“I never know what to expect. What I don't do is, I don't try and anticipate good or bad. I just try and live in the moment and not let it get to me because I can't.”*

Some participants specifically described muscle weakness. One panelist described how his *“grip is weak, so writing, typing and doing anything that requires precision is difficult and causes frustration.”* Another said that *“despite always having a healthy and physically active lifestyle”,* her *“legs could not handle the pressure because of [an] unexplainable heavy sensation that caused weakness and tightness around my tendons.”* Another patient reported the *“weakness and numbness of my extremities due to prolonged undiagnosed Acromegaly.”* Finally, another said, *“My leg strength continues to be weak and therefore I cannot do activities I used to enjoy. I no longer can go in the ocean without help because my legs are weak.”*

Anxiety/depression

Anxiety/depression is experienced by 75% of participants and was selected by 33% of participants as one of their top three concerns yet many felt this symptom is often dismissed.

“I'm sure the depression comes from seeing my face and body change and not understanding why I looked and felt so different than my peers”, stated one patient. *“Depression and anxiety are two very real and commonly overlooked symptoms of Acromegaly,”* stated a panelist, who added that *“because the disease is so rare, it's hard to find people who truly understand what I deal with, which leads to feelings of isolation.”* A patient who spent most of her professional life working in psychiatric healthcare administration stated: *“I realized early on that there was a paucity of information regarding the psychological impact of having Acromegaly. There are mentions of depression or quality of life issues but nothing substantive. For me, living with Acromegaly isn't just about the path to recovery from the medical complications caused by the disorder; it's also about surviving the accompanying emotional turbulence that one may*

weather. Despair, depression, grief, anxiety and impaired quality of life issues are not uncommon."

In addition to depression and anxiety, many patients reported mood swings and panic attacks. One panelist described how her aching body felt old, but how *"my emotions make me feel like I'm a perpetual teenager, like I'm riding a rollercoaster of hormones. I become frustrated, angry, hopeless, or full of tears easily and I would generally describe myself as emotionally volatile."* A caregiver described these mood swings as *"horrible, and that's really the only word I can think of. One minute they're happy-go-lucky, and the next minute yelling at everybody, unhappy, depressed, don't answer you. ... I know it's a rough road for them, but it's a rough road for the caregiver as well."* One panelist described his severe panic attacks: *"For years, I dealt with depression and horrible, horrible panic attacks. I would have sometimes up to 12 panic attacks a day. And for anyone who's experienced those they're very debilitating and it's makes it a lot more difficult to function in life."*

Many patients described experiencing "acrorage", or episodes of anger. For one patient, *"I do feel very angry. The anger is not warranted and there does not seem to be a cause for it... Anger is quick and easy to come."* Another agreed: *"Growth hormone unfortunately can make us very quick to anger. And I always try to be cognizant of it, but I truly do not feel like it isn't entirely our fault."* A caregiver reported what she and other caregivers' experienced, *"it's rage, it's really frightening rage ... And the rage is uncontrolled."*

Patients identified a need for mental health support and resources for Acromegaly patients and family members. *"There's a big mental health component to Acromegaly that needs to be acknowledged. ... I desperately would have needed access to mental health resources, but no one thought about providing those to me."* One panelist described his struggles with mental health, *"While I struggle with daily pain and fatigue, the most difficult thing I have to deal with is the mental health side of this disease. When I had my first tumor resection surgery, I did well for a while. ... Then four years after my first surgery, I started to feel my symptoms return. As things got worse, my mental health was starting to suffer."* Another patient said that, *"As a mental health professional, and a person with Acromegaly, mental health issues are at the forefront of my mind. What is being done to address the mental health needs, challenges, and problems of the Acromegaly community?"* One participant confided that she had suicidal thoughts.

Headaches

Headaches are experienced by 62% of participants and were reported as one of the top 3 most troubling Acromegaly health related health concerns by 28% of respondents. Meeting participants often described their headaches as permanent and debilitating, and it was a symptom that seemed particularly resistant to treatment. *"You can't imagine what it's like waking up in the morning with a debilitating headache"*, said one patient. Another described how she has had a headache for the last 19 years, which peaks several times a day. *"The headache never goes away completely,"* even though she uses medication which manages to

bring the pain back to level 3 or 4 on a scale of 1-10. Another patient described hers as “24-hour, 30-day headaches” which “affected her quality of life”.

Several participants described different types of headaches. One panelist reported how “differentiating a high blood pressure headache from the acromegalic type of headache, it's two different experiences.” Another individual experiences regular visual migraines as well as a “‘severe complex migraine’ that temporarily and intermittently paralyzed the right side of my body and left me unable to speak”. Finally, one patient said, “Even with treatment, my debilitating headaches are still persistent because of unrelenting, nasal congestion and forehead pain.”

Enlarged hands or feet

Eighty-nine percent of participants experience enlarged hands or feet, and this was selected as one of the top three health concerns by 17% of the participants. One patient described how “one of the earliest symptoms that was the tips of my fingers enlarging and the nails curving around my fingertips, which was very disfiguring. As the years went by, my hands grew bigger and by 2007, I couldn't fit into my wedding ring.” Many described how their feet and shoe sizes grew. For one caller, “I couldn't really just go to any shoe store anymore, because my foot was getting large and wide.” For another, “my shoe size went from an eight and a half to a nine and a half wide between onset and diagnosis. After treatment, my feet shrank to nine wide because of the reduction in soft tissue swelling but the bone growth is permanent.”

Soft tissue swelling

Soft tissue swelling is a health concern experienced by 73% of meeting participants and was selected as one of the top three Acromegaly-related health concerns by 20% of poll respondents. One panelist described how she “suffered from ... painful soft tissue swelling on my hands and my feet, especially [when] it is time for the monthly injection.” Another described the pain caused from her inflamed sinuses, and one patient said, “if I need to walk for an extended amount of time, my feet swell and become unbearable to walk on.” Soft tissue swelling is not confined just to hands and feet. One patient commented after his emergency surgery for a serious bowel obstruction, “the doctor mentioned all my organs were enlarged, including my heart.” This patient suspects that Acromegaly had a role in the bowel obstruction, even though his bowel obstruction was due to a congenital birth defect.

Vision problems

One third (37%) of participants with Acromegaly experience vision problems and was selected as a top health concern for 9% of participants. Throughout the meeting, many patients living with Acromegaly described vision loss. For a few, the loss of peripheral vision was one of their first Acromegaly symptoms: “I was diagnosed because I was going blind in my peripheral vision from the pituitary tumor pressing on my optic nerve. I'm extremely lucky that after surgery, my vision recovered.” Another patient described how she was unaware of her tunnel vision until she nearly caused an accident, and now her “right eye is blind. This blindness affects my depth perception and visual field.” For several, vision loss was traumatic: “I'm now permanently blind in that eye as well, because the tumor grew around the optic nerve”. Another described the shock of “gradually losing my vision three months before the surgery”.

Excessive sweating/body odor

Half (48%) of poll respondents experience excessive sweating/body odor and was identified as a top Acromegaly-related health concern by 4% of respondents. This was another symptom that patients said was often dismissed. For one patient, *“excessive perspiration... affects me every single day and is more debilitating than I had ever imagined. It makes it hard to do any physical activity, even light exercise like walking a few blocks. I have to change my clothes all the time and sometimes shower multiple times per day. Even emotions make me sweat. I wake up every night because of sweating. It’s exhausting and embarrassing. It doesn’t seem to matter what my IGF is, it has never gotten any better.”* A panelist added that *“the staining of all my bed linen, clothing, and all furniture I frequent due to the oily skin from the disease is embarrassing.”*

Sleep apnea

Almost half (44%) of participants experience sleep apnea and 11% described it as one of their top Acromegaly-related health concerns. A few reported in the online comments about how their sleep apnea persisted even after treatment, including one patient who said, *“The symptoms that affect me the most now eleven years after what is considered a surgical cure are sleep apnea, chronic hand pain and joint pain.”* For another, *“insomnia was one of my initial symptoms and even though I feel I sleep ‘well,’ I haven’t felt rested in perhaps years. Someone under 30 shouldn’t need to sleep >12 hours a day and yet be as exhaustingly tired as I currently am.”*

Dizziness/vertigo

Almost half (45%) of participants experience dizziness/vertigo and although it was selected as a top health concern by 6% of participants, no specific comments were made during the meeting.

Type 2 diabetes

A fifth (20%) of participants have type 2 diabetes and this was selected as a top Acromegaly-related health concern by 11% of participants. For a few patients, their diabetes led to their Acromegaly diagnosis: *“I was diagnosed with Acromegaly in 2010 by accident when I went into the hospital with a blood sugar of 825 for diabetes.”* For one caller: *“My main symptom that led me to a diagnosis of Acromegaly was the development of type two diabetes. And I was fortunate enough to be sent to an endocrinologist who then discovered I had Acromegaly.”* For other patients, diabetes is a treatment side effect: *“my diabetes, which started a year after my surgery, is a challenge despite the fact that I am taking more and more insulin. It seems that this deterioration is occurring more quickly than that seen in the general population, and general practitioners take too long to recognize / accept that fact.”*

Cardiomyopathy/heart problems

One fifth (18%) of respondents experience cardiomyopathy/heart problems and this was selected as one of the top three health concerns by 5% of participants. One panelist described how *“the enlargement of the heart and the extremely difficult-to-manage high blood pressure - has been one particular area - that as you live with this disease and as you age, it is one of the consequences that we’re all having to deal with.”* Another described that one of the *“symptoms*

that have the most significant impact on my life are an enlarged heart valve.” Many panelists described experiencing cardiac issues including bradycardia, racing or slow heart rate, heart murmurs, irregular heartbeat, heart palpitations, carotid artery disease.

Respiratory problems

One quarter (24%) of participants experience respiratory problems, and 4% of participants selected this as one of their top three health concerns. One panelist described how her respiratory issues were related to the growth of her rib cage, which *“had also gotten quite thick and large. This bone growth has significantly reduced my lung capacity, making it impossible to play long, beautiful phrases”* on her clarinet. Another patient described how: *“I have a large number of lung nodules and a barrel chest. Even though my oxygen saturation is ok, I feel like I can not get a full breath on any given day despite the level of activity.”*

Reproductive system issues (infertility, sexual dysfunction, uterine fibroids, hysterectomy)

Almost a third (30%) of participants experience reproductive system issues yet these were not selected as a top health concern. Several meeting participants discussed challenges with infertility. One caller described how her infertility was attributed to her Acromegaly, yet *“I found out I was about four to six weeks pregnant one day before my scheduled surgery. Doctors were shocked as well as I.”* After a first successful pregnancy, she is now pregnant with a second child and noted that for her, *“while I’m pregnant, I do feel a lot better than normally with Acromegaly symptoms.”* While another patient said, *“when I was pregnant, I had never felt better. After delivery of my first [child] my symptoms came back fiercely,”* not all patients had the same experience. Another patient said, *“I have two children and with each pregnancy I had to stop treatment. Those were the worst months of life. The pain and headaches were so bad I had to stop working.”*

Information is lacking for how to treat Acromegaly during pregnancy. One described that, due to *“the risk of the tumor growing while I was pregnant, my doctor and I made the decision to go back on the lowest dose of octreotide during my second and third semesters [and while breastfeeding]”*. Her son is in perfect health, yet for her, *“My own health suffered, however, from not being on the optimal level of medication for over two years. I also had to make the heartbreaking decision not to have a second child.”* She made this decision because of insufficient information on medication and pregnancy, and because she *“needed to get my acro under control to be an active parent to my son.”*

Many important Acromegaly health concerns were not reflected in the polling.

Half (48%) of poll respondents experience other Acromegaly-related health concerns and for 19% of respondents, these other symptoms were their top three most troublesome. Some of the most frequently mentioned symptoms are described below.

Chronic pain

Pain was not a response option in the polls but was described by most panelists, callers and was frequently mentioned in the online comments. *“Widespread muscle pain is one of the most common symptoms of Acromegaly. ...For those of us with active disease or Acromegaly in remission we can all testify to the at times debilitating muscle pain we encounter. Pain which*

things like nerve meds and pain meds don't seem to help in the slightest.” One panelist vividly described how each day starts with pain: “My day starts in throbbing slow motion. It is even difficult to just hop into a shower or bath. When I wake up, my bloated and constipated stomach sends a painful sensation to my anal fissure. At the same time, a heavy and cramp-like sensation encases my feet - knee down - causing inflammation both on my feet. ... It is an agony to put on shoes or walk in them all day. So, on a pain scale of 1 (dull) to 5 (sharp), a day in my shoes can be described as 1: muscle pain, upper and lower legs. 2: joint pain, right shoulder, knees and feet. 3. digestive disorders, bloated and constipation. 4: headaches and sinus pain and 5: anal fissures.” One patient described how her Acromegaly pain was so severe that it masked her pancreatitis that was left untreated until after significant damage was done. “I would discount [the pain] because ... I always have pain in my back. And so [physicians] wouldn't go any further into it...so the damage was getting worse in my pancreas until it ended up being chronic pancreatitis and unrepairable stuff.”

Bone growth leading to changes in facial appearance, jaws and teeth and bone disorders

Individuals with Acromegaly experience irreversible growth of the lower jaw which leads to drastic changes in appearance.

One patient described how *“The changes in appearance and other health obstacles made me withdraw from everyday life. One cannot understand what it is like to look into the mirror and not recognize the person staring back until it happens to you.”* Surgery can be an option or a necessity: *“Being self-conscious of my facial features, I had plastic surgery to reduce a prominent jaw. I do not rule out undergoing other procedures to help me look and feel better.”* For another panelist, *“high growth hormone levels ... caused major changes in my jaws and my teeth. My lower jaw has moved forward so much that I will require surgery just so I can chew properly. The growth has also caused spaces in my teeth that will require expensive braces, bridges, and other oral surgeries.”* Several other patients described loose dentures and other dental issues.

High GH and IGF-1 levels contribute to other bone changes. One patient living with Acromegaly described how *“I'm always breaking ribs. My rib cage is highly visible. Regardless, if I fall, lean over something, lay on my stomach, or while exercising, my ribs crack.”* One described the impact of bone spurs, *“The large bone spur on one of my big toes makes it difficult to find supportive shoes, as my feet are size 11 extra wide, (used to be 8.5 medium), plus even more room for the bone spur.”* Other patients described degenerative bone disorders including osteopenia, Paget's disease and Kienbock's disease.

Cognitive issues: Brain fog and short-term memory

“Short-term memory in a lot of patients is depleted”, explained one patient. Many others agreed, and one said, *“I have been significantly impacted by the ‘mental fog’ that many of us experience but has yet to be recognized as a symptom of Acromegaly”.* A caller said, *“when I was working, I had brain fog. I mean, basically I've got the same symptoms as everybody else.”* One patient said, *“After my surgery to remove the tumour I felt like I walked out of a fog. It was incredible.”* Unfortunately, *“Now 5 months after surgery I feel like I have brain damage. I cannot focus on business matters, find it hard to work through business problems.”*

Weight gain

Many reported that weight gain was one of their first symptoms and which persisted despite their best efforts. *“Weight gain after surgery.... It’s well known in the Acro Community. But when you go to the doctor, they don’t know anything about this weight gain and lack of fat metabolism. You just get told to diet and exercise”,* reported one patient. A panelist who served in the military described how she *“gained a huge amount of weight and was put into the Army Weight Control program where I had to weigh in every month and show some weight loss. I rarely did.”* For another, *“No matter how well I eat or how much I exercise the weight is so easily gained and extremely hard to lose. It is embarrassing and has caused a major hit to my mental health.”* A caller described persistent weight gain *“even though I work out six days a week and eat healthily, it’s like I have no control.”*

Gastric issues

Patients with Acromegaly described a wide range of gastric issues including ulcers, anal fissures, diverticulosis, diarrhea, nausea, constipation, liver issues, chronic pancreatitis, irritable bowel syndrome, and gastrointestinal pain. Gastric issues are both a symptom of Acromegaly and a side effect from medication. For one, *“Constipation is currently my top symptom I struggle with on a daily basis. I have been trying so many treatments (i.e., fiber, digestive enzymes, laxatives, etc.) to try and figure out a long-term solution.”* She described how her symptom was dismissed, *“I was told by my Endocrine that constipation was not connected to Acromegaly; that I just needed to eat some prunes which is not helpful.”* One caller described how her diverticulitis led to a sigmoidectomy and she described how she, *“had constipation and also rectal prolapse surgery twice. And I think everything that’s wrong with me, ... is due to Acromegaly even though I know that’s probably not true, but I imagine quite a bit of it is”.*

Cancer

Several participants described cancers and soft tissue tumors. This included enlarged prostates, benign brain tumors, a brain stem meningioma, testicular tumors, neuromas, as well as multiple endocrine neoplasia (MEN). For one of the panelists, *“To top things off, I have recently been diagnosed with breast cancer. This has been a complete blow to my daily life. I have no idea if this diagnosis is related to Acromegaly, but I know we are more susceptible to getting cancer.”*

Pituitary damage or dysfunction and secondary adrenal insufficiency

The pituitary and surrounding tissues can be damaged by the growing tumor, or by surgery, radiation or medication. One caller reported being diagnosed with *“secondary adrenal insufficiency as well as... with a partial hypopituitarism.”* One panelist described the impact this has had on him, *“Due to secondary adrenal deficiency, I have concerns about my personal safety when I’m on business, travel or working on projects at home when alone. I keep my phone close, make sure that I have an adequate supply of medications available. And in the case of an emergency, I have an emergency cortisol injection kit.”*

Enlarged tongue

For one caller, a fat tongue was a first symptom of the disease. *“I kept having a fat tongue, and my doctors never could figure out why my tongue was so fat.”* For another, *“My tongue had also enlarged, making it difficult to articulate clearly.”* A third described how she had *“a strange lack of sensation in my oversized tongue.”*

Patients described many additional Acromegaly symptoms.

Some were recognized Acromegaly symptoms such as skin issues including skin tags or skin thickening particularly on the face, a deepening voice, hormone issues including hypothyroidism, hyperthyroidism, hypoparathyroidism, testosterone issues. Other symptoms included clumsiness, tremors, sensitivity to noise and light, tympanosclerosis (a calcium build up in the inner ear bones), leg ulcers, bone infections, McCune Albright Syndrome, fibrous dysplasia and other degenerative diseases. After describing her symptoms, one patient pointed out, *“While I know [these] conditions do happen to people without Acromegaly, the convergence [of] these in one otherwise healthy person seem unlikely that there is no connection.”*

Patients living with Acromegaly experience long and complex diagnostic journeys.

Many reported that it took years - even decades - between the appearance of their first symptom and their eventual diagnosis with Acromegaly. Some of the reasons for this include the lack of information about Acromegaly and the range of possible symptoms, the emergence of one symptom at a time so that they are not connected, and the fact that many patients with Acromegaly have IGF-1 and GH levels that fall within “normal” levels.

Many physicians do not have a lot of Acromegaly knowledge and there are few dedicated specialists. This point was repeated throughout the meeting by many different patients and impacts both Acromegaly diagnosis and treatment. One patient said, *“Sometimes my doctor is not up to date on the current standard of care on prescribing these medications.”* Another agreed, *“Sometimes even members of our medical team just don't know what it really is.”* One patient described that, *“I need to see roughly 12 service providers regularly as there is no Acromegaly doctor. This is incredibly difficult and frustrating and puts a significant strain on me and my entire family. How can we make this easier?”* One caller summarized: *“And just like everybody else has mentioned, the struggle to find out what's causing all the problems is real and big. Finding experienced endocrinologists that care as much about Acromegaly as they do about diabetes can be a challenge.”* Additionally, several patients submitted comments about challenges with their care team not understanding how to administer medications properly, *“One of the issues I had ... was getting someone to follow the directions. It's hard to educate a nurse when you're not one. At least 50% of the medication was following the needle out of my body and ended up on the exam room floor.”*

Many patients living with Acromegaly described how their symptoms were dismissed or misattributed to other causes. For one panelist, *“I was diagnosed in Acromegaly in 2010 after about 20 years of doctors not connecting all of the dots I was presenting to them. My dots were intense joint pain in my ankles, knees, hips and wrists, which was ‘supposedly’ caused by all of my physical fitness training for my career in the military as a soldier-musician. Running and marching [in] parades was excruciating. I also had debilitating migraines at least once a week.*

These migraines were 'stress-related'. Funny. They were so bad I would have to stop whatever I was doing, even if I was in the middle of a band rehearsal, to go sit down in a dark, quiet room. Horrible jaw pain: diagnosis [was] temporomandibular joint disorder, also known as TMJ. Wrists were numb and painful from the many hours of practicing my clarinet." Another patient confirmed: *"The dismissal is devastating, time-consuming and expensive!"* One caller said, *"this disease takes so long to diagnose for the average patient. And many of us, myself included, have spent multiple years with multiple physicians in multiple disciplines, complaining of symptoms and not having any reasonable progress in a diagnosis for many years and often are either very directly or very subtly led to believe that they're complainers or whiners."* She described how being dismissed for so long came at a heavy psychological cost, *"we learn to kind of brush over symptoms, we learn to not complain, we learn to not talk about things."*

For many patients, their Acromegaly diagnosis was incidental. One panelist was diagnosed with Acromegaly when investigating Parkinson's disease: *"I realized that I had been exhibiting signs and symptoms for over 12 years, which included snoring, my dentist noticing that my teeth had been moving and my bite had changed. I was having difficulty controlling my blood pressure and blood sugars with diet and exercise. I had to stop wearing my wedding ring because it was too small. My shoe size increased two full sizes. I never recognized that these were an issue other than a normal aging process. It was not until after I was diagnosed that it made sense why diet and exercise were not helping me control these symptoms like blood pressure and blood sugars."*

Many patients described how hard they had to work to advocate for themselves. One patient *"suffered roughly 12 years prior to diagnosis, and firmly believed, because of the changes within my Acromegaly, that I would not be here now to tell my story if I hadn't actively sought out a correct diagnosis."* Her diagnosis was only made after she found the right physician, *"I found one that was familiar with Acromegaly that I was able to get the diagnostic test needed to prove that Acromegaly was the cause of my issues."* One patient blamed herself for ignoring the many signs and symptoms of Acromegaly, *"if I would have, if that sign would have been reported better, would I have discovered what I had sooner or if a doctor would have picked that up. And so that is, and you hear that a lot."* Another patient, described how she finally self-diagnosed her disease after years of dismissal, *"I visited doctors from age 20 with symptoms and was not diagnosed by a doctor (I connected the dots and self-diagnosed via the internet) until I was 46 and even then, I was told I didn't LOOK like I had Acromegaly!"* She added, *"Even my current specialists have a tendency to dismiss my symptoms as psych[ologically] or gender related!"* One caller added, *"I'm just driven to keep researching or if I need to seek another medical, professional opinion to see if there's maybe something else that my current doctor might be missing."*

Not all Acromegaly journeys are the same. A patient diagnosed with Gigantism as a child reminded everyone that *"The effects of being diagnosed early are tremendous but I'm proof that even if that were to happen, there are still challenges."* Several patients found the diagnostic experience extremely traumatic: *"I've spent many hours wondering why this happened to me and what I might've done differently to have avoided Acromegaly."* Others described their relief when a diagnosis was finally made: *"when I first was diagnosed, it was a huge relief that I could finally pinpoint something, a specific diagnosis."*

By the time a diagnosis of Acromegaly is made, many patients have accumulated irreversible damage to their tissues and organs. *“I wonder if I was diagnosed earlier, if my old [doctor] really listened and put symptoms together, would I have to deal with tissue damage...colon, heart, joints. I was diagnosed at age 62 and was told I had that tumor for at least 20 years!”*, said one patient. Another agreed: *“Even after having to have two surgeries and 6 weeks of radiation ten years later, I still suffer on a daily basis with the damage that this condition has done to my body inside and out. Every time I go to the doctor, it’s something else.”*

Acromegaly negatively impacts all aspects and activities of daily living.

Patients living with Acromegaly described the many impacts that the disease has had on all aspects of their lives. They described how their life was split into “before and after” diagnosis, they recounted their best and worst days, and described the things that were lost to them because of their disease. One caregiver described the hopelessness she felt for her son diagnosed with Acromegaly: *“This illness has taken every part of his past and future away, we continue to fight for medication which may be able to lower his IGF-1 and give him some kind of normal.”* A panelist said, *“I’ve had to accept that I will never be the confident, competent [clarinet] player I used to be. Acromegaly has forever changed my life.”* Another patient stated that *“I feel like my life is now defined by a disease that has wrapped its ugly hands around me. I feel like the possibility of living a real life is over for me.”* A patient summarized, *“I was not living, but just existing. I had no dreams, and for one to be alive, one has to have dreams, to take a vacation with a loved one, go to a family reunion, travel to another country, take walks with your wife, whatever it is, one has to have dreams to feel alive.”*

When asked to select the top three specific activities of daily life that they were unable to do due to Acromegaly, participants rated the seven response options similarly. Forty-nine percent of respondents reported that Acromegaly interferes with their social interaction and participation; 42% with exercising; 39% with participation in sports/recreational activities; 38% with household activities like cleaning or cooking; 38% with attending school or having a job; 33% with family relationships; 26% with walking. Results are shown in **Appendix 5, Q3** and summarized with patient comments below.

Social interaction and participation

Patients living with Acromegaly described how their fatigue and headaches impact their relationships. For one, *“I loved to socialize more, but find myself hiding instead because I cannot explain the fatigue and pain that I am in daily and get tired of being tired!”* Another agreed, *“My fatigue has made it very difficult to do normal activities and keep up with my friends and family. ... I felt like I was sleeping through my son's elementary school years and lost friends because I just didn't have the energy to socialize.”* Another patient said, *“Fatigue has also caused me to cut back on socializing, and I know this hurts people that I care about. Once I had a close friend accuse me of using Acromegaly as an excuse to blow off a party invitation. She couldn't comprehend that I really didn't have the energy.”*

For some, facial and physical changes led to a loss of self, perceptions of being different and feelings of reduced confidence. A panelist described how, *“I feel like I've lost my sense of self, and I'm always closing doors away from society.”* One patient reported that her *“change in features...has impacted daily how I feel about myself and my interactions with others. I feel people stare at me, I have been called a freak and a man. ‘Look at those hands’. People who I grew up with do not recognize me.”* Another described how *“living a normal life ... is very hard to do...It's hard for me to even socialize with people I've known my whole life. I feel Acromegaly has taken over my whole life.”* One patient said, *“I am physically different from others and I experience discrimination.”* Heartbreakingly, one described how *“I have stepped back from many relationships because it's hard to be dismissed as being a hypochondriac or too much of a liability. I have voice, body and face dysmorphia and hate how I look and sound.”* Covid-19 revealed that Acromegaly made one patient feel self-conscious, *“I feel more confident while wearing a mask because it covers my jawline. ... I didn't realize how much I was self conscious I was until I noticed the difference wearing the mask.”*

Exercising, participation in sports and recreational activities

Patients living with Acromegaly described having to give up all the things they loved doing the most and expressed their desires for things that they wished they could do still. A professional musician said *“here's the sad part of this story, the part that impacted me the most, I had to stop playing and doing what I was trained most of my life to do, be a clarinetist. I could no longer hold my clarinet because it hurt my wrist too much.”* A panelist described *“I would give anything to be able to get up in the morning, go to work, help around the house and go out and play a round of golf.* Because of the disease, one said, *“Gardening and sewing are no longer possible, and biking/aerobic exercise is out.”* A patient described how she *“had to give up my tennis that I enjoyed, being on a league for 50 years”*. For another, *“I used to love going dancing, hiking and bouldering, but that is too difficult now.”* Another said, *“When I hurt, I stay home and rest and sometimes I cancel dance classes and don't do the normal things in my life that I'm used to doing.”* One described how *“I no longer have hobbies and not very much to do with my time. ... This disease has robbed me of so many things I once loved to do.”* A father with Acromegaly, who cannot take part in sports with his son, expressed the wish that he could do so.

Several meeting participants specifically described hiking as an activity that they could no longer enjoy. One, described how she *“Loved going for long hikes...today hikes if at all are short, after a while the pain my hips present is too much, and I give up.”* One said how he *“loved walking the hills.”* This was something that one only dreamt of: *“If I could, I would hike the Appalachian trail.*

Attending school and having a job

Patients living with Acromegaly reported fragmented educational and career trajectories, job losses and early retirements. A panelist described how Acromegaly robbed him of his career. *“I had to go on full time disability in 2009. My life is pre-acro and post-acro. my disability was driven by my short-term memory deficiency, and my cognitive deficiency. And so that interfered with my architectural job as a project manager.”* A caller said, *“I ended up losing my job that I*

adored. I couldn't remember all the details I was supposed to do, even if I wrote meticulous notes. And that was a real blow to me.” Another commented, “Reducing work results in no promotion for years.”

Others described trade-offs to maintaining employment. One panelist said, *“Because of the fatigue, I've had to scale back my ambitions and accept that I will never achieve the potential that I had before developing Acromegaly. My career has been limited. I went from working full-time to freelancing so that I can control my hours and choose the projects that I dedicate myself to.”* Another patient described, *“I run my own full-time business. I keep going because I need to, but it's such a real challenge”,* and listed her short-term memory loss, brain fog, headaches and cognitive issues as challenges. And another described carefully allocating her energy, *“If you need to or want to continue to work, you have to factor everything around that. Like, ‘okay, this is my schedule, these are my workdays, this is what it's going to take out of me’.”*

For many, job losses and early retirement created financial challenges which are particularly difficult for people who require expensive medications. One patient described the loss of her *“professional career, which cost me a secure monthly income and ... security of having a pension for a comfortable retirement.”* A teacher called in and described how she had to retire early, *“Now my pension is much less because I had to get an early retirement penalty.”* For one panelist, *“Financial issues were huge. I retired back in 2019 and went on Medicare. [I experienced] a big, big shock financially for Pharm D. Here in the United States, we're required to sign up for Medicare, or we're monetarily penalized. But you need the pharmaceutical benefit. Particularly in our community because we're all taking numerous types of medications.”* For another panelist, *“this is a very expensive condition to treat and to keep in control. I think that's part of the anxiety ... what happens when that life company insurance policy is gone? Yes, we get pre-existing conditions covered now. But the insurance environment is scary, and it can wipe out any retirement nest egg that any of us have. So, the physical aspect of the disease is one thing. The mental aspects are just expanding all the time. And a lot of it is stuff that we don't have control over. Like finances.”*

Job loss was accompanied by feelings of failure, shame and unfulfilled potential. After having to file for disability, one panelist said, *“my self-worth was gone. Not being able to work and provide for my family, when that is all I've ever done, was such a hit to my pride.”* And for another, *“The worst feeling of all is the embarrassment of what I saw as a failure to serve my country and fulfill the plan I had when I made my commitment to the United States' Army. ...I lost out on a lifetime of experiences where my abilities would have taken me.”*

Household activities

Many panelists described their challenges in managing household activities. One said, *“I struggle with simple tasks, such as lifting laundry, carrying groceries, or mowing my lawn and doing simple housework.”* For another patient, joint replacements, pain and mobility issues mean that *“I can't cook very well for myself because I can't lift things, I can't stir things, I can't chop things.”* One panelist described how much he used to enjoy home improvement projects

and maintenance but now if, *"I do have the energy to tackle a project. It takes longer to complete some of the simpler tasks. Some days, just using a pair of pliers is difficult because my fingers lock up. They can't bend and get into a comfortable position to do some things. When it comes to handling small parts or precision tools, it takes me several attempts because I wind up dropping things. When I get really frustrated, I must swallow my pride, ask my wife or daughter for help, or I just give up and put it off for another day."* Another described how, *"I have low energy to the point where I have difficulty doing some of my daily activities (cleaning my house). I also usually take a nap during the afternoon."*

Several individuals described how Acromegaly has compromised their independence. One patient said, *"I must ask for help buttoning the cuffs for long sleeve shirt or the collared button of a dress shirt."* For another, *"As a result of [Acromegaly], I am no longer independent and have become a burden on my family. It is awful."*

Family relationships

Patients living with Acromegaly described how pain and fatigue limited the activities and time they spent with other family members. For one patient, *"When the fatigue wall rises, there is nothing you can do. You have to step down. And it doesn't matter whether you're at a basketball game or at a family birthday party, you're done."* Some described budgeting their time and energy: *"The chronic fatigue and joint pain and headaches and having to completely structure and schedule your life because you don't have enough energy to do everything that you want to do... And so then when it comes to family and home and social life, what do I have to say no to? What do I have to not do? Who's going to be affected by that? Are my kids going to understand? Is my spouse going to understand? It's very complicated and requires a lot of attention to symptoms and attention to energy levels. And there's often not enough currency in the bank, so to speak, to do everything that needs to be done."*

Many reported how their disease robbed them of experiences with children or grandchildren. For one patient, *"The worst part is that I didn't do things I wanted to do with my son as he was growing up - activities, travel, even having friends visit, organise a birthday party."* For another, *"Because of this condition, I do not feel like I was the wife, mother, or person that I was meant to be. The effects of all the above led me to limit myself to the one child that I have, and even with her, I feel like the fatigue and the other health issues impacted her childhood negatively."* Some patients living with Acromegaly made the decision not to have children, *"Fatigue is also a factor in my decision to not have children as the idea of trying to care for a child while having Acromegaly is simply overwhelming."*

Many reported withdrawing to hide their pain and suffering from the ones they loved the most. One patient said, *"My family does not always understand how or what I'm feeling, and I have a hard time describing how I feel. This does create friction between us sometimes.... On my worst days, I just want to check out and hide from everyone and everything. When this happens, I hope my family realizes I'm not angry with them, it's just the Acro."* Another patient living with Acromegaly described how, *"I'm one to hide my pain, hide it from my family as much as I can. And I'm like a wounded animal, I'll go curl up and hide. And I'm just kind of crappy with my family and they know probably that I'm in the pain that I'm in, but I don't want to express it"*

when I'm struggling." A wife and long-term caregiver of an Acromegaly patient described how family members often feel like *"they're basically being pushed away by their behavior."*

Some participants described how acromegaly and mood swings impacted their relationships.

The husband of an Acromegaly patient described how *"Dealing with fallout of the neurological and emotional impacts"* is a *"perpetual roller coaster. ... [The] kids don't get the mom they deserve; I don't get the wife I married."* Another patient described how *"Mental illness tore apart my family and I now have irreparable damage to family and insofar as my daughters claim (and I believe them) they have scars because of me. I no longer have much of any relationship with them."*

Additional impacts: diagnosed with Acromegaly (Gigantism) as a child

When Acromegaly occurs in children or adolescents, it causes pituitary gigantism. When untreated, these children experience excessive bone growth and abnormal increases in height.

- Although there were few children at the meeting, a patient advocate highlighted unique challenges for those diagnosed as a child or a teen, *"they have a totally different set of needs and requirements for treatment and care. For a hormonal degenerative disease such as Acromegaly, the age of patient population is extremely important."* For children, *"the disease affects their sense of worth, of self, how they perceive others and how their behavioral patterns that make up their personality form."*
- This patient also described how it harder to determine the side effects of the drugs on children/teens, *"the side effects of the drugs on young children and teens are confusing because they are given before the child can form a sense of self, before they can understand and identify their emotions, feelings and bodily sensations and it takes a while to know what sensation is real and what is caused by the side effects of medication or disease."*
- Mental health support is lacking, *"The only thing that wasn't offered to me was mental health support and I really needed it / need it at the time."*
- A particular challenge is the lack of support provided when the young adult with Acromegaly transitions from paediatric to adult care and has to learn to advocate for themselves. *"Once I turned 19, I was left to my own devices and my mom was told by my doctors that she can't join me at my medical appointments anymore. ... I had to start from scratch working with doctors who expected me to know more, who did not properly explain my health conditions and how Acromegaly plays a part."*

Patients living with Acromegaly shared their fears, particularly of tumor regrowth.

For patients living with Acromegaly, tumor regrowth and disease progression are very common. *"I worry about the tumor growing and my symptoms worsening"* stated one panelist. Another described that her greatest concern *"is the tumor regrowing, because there is still some there, and it affected my remaining eyesight."* She feared losing her remaining eyesight, *"you couldn't think of anything worse than going blind. I have no light perception in this side. So, for the tumor to possibly regrow and affect the remaining eyesight would be hell."* Another patient shared how she felt every time she had a symptom, *"The fear I have EVERY TIME I feel a migraine, brain fog, blurred vision, fatigue, pure exhaustion, a new gap between my teeth, a*

snug ring, or a need for a bigger shoe size is unbearable...What worries me the most is that the tumor could come back.” Some expressed this simply as “fear of what’s next”.

Some worried about additional comorbidities of the disease. *“My biggest concern regarding my condition is the co-morbidities that it causes and the risk of premature death,”* stated one patient. *“I also worry about developing additional comorbidities beyond my osteoarthritis, such as diabetes, heart disease and colon polyps.”* This was echoed by another patient who was as *“concerned about the long-term effects of diabetes as I am about the Acromegaly.”*

Patients feared their symptoms being missed or dismissed. One patient said, *“My biggest fear right now is that what if something is wrong and no one catches it in time...What if they don't catch it at all and it ends up killing me because these [doctors] have no clue what to look for or what to do.”* Another said, *“I worry that my endocrinologist thinks I am a hypochondriac and will refuse to help me. I worry that if I keep feeling like I do, I will become more reclusive by the day. I keep these all to myself, I rarely tell anyone, but I have these thoughts daily.”*

Other participants feared that they will no longer be productive, they will run out of support and finances. One patient said, *“I do have a lot of fear. Fear that I can not longer be productive and fear that because of that, my brain will get weak and stop thriving.”*

Parents of children with Acromegaly expressed fears for their children’s futures. This included fears of not knowing how their children will manage the disease on their own. One parent said, *“We worry about future symptoms and damage to [my teenage son’s] body and if the tumor will come back after surgery and will he be on lifelong medication.* One caller described her son who was diagnosed with gigantism at age 14, *“Our concerns are, how long will he be controlled? I'm a nurse, too, so I have concerns about him getting injections for the rest of his life, building up scar tissue.”*

The fear of premature death is widespread. One patient said, *“It is not easy to accept the life expectancy of acromegalic's is shorter than average. I would love to be able to live longer than what acromegalic's are expected to live.”* Another added that *“Not knowing whether my son would have to grow up without his mother, was the scariest part of it all.”* Another said, *“I've seen premature death on a list of Acromegaly symptoms and contemplating my mortality sets me off into an existential crisis.”*

Topic 2: Patient Perspectives on Current and Future Approaches to Treatment

Patients living with Acromegaly described long treatment journeys with many therapies.

This was consistent for most patients and was repeated throughout the meeting. For one panelist, *“My journey with Acromegaly has spanned 12 years, and most of those years were not easy, two brain surgeries, radiation and pharmaceutical treatment. ... If there was one thing that I have learned about the treatment of Acromegaly is that there is a multifaceted approach to it, and it's definitely not one size fits all to feeling well.”* For another patient, her treatment required *“two surgeries to resect my tumor, seen three endocrinologists, and tried five different*

medications to treat my Acromegaly before my doctor finally found a combination that seems to be working.”

Using online polling, patients selected all medications or medical treatments that they had recently used. The medications or medical treatments recently used are summarized in **Appendix 6, Q1** and described below along with patient comments about treatment efficacy and trade offs.

Surgery was the most frequently selected treatment approach in the poll.

Eighty-three percent of participants reported that they had surgery to treat their disease, including transsphenoidal or craniotomy procedures to remove the pituitary tumors. The polling number may include surgeries to address Acromegaly symptoms including joint replacements and spinal fusions and other surgeries to address treatment side effects such as gall bladder removal. Many participants described multiple surgical procedures, *“I've been battling this disease for 21 years. ... I've had two transsphenoidals, radiation, craniotomy, both hips replaced. All due to my acro.”*

Patients reported a wide range of surgical outcomes and experiences.

- **For several participants, surgery was the answer.** For one patient, *“I had the surgery a year ago with 98% removal of the tumor. My symptoms improved and are being followed closely. I don't take any medications at the moment, and I declined the [neurosurgeons] recommendation to proceed a few months after surgery with [gamma knife surgery].”* For another, *“I was on Sandostatin LAR for 2 and half years and then had surgery, and although I have a residual tumor, I currently don't need any treatment as my values were so far in normal range.”*
- **Surgery is not always curative. Residual tumor is common and multiple surgeries are often required.** One panelist described her 7 cm giant macroadenoma that *“grew up on my carotid artery and optic nerve. ... But because the tumor was so large, they couldn't debulk all of the tumour just through the endoscopic approach. So, I came home and recovered from that and then went in for my first craniotomy, which obviously was a horrible experience. Unfortunately, I needed another craniotomy about three weeks after I came home from recovering from my first one.”* One caller found out she was pregnant the day of her surgery and initially had a successful operation, *“But later, that I learned; about six months postpartum, that I still had residual tumor, so I had a second surgery, eight months postpartum, and I'm currently in remission. But there's still some residual tumor there that we're closely watching. I've had fluctuating growth hormone lab results which we've been closely looking at.”*
- **Surgery doesn't always address all the symptoms.** One patient said, *“My headaches disappeared after surgery, but my hands and feet are still really large. Symptomatically, I haven't improved at all.”*
- **Several described a difficult recovery from brain surgery.** For one patient, *“A week in hospital in intensive care, I developed diabetes insipidus plus having to deal with being jabbed multiple times a day for blood tests, not being allowed to sneeze, get water up my nose or lift more than five kilos for six weeks; very hard with a one-year-old and a pregnant wife. I also developed a mild spinal fluid leak, which was an awful feeling. Luckily, that*

sorted itself, but it was a very physically and emotionally rough six weeks. ... Unfortunately, at the six-month blood test, my hormones had gone up to their higher levels, meaning that residual tumor remained though not visible on MRI, so the surgery and hardship was a massively disappointing failure.” For another, “although the surgery was an effective treatment (we no longer see the tumor on the MRI), I had to go to the emergency room to have blood clots in my nose removed.”

- **Surgery can damage surrounding tissue leading to other side effects.** For one patient, “I had two surgeries in 2018 to remove the tumor, which has left me with pituitary shutdown, requiring full hormone replacement therapy.” Another reported that “The two endoscopic endonasal TSH surgeries have left me with chronic sinusitis/laryngitis due to removal of my bony nasal septum and resection of several nasal turbinates.” Many patients described experiencing cerebrospinal fluid (CSF) leaks after their surgeries. For one, “Following transsphenoidal resection, I had a CSF leak leading to a week in the hospital with a spinal drain extracting spinal fluid every hour. The surgery also left me with diabetes insipidus leading to daily medication and fluid management issues. I did not achieve remission after transsphenoidal resection of the tumor.”
- **Some found it hard to accept that the surgery did not remove all the tumor.** For one panelist, “It was hard for me to accept the fact that the entire tumor was not removed, and to know there are active cells that may, if left untreated could turn into another tumor.” For another panelist “Unfortunately, they were not able to remove the entire tumor, because it was wrapped around my carotid artery,” and despite the surgery “my IGF-1 and growth hormone levels were still above normal levels. I have to say this was the lowest point in my life. I felt lost, unsure of life. I had no meaning, and unsure of what was going to happen to me. Would I ever feel more like myself? Would I get my energy back? Would I have less joint pain?”
- **A patient who did not have surgery described self-doubt about that decision.** “In my case the doctors here in Norway did not want to risk an operation to remove my tumor...I wonder sometimes if that was the wrong choice to take. What would my health be like if I would have had the operation?”

Patients living with Acromegaly require many different medications to treat their disease and symptoms.

Of the response options included in the polls, 71% of patients tried medications that reduce growth hormone secretion (Sandostatin, Somatuline Depot, Signifor), 43% tried medications that block the action of growth hormone (Somavert), 38% have tried medications that lower hormone levels (Cabergoline, Bromocriptine) and over one third (37%) reported using antidepressant or anti-anxiety medication (Wellbutrin and L-methylfolate).

Patients living with Acromegaly described a very wide range of experiences and challenges with different medications.

- **Many patients living with Acromegaly have tried many medications before finding one that works.** One panelist described her difficult journey: “I was on the lanreotide probably for two years. Following my second craniotomy, I had radiotherapy for a month like we all kind of do in a few months after that. And then we had to apply for funding for the

Pasireotide. And then now I'm on Somavert 30 milligrams. And I was on cabergoline." A caller said, "I did try quite a number of different meds I was on octreotide, Somatuline, Somavert and cabergoline." One described how: "Following my surgery, I was prescribed Somatuline, testosterone, and Synthroid. A year later, I was prescribed Somavert (30 mg twice per week). It is only this year, six years later, with 30 mg of Somavert per day, that my IGF-1 is below the upper limit of the standard."

- **Some found that medications provided benefits.** One panelist said, "as soon as we went on the pegvisomant, the Somavert, all of that resolved. So, it was just almost immediate." He described his symptoms as, "they're very well controlled." After a long treatment journey, one patient said, "my doctor finally found a combination that seems to be working. For the first time since diagnosis my swelling has significantly improved, I'm not as tired, I can focus better, nor as moody or emotional. Just last year I required a significant amount of help just to complete daily tasks or chores, and now for the first time in any I almost ten years I can do normal things." For another, "I was happy to take subcutaneous octreotide 3 times a day rather than a monthly lanreotide or octreotide injection because the subcutaneous injections gave me instant relief from excruciating head pain. It helped me manage my pain better because I knew that for 90-120 mins after the injection, I'd be able to "get things done". Then I could use painkillers in between injections." Another patient also found success with a combination approach, "Since switching to pegvisomant in late 2013, my IGF levels and overall feelings dramatically improved. I use this in conjunction with a cabergoline dosage as well. I still feel some fatigue but believe it is due to the meds, but otherwise feel well controlled."
- **For some patients with Acromegaly, medications are ineffective or lose efficacy with time.** One panelist said, "Since my IGF-1 and growth hormone levels were not within the normal range, my doctor put me on a drug called [Somatuline]90 milligram. This drug is administered with a very large needle, and it's a very painful injection. After another three months of this medication, my IGF-1 and growth hormone level were not going down, so my doctor raised the dosage to 120 milligram a month. After another three months of 120 milligram injections, my IGF-1 and growth hormone rose, instead of going down." Another said, "My endocrinologist believes that over time my body's gotten used to it and it stopped working. A new, larger tumor has now grown, and my growth hormones and IGF-1's went back up to their original state, which was three times the maximum levels." Another caller described her frustration "You go through the transsphenoidal surgery, you get your tumor removed, you get put on medication and some symptoms stop but they all come back. Now, 90% of them all came back for me."
- **Many patients suffer from breakthrough symptoms as medications wear off.** One patient said, "I usually feel symptoms before my next dose. My joints ache and headaches are common usually a week prior to my next injection." Another said, "It was usually within two weeks after taking the injection that I would start having severe leg cramps like pain, joint pain. I couldn't get up and do much. I do work 40 hours a week, but even then I was missing work due to the pain. I was having a lot of headaches. And then the exhaustion was just overwhelming." One patient described, "When my medication wears off, I feel like I am getting flu like symptoms and have to push myself through the week of feeling body aches, light headache, and body temperature going up slightly, I make sure that I don't make any

plans, so I can stay home and rest, my husband takes over the making of meals and doing the chores that need to be done. For another, “Breakthrough symptoms have also been a huge issue for me - I have known it is time for my injection because I could feel it in my knees (and I’m only in my early 30s!).” Luckily for her she switched to medication that “so far it has helped to control my breakthrough symptoms. I appreciate that I no longer have to go into the doctor’s office every month to get the painful injections.”

- **They described breakthrough symptoms are unpredictable and persistent.** For one patient, breakthrough symptoms included migraines and extreme fatigue, “I’m not giving up, but I wish my meds would be more predictable and consistent in their symptom control so that I can be there for my family and my career.” One panelist described how persistent his breakthrough symptoms could be, “I was in remission for two years and it started... It came back. The residual tumor came back. So, I started on Somatuline and... Eventually, I was having severe breakthrough symptoms with the Somatuline I was on. I was on 120 Somatuline with cabergoline. So, I switched to Somavert [which eased] those breakthrough symptoms for about a year. ... Eventually, breakthrough symptoms started coming back, but not as severe.” One patient summarized: “The side effects of the medication make it impossible to have a consistent routine and schedule life events as necessary because I always have to plan around the week before the shot and the week after.”
- **Medication-related side effects are abundant and are often difficult to distinguish from the side effects of Acromegaly itself.** Patients with Acromegaly described experiencing recognized medication side effects including hyperglycemia/type II diabetes, worsening thyroid hormone function, gallstones, gastrointestinal issues, injection site pain and reactions and liver enzyme elevations. As many patients are on multiple medications, it is hard to attribute side effects to specific treatments. For one caller, “the side effects are often as debilitating as the disease itself. And when you’re on a cocktail, like I am, sometimes it’s even a combination because you have more than one medication, so you have more than one set of side effects.” This was echoed by another patient, “I find it very difficult to wade through the side effects of gamma-knife radiation (which I had) and Somavert (which I take daily) vs. the symptoms of the Acromegaly disease itself. It seems my endocrinologist does as well.” Other medication side effects that were mentioned include fatigue, cognitive issues, a loss of taste and a decreased heart rate. GI side effects, including gallbladder removal and severe psychological, sexual and emotional reactions are described in the paragraphs below.
 - **GI side effects were a side effect of most medications: nausea, diarrhea, IBS and gastroparesis, pancreatic insufficiency.** For one caller, “for me, the biggest is the GI upset. There’s nausea, diarrhea... it’s kind of hard to function when you can’t get out of the bathroom.” She described her symptoms, “They’re mostly in the beginning, a few days after treatment as others have said. And then they kind of taper down from there. ...It’s not constant, but definitely reoccurring.” Another caller also experienced this, “The gastric problems with that were so severe that I debated on whether I was even going to continue the medication. And they last for about two weeks. I stuck it out and luckily they went away or else I would’ve... it just was too disruptive to my life. It wouldn’t have been worth it for me to stay on it.” Some reported long term gastrointestinal issues from their medications.

- **Many patients with Acromegaly patients have had their gallbladders removed.** For one panelist, *“Although taking Somatuline has been an overall positive experience, it's had its drawbacks too. I ended up with a necrotic gallbladder that was full of gallstones due to the medication. Although the surgery was laparoscopic to remove it, it was just another surgery that I had to deal with through this journey.”* For another, *“emergency removal of the gallbladder 11 years ago”,* was just one of many surgeries.
- **Some patients suffered severe psychological, sexual and emotional side effects from medications.** One panelist described a challenge with cabergoline treatment and how he had, *“an extremely strong urge to want to place a bet on any sport, though I have never gambled. It also caused extreme anger outbursts, constant agitation, and an extreme libido.”* He ended up discontinuing the trial as *“the side effects were at dangerous levels to myself, my wife and kids”*. Another woman reported that while her *“prolactinoma was controlled with cabergoline, she eventually became intolerant to the drug, as it gave me sexual dysfunction in the form of acute pain in my clitoris due to the effects of the cabergoline constricting the blood vessels in that area. That dysfunction healed but I can still feel the psychological and emotional effects of it.”*
- **Patients reported that injections are painful, cause lumpy tissue and bruising, and can cause anxiety.** One panelist described her injection challenges: *“After cycling between the four approved injection sites for over a decade, I've developed scar tissue which more and more often makes it difficult to inject the medication - it's like trying to inject into a cork versus injecting into normal muscle tissue. If the medication won't go in, the only thing to do is to pull the needle out, put on a fresh needle and try a new site, and sometimes I've had three injections before the medication is delivered.”* For another panelist, *“Aside from the amount of time it took to receive the injection, the painful knots and bruising at the injection site was very uncomfortable. I would be amiss if I did not mention the pain of receiving the shot, something I did not look forward to every month. ... Quite frankly, my whole life revolved around injection day, and made sure that if I traveled, it would not interfere with me getting my injection.”* For one patient, *“The daily, weekly and monthly medication doses are a constant reminder of his dreadful disease that has affected my life and that of many others.”*
- **Acromegaly medications are inconvenient to prepare and limit travel.** One patient described how medications are *“delicate and requires specific storing, handling and mixing. This is time consuming and can also be a struggle for storage and transport for travel or shift work.”* Another echoed, *“The frequent injections and the fact that it needs to be individually mixed and refrigerated is annoying and impractical.”* One patient described how, *“having to keep the vials in the fridge, so camping trips or holidays can be a bit trickier to organize.”* Finally, one patient summed it up: *“Traveling with these medications is also very difficult, even a short road trip with an overnight stay, I have to make sure I can keep the medication refrigerated and if the medicine upsets my stomach that there's a bathroom nearby. It's yet another way Acromegaly controls my life.”*
- **Injections require a lot of time.** One panelist described how *“it was very inconvenient for me to receive the injection. I would have to take a half day off of work between travel,*

picking up the injection from the pharmacy, wait time at the doctor's office for the medication to get room temperature, administering the injection and traveling back home, it was three and a half to four hours of my day." Another, described the difficulty of *"scheduling your life around a monthly injection" and "having to take time off of work every 28 days to get a shot in your behind."*

- **Acromegaly medication is expensive, and some described having limited access.** Many patients described how costly the medication is. One patient described their anxiety about the cost of treatment and said, *"it seems wrong to me that in addition to the burden of the disease is the burden of the expensive treatments."* For her, *"My insurance has covered it so far, with fairly large copays, but as I move into Medicare next year, I am uncertain how well Medicare will pay for the treatment. The monthly injections are billed to the hospital at more than \$16,000 per month."* A patient described her challenges in obtaining treatment, *"As I consider possible treatment options, the American relationship between patient, insurer and doctor has been absurdly prohibitive to me starting treatment. I received non-curative surgery in September 2020 and my doctor prescribed medical management in October, yet here at the end of January I have yet to receive any sort of treatment because our insurer has been so prohibitive, and [this] has now changed due to pandemic-related job loss."* One patient described problems when switching to a generic, *"I was taking cabergoline made by PAR Pharma and had virtually no side effects. As of 2021 PAR Pharma no longer makes cabergoline. I just started taking cabergoline made by Greenstone Pharma and have severe side effects to the point I've had to cut the dose and may have to stop taking it. If all generic drugs are the same what could account for this?"*
- **Medications may cause malabsorption and limit efficacy.** One patient drew attention to malabsorption issues, *"This isn't recognized so medications aren't dosed appropriately."* Not only did it leave her pain untreated, but *"my doses for all my other medicine need to be adjusted, but that's not being taken into consideration. So, sometimes we may go under treated for other ailments, because they think they're giving us the maximum dosage, but really we're not getting all of it."*
- **Patients living with Acromegaly fear long-term side effects of being on medication for life.** *"I'm 38 and the thought of being on medication for life, and particularly having to do daily injections is daunting! Although she was grateful for treatment, one added "I would be lying if I said that I wasn't worried about the long-term side effects of many of these drugs. I often wonder if I'm trading temporarily feeling better for something worse later on."* Another described how hard it was to select the most appropriate treatment to address an upward trend in IGF-1 *"I'm scared of developing adrenal insufficiency or replacing one medicine with another if I choose radiation. I don't have enough data to make a decision I'm confident about."*
- **Some participants do not require medications or are trying to be medication-free.** Several participants described another approach, *"I am off medication for the first time in my life just to see what it is like, and my hormones are really high if I don't eat properly. Stress can also amplify them. I've felt better than ever being off medication. ... I'm not sure if I will get back on medication any time soon. I feel like I need to be on something that is specifically designed for Acromegaly instead of taking repurposed drugs."* Another

participant reported his success, *"I've been dealing with my Acromegaly for over 12 years now and in that time I've reduced my medication to nearly zero now."*

Over a third (35%) of poll respondents reported using other medications including those to treat secondary symptoms including diabetes and hypothyroidism. Many had stories like this: *"I take pain medications to help combat the joint pain in my shoulders and hands. I also take high blood pressure medicine, diabetes medicine, ED medicines, all due to the effects of Acromegaly."* Participants mentioned pain relief, diabetes medications, headache medications, hormone replacement, blood pressure medications, thyroid medications, statins, medications for wakefulness during the day, medications to sleep at night and medications for osteoarthritis. One described how she requires *"22 pills a day along with 2 daily injections and 1 monthly injection. All of this medication is the only way I can function."* For another: *"I need to see a myriad of doctors and am on over 30 medications. It is exhausting to manage all this."*

Another 11% of participants tried experimental medications as part of a clinical trial; some of participants described success, others less so. One patient described how enrolling in a combination therapy study *"was one of the best decisions I ever made"*. He previously tried many therapies, but his symptoms kept coming back. *"I was selected to conduct a one-year combo therapy study ... This became the greatest achievement in my treatment of Acromegaly and the horrific symptoms associated with it. Somatuline 60 + Somavert gave me my life back. Energy and strength were most notable as I could do my favorite passion of Spring Turkey hunting again.* For another panelist *"I was elated that I qualified for the clinical trial.... Within a few months, my IGF and growth hormone were in normal range. There are restrictions on how to take the pill. The pill must be taken on an empty stomach, this was not a hurdle for me. I was in the clinical trial for three years. It was a 100% better experience than on the injectable."* For yet another panelist, *"I eventually had the opportunity to join a research project out of California that allowed me to try an additional Acromegaly treatment. I jumped at the chance of taking the daily medication that could possibly relieve my fatigue, however, it made no difference."*

Patients strongly encouraged others to participate in trials. One patient was in a trial for five-years and described, *"Being so honored to be a part of something that could possibly help so many patients like myself. There were challenges being in a study. Mine being in another state and flying back and forth sometimes not feeling so well. But I was 'all in' no matter what. ... I would express to anyone that could take part in a study to do it. I have grown so much from doing something like this for myself and hopefully for others."* The husband of another patient said that *"My wife, who has Acromegaly, was a participant in a clinical trial for an oral octreotide. I would like to encourage others with acro to participate in the clinical trials. This a way for patients to become part of finding a treatment and also to benefit from the research that is being performed."*

Radiotherapy, stereotactic radiosurgery and proton beam therapy

One fifth (18%) of attendees had experienced radiotherapy, and only a small percentage of respondents selected stereotactic surgery (5%) or proton beam therapy (2%). Radiosurgery is

often offered after conventional surgery, and after medications have stopped working. These approaches come with their own challenges, as described by patients.

Radiotherapy treatment is challenging and can take a long time to take effect. A caller explained, *“because my growth hormone levels were elevating and I maxed out on the dose of both the Somavert and Somatuline, in 2018, we decided to move ahead with doing CyberKnife radiation. So, that was five days of treatment where you're bolted to a table with a mask on your head. And it's a little bit anxiety producing for somebody who has claustrophobia.”* She described a year after the therapy, *“I had a headache for about four or five months, but nobody could figure out why. The scans were all normal. They were really debilitating. I would go to work and then when I came home, I would pretty much go to bed because the pain of the headaches was pretty intense. So far, the radiation has not taken full effect. They said that it could take at minimum two years before you start to see a response from the remaining tumor.”*

Radiation has side effects including secondary adrenal insufficiency. For one patient whose hormone levels were not controlled by treatment, *“within 6 months IGF-1 levels climbed to pre-surgical levels due to tumor remnants. Underwent fractionated stereotactic radiation treatments. Six years later, I have started to deal with initial loss of hormones due to hypopituitarism.”* She also *“developed migraines since radiation treatments.”* A panelist reported fatigue as a side effect: *“I had two surgeries and one round of radiation. By having the effect of radiation over an amount of several years, I've damaged and slowly killed my pituitary gland. Because of this, I now suffer from secondary adrenal insufficiency. This is important because Acromegaly and adrenal insufficiency together cause heavy fatigue.”*

Strategies for managing Acromegaly symptoms other than medical treatments.

Individuals with Acromegaly described many other approaches that they used to manage their disease symptoms. Responses to the polling question are in **Appendix 6, Q2** and described below, along with patient comments and a description of management strategies not included in the polling response options.

Most patients living with Acromegaly use a combination of lifestyle strategies to help manage their symptoms. Most respondents (76%) reported managing Acromegaly symptoms with a healthy diet, 60% used increased exercise and half (48%) used stress management strategies.

They shared their success using these approaches. One patient said, *“I am willing to do whatever is within my control to benefit my health. Eating right, sleeping, exercise, etc. ... Recently I changed my diet, eliminating sugar, salt, caffeine, and eating quite low carb. The changes in my joint pains and my nighttime heart rate were immediate.”* Another panelist shared his success: *“I supplement my medical treatment with exercise as much as I can, because I have a lot of joint issues, and nutrition and watching what I eat. And so, that's pretty much it. It's been fairly steady for me, the control. And there's still obviously residual tumor about 5%, that has been very stable, which is apparently not that usual.”* One patient described her diet regimen and her success, *“With help from a nutritionist, I adopted a diabetic eating plan, monitoring carb consumption and adding more lean protein and healthy fats to what had been a more vegetarian diet. I have lost 30 pounds, my BMI is in the normal range, my A1C is now*

5.9, and I feel very comfortable with eating this way. Before my Acromegaly treatment I always felt hungry, and it was difficult to stay on an eating plan. My blood pressure has also returned to the normal range after the weight loss.” This care comes at a cost, as one panelist reported: “Health is just my number one priority, it's all I'm doing. I can feel pretty good. Really good. But that means my whole life is focused on self-care basically. It's like a full-time job.”

Many described how challenging exercise can be with the pain and joint issues associated with Acromegaly. For one caller: “Movement is really important especially with the joint issues. It's hard to get started because of the pain but once you overcome that kind of hill, it gets better and then you can do more.” She reported that she has experienced minor improvement in bone pain. One of the panelists described, “I started doing a little bit more walking. It's not a big walk. It's like maybe a 10-minute walk around the block kind of thing, but I try to get out there and have a short little walk just to keep up my muscles and bones a little bit more flexible. The bone pain is now starting to present itself. Well, the walk helps me to mentally be clearer, and more focused and try to be... How can I say it? Happier.” Other participants described using daily yoga, or warm water arthritis exercise classes to help with constant joint pain.

About 43% of the poll respondents reported using dietary supplements to control symptoms. Supplements mentioned included high dose magnesium, fish oil, probiotics, and apple cider vinegar tablets daily and take glucosamine and/or turmeric for inflammation. *One patient said that she, “Added amitriptyline for headaches plus glucosamine and turmeric. How well have these treatments treated the most significant symptoms of Acromegaly? Very well - minimal joint pain. Headaches - minimal and fluid retention is minimal. ... It's very well controlling the symptoms that were my biggest concern and everything else has become much easier.”*

One third (34%) of respondents used other weight maintenance strategies. Several reported successes with gastric sleeve procedures for symptom control. One panelist who was in remission for a decade prior to surgery, “I didn't feel a whole lot better even in remission. ... I still felt like I had Acromegaly. 17 months ago, I had a gastric sleeve procedure, which is removing a good portion of your stomach, like about 80% of it, that's where the ghrelin is produced the most in our body, some of them produced in the liver also. But, immediately after that surgery, I have no more body pain, no more headaches, nothing, I feel amazing... “without that extra ghrelin, it's just been amazing. My ghrelin level was three times higher than what it should have been.” For another, weight loss surgery wasn't as successful: “my weight did become out of control so I decided to have weight loss surgery in the hopes that it would help improve my quality of life. Although I lost weight, my fatigue continues, and it is very hard to keep up with my normal activities.”

One third (33%) of Acromegaly patients used therapy and counseling to deal with their disease. One panelist said, “I have found that seeking the help of a therapist has really improved my quality of life. And I think that's something that is appropriate to address with Acromegaly. ...But I've also gained a lot of help from meditation. So, I start each morning with meditation, that seems to kind of calm my mind a little bit and get me started off on the right track. Another said, “I'm also seeing a psychologist to help with the mental aspects of dealing with a chronic condition.”

Almost one third of respondents (28%) mentioned using other approaches including chiropractic, massage especially for injection site issues, peer/patient support, positive thinking.

- For one panelist, *“chiropractic appointments are another thing that are not necessarily recognized as being helpful but for me, they really have. And massage also helps a lot with the muscle tension and also, I think there's mental effects from massage and relaxation, meditation and that kind of thing. ... “because of the pandemic, I haven't been doing massage and chiropractic appointments. So, I definitely feel the results of that absence and I would say it's pretty significant.”* Others also reported that massage therapy works for them, *“I use a heating pad to ease the pain and have now started having massage therapy to break down the lumps and relax the swollen muscles, which helps really well, and can use the area again for another injection and the injections go in smoother for the nurse.”*
- Many meeting participants described how much they relied on peer support, including the Acromegaly Community Facebook group, for education, information, support and comfort. For one, *“I have learned the most about Acromegaly in the Acromegaly Support group on FB”*. For another, *“I learned ALL I know from this group. 9 doctors and 8 years it took to get to my diagnosis. Have the MD tell the patient about this wonderful group!”* One caller formed her own support group *“I did not have anyone to talk to here in Ottawa. So, I did form a support group, and I've talked to many, many people here in Ottawa and abroad about what they're suffering from. And again, I feel very lucky and wanted to get people together so that no one would feel alone and to try to advocate for early diagnosis.”*
- Finally, others relied on positive thinking in addition to a healthy diet and exercise *“I mentally and emotionally work hard to keep a positive attitude about life... I try to block the negative thoughts and think of positive thoughts to try to keep me balanced.”*

Other approaches described in the polls include modifications/accommodations at home (28%), CBD/cannabis (28%) and decreased exercise (22%). One parent described how her *“son takes CBD - has brain neuro-protective mechanisms. Also helps provide calmness.”*

How treatments address the most significant symptoms of Acromegaly: for many, there is an enormous gap between biological control and symptom control.

In the previous section, patients living with Acromegaly discussed successes, challenges and trade-offs with existing Acromegaly treatments. Patients were asked two final questions to evaluate how well treatments work and improve the ability to do specific activities that are important in daily life. First, they were asked if they considered their disease biochemically controlled, which means their IGF-1 was within the normal acceptable range for their gender and age. For the second question they were asked if they consider themselves symptomatically controlled. The results of these polling questions demonstrate a very large gap between biological and symptomatic control and reveals a huge unmet treatment need for patients with Acromegaly. Polling results are in **Appendix 6 Q3 and Q4.**

Many patients living with Acromegaly described how their symptoms remain unresolved despite biochemical control. For one panelist, *“Even though my IGF-1 and growth hormone levels have been within normal range, I still have fatigue and joint pain.”* A similar story was

echoed by many other patients: *“Having had surgery, drug therapy and radiotherapy my GH is now in normal range. I am still left with constant headaches, fatigue, weight issues, lack of sleep amongst other things.”* And another, *“I’m now on Somavert, which has normalized my IGF-1 and improved fatigue, but I still experience joint pain (both peripheral in hands/feet/knees and centrally in the entire spine), pain/swelling in hands/feet with just minimal walking and cooking.”* One caregiver expressed her frustration: *“While my daughter’s IGF-1 is just inside the normal range while she is on oral octreotide (which she dislikes and will be returning to Somatuline soon) and injected Somavert, she is still experiencing symptoms.”* One patient described how, *“Doctors and Pharma focus mostly on controlling IGF-1, but once we are on this crazy and painful emotional rollercoaster, the symptoms don’t all STOP, they keep tumbling like dominoes.”* A panelist summarized the thoughts of many: *“I wish more doctors would take more of an interest in the quality of life instead of just dismissing us, because our IGF-1 and growth hormone levels are within normal range. I do believe there needs to be more of a focus on the quality of life with the rare disease of Acromegaly.”*

Even with optimal treatment, participants living with Acromegaly experience a heavy disease burden. Some experience a sense of hopelessness. A panelist emphasized that even with treatment and symptom control, his life is not normal. *“One of the biggest things I want to stress about Acromegaly, just because the medicine has our IGF-1 and growth hormone levels within the normal range does not make us normal. We still have to live with how Acromegaly has disfigured our face. We are still fighting every day with our fatigue and joint pain. Also, as a male, I deal with the emotions of ED. I had both my knees replaced due to the effects of Acromegaly at the age of 54.”* For one caller, *“a year and a half into working towards remission, I know I still have a long way to go. It’s still kind of mind-boggling to me that I am having some of these symptoms that seem to be either increasing or new ones coming up.”* And for one patient, *“Most days I question whether taking my Acro shot is worth it.”*

Even successful Acromegaly treatment can’t reverse or repair the damage already done. One patient stated, *“When discussing the management of this Acromegaly you need to include the damage caused by the years of uncontrolled IGF-1 or the side effects of the medication.”* Another patient described how her medication, *“helps me to reduce symptoms but it cannot reverse the damage that was already done. Without Somavert, the quality of my life would be miserable and I would die much sooner.”*

Recommendations for the future/drug development: What patients with Acromegaly need in an ideal treatment.

For the final polling question, patients living with Acromegaly were asked to select their top three health concerns that they would rank as most important for a possible drug treatment, short of a cure. The results closely reflect what patients chose as their most frequently experienced and most troublesome Acromegaly health concern. A total of 57% of individuals with Acromegaly selected a treatment for fatigue/muscle weakness, followed by 49% who would like a treatment to address joint problems and arthritis. A drug for biochemical/IGF-1 control was selected by 44% of participants as one of their top three priorities for possible drug development. The remaining health concerns selected for potential drug development were

ranked much lower than these initial three, and include cardiomyopathy/heart problems, headaches, soft tissue swelling, anxiety/depression, enlarged facial features, type 2 diabetes, enlarged hands and feet and others, and are presented in **Appendix 6, Q5**.

In addition to drug treatments for the health concerns mentioned above, patients living with Acromegaly made many recommendations throughout the meeting and in online comments. These are captured in three categories below: Acromegaly treatment priorities, Acromegaly research priorities, and education/resource priorities with a focus on earlier diagnosis.

Acromegaly treatment priorities

The following is a list of the many treatment priorities and recommendations made by Patients living with Acromegaly.

Therapies to address the following health concerns not included in the polls.

- Therapy to shrink or control tumor growth. One patient requested, *“A future treatment from a drug that wasn't listed in the final survey was tumor growth control. A drug controlling tumor growth is a priority.”* She specified that *“The control needed would be for the pituitary tumor, but quite a few of us with acro have or grow other tumors. There are a number of patients who have genetically tested negative for various types of MEN (MEN-1, MEN-4, etc.); however, we still have multiple unexplained MEN-like tumors.”* A panelist requested: *“More research with medications that aim to reduce the residual tumor size. So, it makes it easy to take the whole tumor out.”*
- Therapy to restore or preserve pituitary function. One patient said, *“I would like to add that for most Acromegaly patient's quality of life gets worse with hypopituitarism. Preserving pituitary functions should be the most important.”*
- Therapy to address hunger and weight gain. One patient said, *“I believe that we feel hungrier than other people and that this urge to eat must be one of the important factors somehow related to our disease. Most of us struggle to maintain healthy weight. I hope that there will be further research on Ghrelin and other hormones which increase and/or control hunger.”*

Improvements to medication efficacy, tolerability and administration. One patient provided a list, *“I would like to have more options on medications that are far more effective, preferably well-tolerated, and non injectable.”* She added: *“Why only a few medications are being made, and most aren't close to 100% effective? Why do most patients have to take combo therapy and often on the max dose to be effective? We should have different drugs to better control and effectively lower IGF-1 in all types of tumors without the side effects of diabetes, cholelithiasis, etc. Medications should be improved substantially, so there's no need for radiation, which according to some studies, complicates disease management and increases morbidity and mortality years after the radiation therapy.”*

- **Greater medication efficacy.** For one patient, *“Regarding future treatments, the method of delivery is less important to me than the effectiveness. A daily injection is really no problem at all if it's having the desired effect of improving IGF-1 and symptoms.”*
- **Improvements in the way medications are administered.** Their recommendations included more oral formulations and less frequent dosing. A panelist said, *“I think that any medication that is away from injections and the burden of injections and aura would be*

great.” The mother of a patient with Acromegaly stated, “It is my hope for him in the future, that there will be more oral medications available that have low side effects and decreased frequency in the need to take them. Quality of life is so important to me and him.” Another panelist stated, “The quality of my life will drastically improve if the daily Somavert injection could be either an oral dose or have a long-lasting effect as to not inject myself every day, it'll be a game changer. How wonderful it would be to not have the daily painful injections, which leave bruises on my legs and my arms, and are a constant reminder of my incurable disease.” And from another, “Short of finding a cure, I'm hoping that the future brings with it a once-a-day oral therapy for Acromegaly. Only having to take it once a day would simplify my treatment regimen and I am hopeful that this medication will relieve my daily fatigue.” And another, “For future treatment, something more long acting (I'm currently on Sando LAR and biweekly Somavert) that could help eliminate the breakthrough symptoms and the cyclical nature of my good days.”

- **Improvements to the way medications were packaged.** One asked, “can they stop packaging it in single dose boxes?! The amount of waste created by each dose is crazy. It's a medication that's designed to be given every day, why would you ever need an individual dose? We don't need 16 copies of the prescribing information every month.”

Lowering of the GH/IGF-1 reference ranges. Noting the difference between biochemical and symptomatic control of the disease, many meeting participants recommended a change to the current GH/IGF-1 ranges. One asked, “It may be too late to help me, but should lower GH and IGF- 1 recommendations be considered?” Another said, “I wish that normal range would change for Acromegaly patients. The high third of normal range is set too high. Most of us feel best and most pain free when our IGF-1 levels are in the lower third of normal range. I hope that this will soon be part of official Guidelines for treating Acromegaly.”

Greater standardization of IGF-1 laboratory testing. One patient stated, “It would also be important to get a standard IGF-1 level test. I have heard too often that each lab does it differently so across the board it seems to be difficult to be doing a comparison of apples to apples.”

Hormone monitors to allow IGF-1 and GH evaluation in real time. One panelist pointed out, “One of the key factors that's really lacking in the Acromegaly community is our ability to monitor our IGF-1 levels. Getting IGF-1 levels done, it's a process. I mean, it's getting blood work done, but then it's waiting for one to three weeks for results. ... So, if there was some type of thing we could wear that could monitor our IGF-1 levels throughout the day, we could make more appropriate changes in our diet and our sleep schedule and a lot of different things. So, boy I'd love for the FDA to approve something like that.” Many others agreed. One said, “If I had a hormone monitor (especially during my monthly cycle when some symptoms seem to be worse), I could better understand how my behaviors contribute to my hormone function and I could HELP MYSELF BETTER which would increase my feeling of control about this disease.”

Drug implants for consistent delivery. Many participants wished for a device similar to an insulin pump used with a glucometer. One panelist suggested, “if there was something like that, ... that can be used with checking your IGF-1 and regulating some sort of treatment program that would dose you based off what your IGF-1 were to try to keep it within control of those

levels would just be awesome.” A patient said, “Years ago I participated in an implant study. I would love to see our medications use this form of administration. This study tested a 6-month implant and to be able to forget about medication for a while was wonderful. I would love for a therapy that was safe and effective that truly allows patients to forget that they are sick because they don't have to administer it daily, weekly or even every 28 days. Something that lasts until the next dose and not have breakthrough symptoms.” Another reinforced this, “I'd like to see an implant, maybe just under the skin or even a patch that we can wear that just slowly disperses our medication, because I know that there are a lot of us that have problems with the injection sites.”

Acromegaly research priorities

Patients with Acromegaly made many other Acromegaly-related research recommendations, many of which can be found in **Appendix 7**. The following three priorities were mentioned several times.

Research to understand the contribution of ghrelin. The enormous gap between biological controls and symptomatic control points to the existence of other important and unrecognized biological pathways. This includes more research into the role of other hormones including ghrelin. One panelist described ghrelin, *“it's part of the growth hormone spectrum, and it was causing me all kinds of issues. It's also known as the hunger and fat storing hormone.”* One of the panelists echoed that ghrelin, *“is something that I'm hoping the medical community really starts to pay attention to because I also believe that ghrelin levels are greatly impacted by Acromegaly and our pituitary tumors.”* Another agreed, *“I believe that we feel hungrier than other people and that this urge to eat must be one of the important factors somehow related to our disease. Most of us struggle to maintain healthy weight. I hope that there will be further research on ghrelin and other hormones which increase and/or control hunger.”* One patient suggested several ghrelin-related research topics: *“More research on Ozempic and how it could potentially decrease the ghrelin hormone. More research on ghrelin. More research on how a gastric Sleeve decreases ghrelin and see endocrinologists learn more about this hormone and how they can tackle the issues that may arise from this.”*

Finally, one described a challenge that patients in the Acromegaly community face, *“It's very hard to get the endocrinologist on board with even checking the ghrelin levels. They don't seem to believe it right now, but the bariatric community is very much into what ghrelin does to a person besides making them obese. So, it's an interesting hormone and something that really needs to be looked into. The endocrine society is getting better at acknowledging that, but still they don't want to test it. They don't want to write about it. So, I really would like to push that issue a little bit.”*

Research on fertility, the effects of Acromegaly medications on pregnancy and their safety and efficacy during breastfeeding. One patient said, *“I would love to see more research on the effects on these medications on pregnancy and their safety and efficacy during breastfeeding. Making a decision that could impact your unborn child or infant is agonizing. If we knew what was safe, we would not have to reduce or delay taking medications that are vital to getting and keeping our Acromegaly under control.”* Another patient wrote: *“I wish more could be done to help women with this condition that want to have kids.”* Another asked: *“What have you found*

over the years in regard to Acromegaly and pregnancy? How does the current medicine affect children born to mothers on Octreotide at conception?" Related to this was a suggestion for research on how Acromegaly impacts women throughout their different life stages including perimenopause.

Establishing a national database of information or a patient registry. Several patients mentioned this research need. One said, *"The scientific community could look at the possibility to create a patient registry containing information about how the disease is evolving over time. We still have to learn about the disease. Quality of decisions is related to the quality of information we have to make those decisions."*

Education and resource priorities with a focus on earlier diagnosis

During the meeting, patients living with Acromegaly recommended other important priorities.

Earlier diagnosis to reduce the initial and ongoing damage that Acromegaly presents and ultimately an improved quality of life. Many patients articulated the wish for earlier disease diagnosis, to help others not yet diagnosed. One suggested, *"Early diagnosis could be the key to reducing the burden on our medical system both in terms of costs in dollars and negative health consequences to individuals. The FDA could take an active role in education of Acromegaly by teaming with advocate patients, groups and community leaders to provide funding for an ongoing campaign to make Acromegaly a household word that everyone understands."* One participant recommended developing an *"app that everyday people can use to find out if they may have Acromegaly based on a series of questions and answers. This may help in getting people an earlier diagnosis."*

More education for the general public. One patient said, *"I think it's important to teach the general public as well as healthcare professionals about the symptoms of Acromegaly, so that it's all put together in one package and healthcare professionals are not just looking at one symptom and treating that one symptom alone. ... I believe that there are many more people out there that are suffering from Acromegaly that have yet to be diagnosed. And many years are going by for these patients, that their bodies are deteriorating."* Another commented: *"It's very challenging to educate people what Acromegaly is. I think it is such a hard disease to have when no one knows what it is, and you feel so alone."*

Wider coverage of Acromegaly in medical school curriculums. One patient said, *"Health care professionals on all levels need to be educated [that] this disease ... is more prevalent than once thought. When a patient presents with symptoms, the health care professional must think about the whole picture and not just focus on the pieces. The general public needs to understand what the symptoms are so they can have discussions with their medical team about Acromegaly."* This was echoed by another, who said, *"Require Medical, Nursing, PA and osteopathic schools to cover Acromegaly as well as other diseases of the pituitary gland."* This approach might also prevent Acromegaly pain being misattributed to idiopathic fibromyalgia, as one patient who was also a physician observed, *"If we can stop outsourcing every symptom of this condition to another rare or perhaps common condition then we can develop better treatment strategies which will actually benefit people with Acromegaly instead of filing them in an "idiopathic" filing*

cabinet. You see if we are saying we don't know the cause of something we are less likely to find a cure or an effective treatment.

Additional patient education and mental health resources. Many participants described how they had to educate themselves or were educated by patient/peer support groups, including one who said, *"I wish that patients would be more educated about diet and effect of different food on Acromegaly. I have learned most facts about this on my own and by comparing experiences with other Acromegaly patients in the Acromegaly support group."* Other patients wished for the development of Acromegaly- specific therapy, *"physical therapy specifically developed for those with Acromegaly, to address the Acromegaly-related structural and functional changes to the musculoskeletal system that lead to changes and accelerated wear and tear on the joints along with inflammation, muscle pain, fatigue and nerve changes."* Two other resources that were identified as lacking during the meeting and are mentioned here again include:

- Mental health resources to support patients living with Acromegaly and the challenges they face.
- More resources, information and continual support for people transitioning from childhood and adolescent care to adult care.

Incorporating Patient Input into an Acromegaly Benefit-Risk Assessment Framework

The FDA uses a Benefit-Risk Assessment Framework which includes the following decision factors: analysis of condition, current treatment options, benefit, risk, and risk management. The Framework provides an important context for drug regulatory decision-making, including valuable information for weighing the specific benefits and risks of a particular medical product under review.

Table 1 serves as the proposed introductory framework for the Analysis of Condition and Current Treatment Option rows, which could be adapted and incorporated in the FDA's Benefit-Risk Assessment for a new Acromegaly treatment under review. The information presented captures the perspectives of the patients living with Acromegaly presented at the January 21st, 2021 meeting, as well as polling results and comments submitted before, during and after the meeting through the online portal. The table speaks to the severity of the disease and the limited treatment options currently available. Note that the information in this sample framework is likely to evolve over time.

TABLE 1 Sample Benefit Risk Table

	EVIDENCE AND UNCERTAINTIES	CONCLUSIONS AND REASONS
ANALYSIS OF CONDITION	<ul style="list-style-type: none"> Acromegaly is caused by the growth of a benign pituitary tumor resulting in high circulating GH & IGF-1 levels. This leads to somatic growth increases and metabolic dysfunction throughout the body. Patients living with Acromegaly experience high numbers of severe symptoms affecting many body systems including fatigue/muscle weakness, arthritis, joint pain, anxiety, depression, mood swings, acromegaly, headaches, enlarged hands/feet and others. 	<ul style="list-style-type: none"> Acromegaly has a heavy health burden, impairs physical appearance, increases mortality, and is associated with poor QoL. Delayed diagnosis is a significant determinant of adverse outcomes. Cumulative, persistent high levels of GH & IGF-1 irreversibly damage bones and other body tissues.
IMPACT ON ACTIVITIES OF DAILY LIVING AND QoL	<ul style="list-style-type: none"> Uncontrolled Acromegaly symptoms and comorbidities profoundly affect all aspects and activities of daily living. Patients with Acromegaly live in fear of tumor regrowth, disease progression, additional symptoms, comorbidities, missed/dismissed symptoms, premature death. 	<ul style="list-style-type: none"> Acromegaly impacts patients' physical, social, emotional and psychological health.
CURRENT TREATMENT OPTIONS	<ul style="list-style-type: none"> Acromegaly management involves an integrated surgical, radiation, and medical therapy approach. Patients have chronic treatment regimens which lasts for their lifetime. Acromegaly treatments are not curative and can't reverse or repair damage already done. Treatments must address both the pituitary tumor as well as many consequences and symptoms. 	<ul style="list-style-type: none"> Despite extraordinary treatment efforts, most patients with Acromegaly are unable to achieve symptom control. Treatment goals are misaligned to outcomes: symptom control is not achieved, despite having biological control of GH & IGF-1 levels.
PROSPECTS FOR FUTURE TREATMENTS	<p>Acromegaly drug therapy priorities: address fatigue/muscle weakness, joint problems, arthritis and biochemical/IGF-1 control; shrink or control tumor growth, restore or preserve pituitary function and address hunger and weight gain; improve medication efficacy and administration; lower recommended GH/IGF-1 ranges, hormone monitors to evaluate IGF-1 and GH in real time, drug implants for consistent delivery.</p> <p>Acromegaly research priorities: elucidate disease pathways especially the role of ghrelin; determine Acromegaly's impact on fertility and unborn children; determine safety and efficacy of Acromegaly drugs in pregnancy/breastfeeding.</p> <p><i>See the voice of the patient report for a more detailed narrative.</i></p>	<ul style="list-style-type: none"> Acromegaly knowledge is lacking in both general and specialist medical communities. Many patients remain undiagnosed. A paradigm shift is necessary: focus on symptom-free living and QoL rather than reaching recommended IGF-1 & GH levels.

Conclusion

The January 21, 2021 Acromegaly EL-PFDD meeting was attended by individuals from across the Acromegaly disease spectrum, including patients along the full spectrum of disease severity, and as well as individuals who both have or have not utilized existing treatment options. The information gathered at the meeting is presented in this Voice of the Patient report. It will inform and impact decisions regarding the development and review of drugs to ultimately catalyze significant improvements for the health and quality of life for those living with Acromegaly. We believe that the outcomes of this meeting can change the future for patients living with Acromegaly.

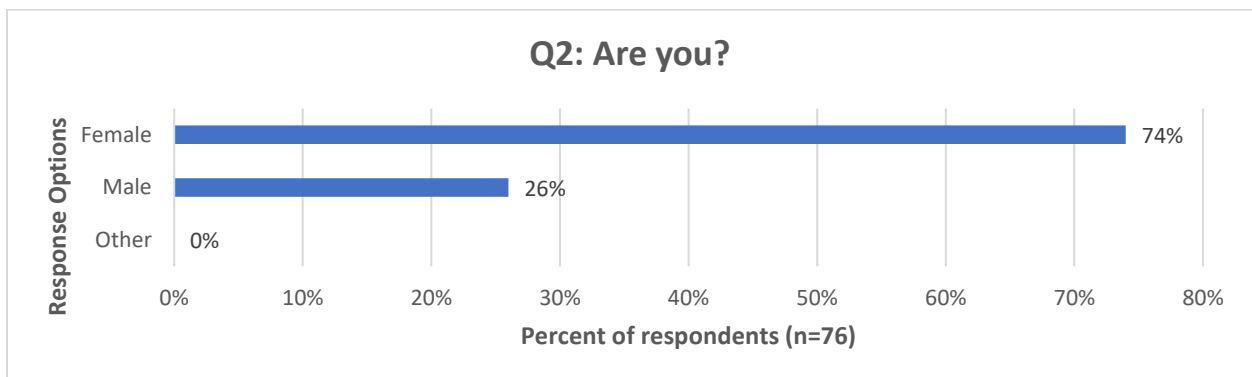
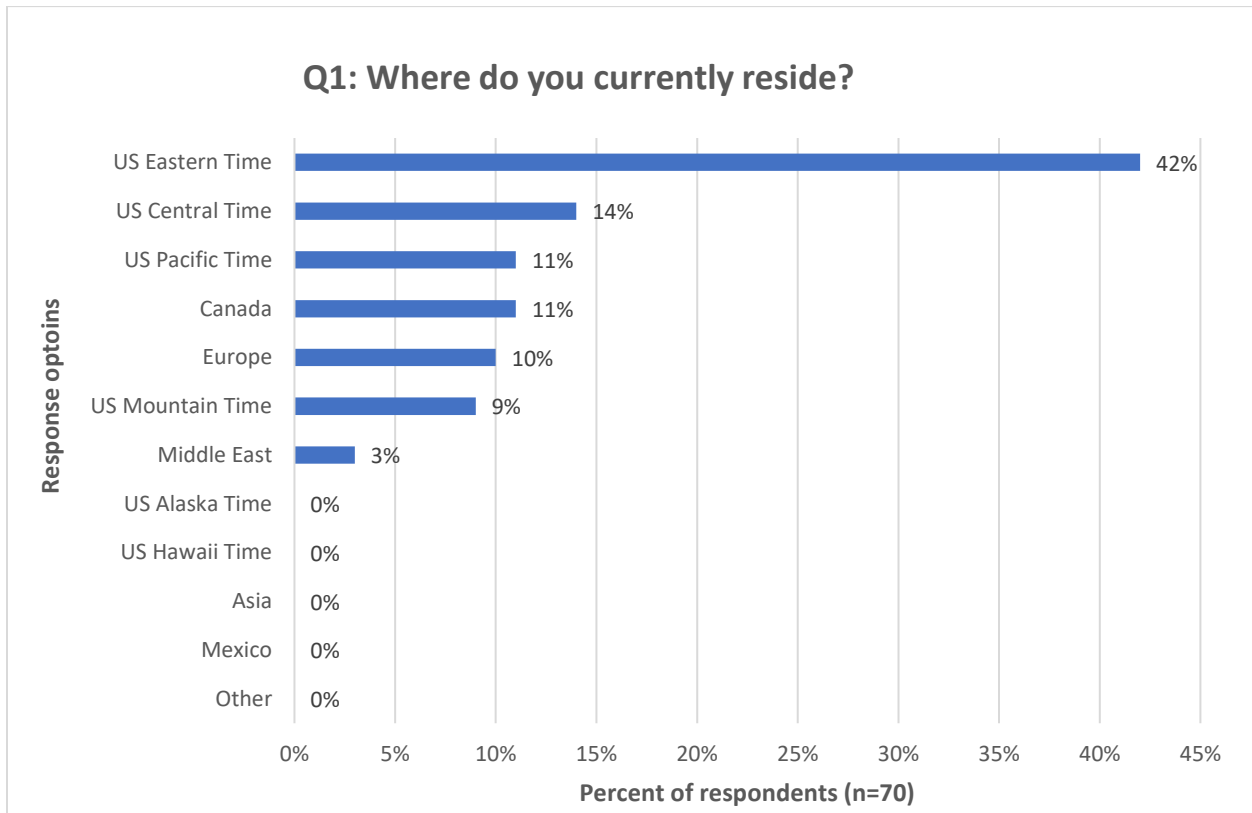
Patients living with Acromegaly demonstrated that they are passionate about supporting one another and educating others about the disease. This includes the medical community and the general public in order for more patients to be diagnosed at an earlier stage, to be less severely impacted by the irreversible damage, and to receive the support and knowledge that they need to achieve the best outcomes.

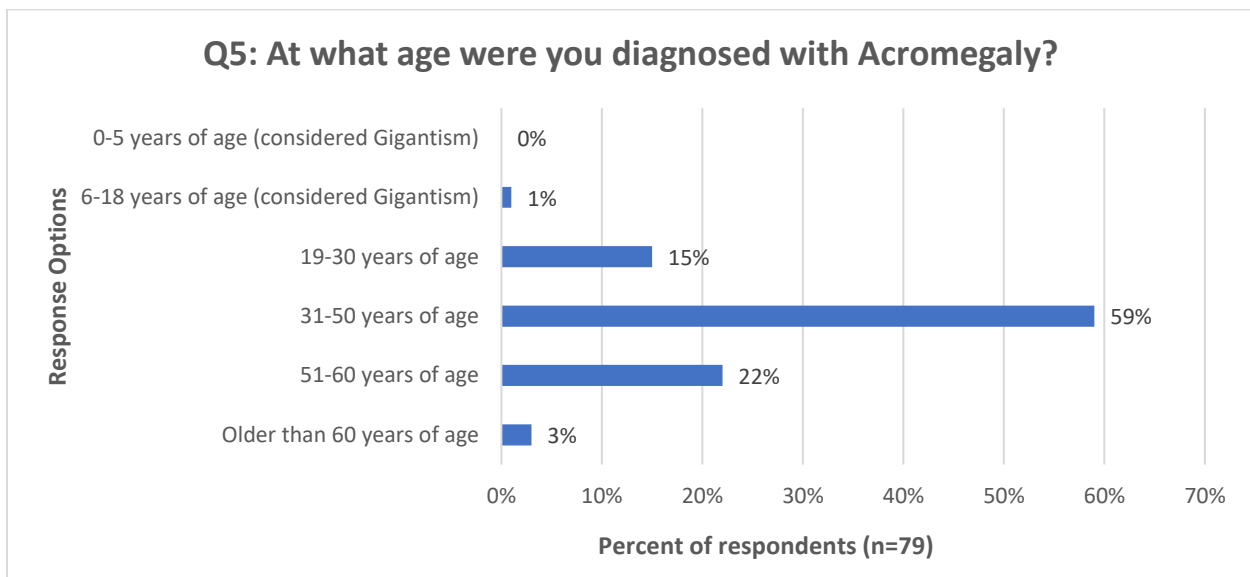
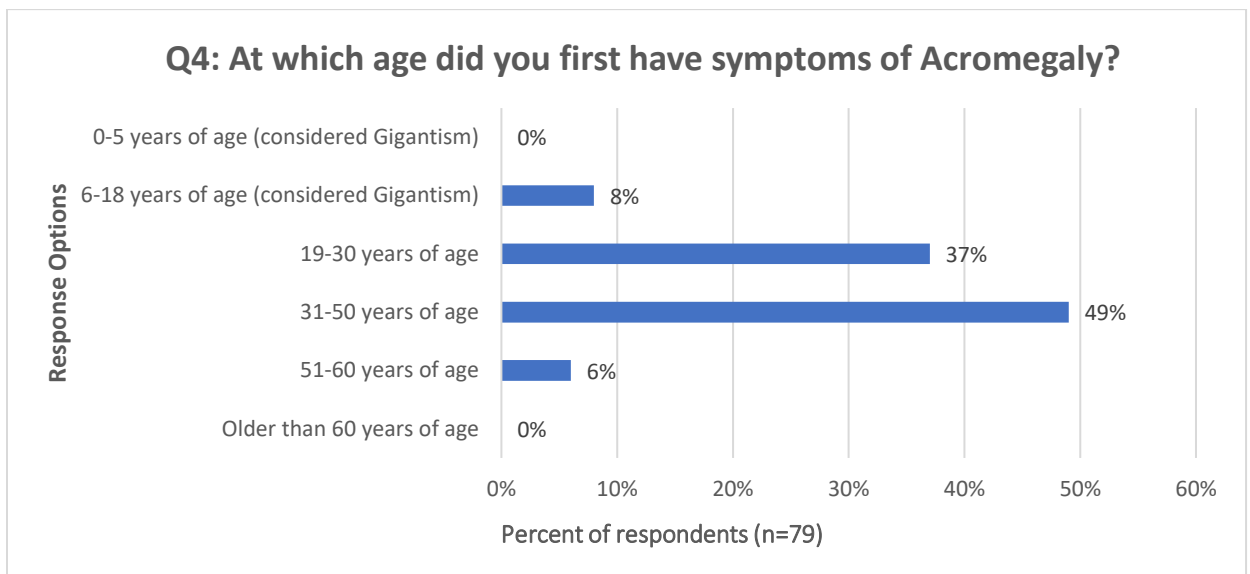
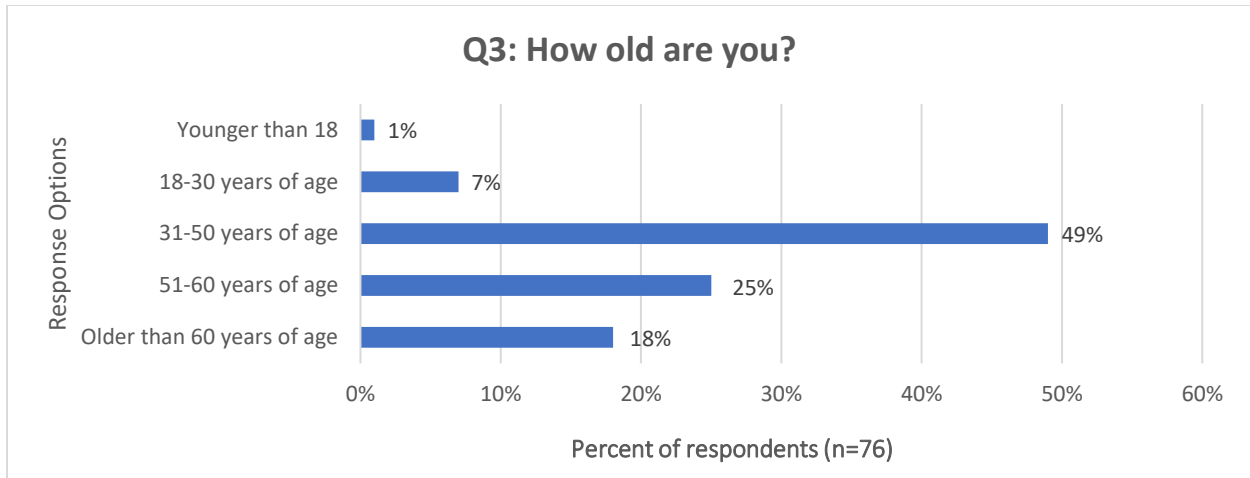
Acromegaly Community Inc. is grateful for this opportunity to share our community's voices through this report and, in turn, teach everyone and decision-makers about this disease to work on finding better treatment options for Acromegaly and improving the quality of life for the patient.

Appendix 1: Meeting Demographics

These graphs include those attendees who chose to participate in online voting. The (n=x) on the X axis shows the number of patients who responded to each polling question.

While the response rate data for these polling questions is not considered scientific data, it provides a snapshot of who participated in the EL-PFDD meeting and is intended to complement the live and pre-recorded comments throughout the meeting.





Appendix 2: Acromegaly Meeting Agenda

Virtual Externally Led Patient-Focused Drug Development Meeting

Meeting Date: 21 January 2021

10:00 am – 3:00 pm EST (Virtual Meeting)

- | | |
|-------------------|--|
| 9:30-10:00 a.m. | Online Registration |
| 10:00-10:05 a.m. | Opening Remarks
Jill Sisco, President, Acromegaly Community Inc. |
| 10:05-10:15 a.m. | Welcome Remarks FDA
Theresa Kehoe MD, Director of the Division of General Endocrinology within FDA Center for Drug Evaluation and Research |
| 10:15-10:25 a.m. | Scientific Overview: Medical review
Shlomo Melmed, MD, MB Cedars-Sinai |
| 10:25-10:30 a.m. | Introduction & Meeting Overview
James Valentine, JD, MHS, Meeting Moderator |
| 10:30-10:35 a.m. | Demographic Polling
James Valentine, JD, MHS, Meeting Moderator |
| 10:35 -11:00 a.m. | Session 1 Panelists: Symptoms and Daily Impacts |
| 11:00-12:15 p.m. | Audience Discussion & Polling |
| 12:15-12:45 p.m. | Lunch |
| 12:45-12:50 p.m. | Introduction to Afternoon Session |
| 12:50-1:00 p.m. | Scientific overview: Current and Future Treatments
Dr. Alan Harris, MD, PhD, NYU-Langone Medical Centre |
| 1:00-1:25 p.m. | Session 2 Panelists: Current and Future Treatments |
| 1:25-2:50 p.m. | Audience Discussion & Polling
James Valentine, JD, MHS, Meeting Moderator |
| 2:50-2:55 p.m. | Summary Remarks
Larry Bauer, RN MA, Hyman, Phelps, & McNamara, P.C. |
| 2:50-3:00 p.m. | Next Steps & Concluding Remarks
Jill Sisco, President, Acromegaly Community Inc. |
| 3:00 p.m. | Adjourn |

Appendix 3: Discussion Questions

Discussion questions were posted online to guide Acromegaly patients calling into the meeting and for those submitting written comments to the online portal.

TOPIC 1 Living with Acromegaly: Symptoms and Daily Impact

1. Of all the symptoms of acromegaly, which 1-3 symptoms have had the most significant impact on you or your loved one's life?
 - a. Which symptoms most affect you or your loved one now?
 - b. Which symptoms were the most significant at other times in you or your loved one's life?
2. How has acromegaly affected you or your loved one on best and on worst days? Describe your best days and your worst days.
3. Are there specific activities that are important to you or your loved one that you or your loved one's could not do at all or as fully as you would like because of acromegaly?
 - a. How does this affect relationships/friendships with others?
 - b. How does it affect life activities (school/work, abilities, relationships, self sufficiency, living situation, activities, etc.)?
 - c. If you or your loved one could do one activity that you or your child currently are unable to, what would it be?
4. What worries you most about your acromegaly?

TOPIC 2 Perspectives on Current and Future Approaches to Treatment

1. What are you currently (or recently) doing to manage your acromegaly symptoms or your loved one's symptoms?
 - a. Which specific acromegaly symptoms do the treatments address?
 - b. How has this treatment regime changed over time and why?
2. How well have these treatments treated the most significant symptoms of acromegaly?
 - a. How well do these treatments improve the ability to do specific activities that are important in daily life?
3. What are the most significant downsides to you or your loved one's acromegaly treatments and how do they affect daily life? (Examples of downsides may include bothersome side effects, going to the hospital for treatment, etc.)
4. Assuming there is no complete cure for your acromegaly, what specific things would you look for in an ideal treatment for your acromegaly? What factors do you consider when making decisions about selecting a course of treatment?

Appendix 4: Patient Panel Participants and Callers

Unless otherwise indicated, all individuals listed below are living with Acromegaly.

Session 1: Living with Acromegaly - Symptoms and Daily Impact

Pre-recorded Panel 1

Judy K.
Jason M.
Ellen K.
Jim R.
June M.

Live Zoom Panel 1

Mary K.
Bonnie E.
Steven K.
Donna W.

Live Callers

Diane
Connie (*Caregiver for her husband*)
Tracy
Carrie
Suzanne

Brenda
Jill
Emorine
Patty (*Caregiver for her son*)

Session 2: Current and Future Treatments

Pre-recorded Panel 2

Traci
Byron & Alicia D. (*Patient living with Acromegaly and his caregiver*)
Helena C.
Kenneth S.
Shannon G.

Live Zoom Panel 2

JD F.
Deanna B.
Bert N.
Lauren B
John G.

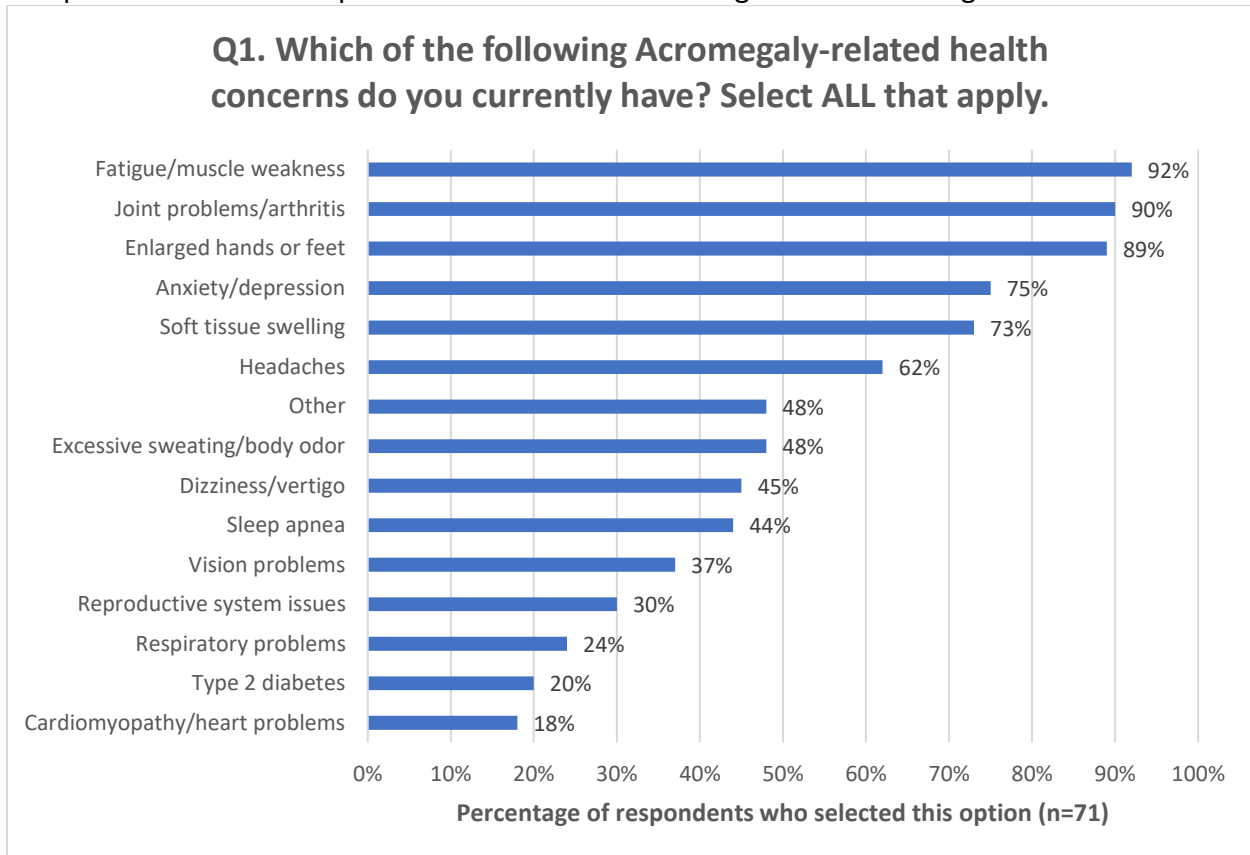
Live Callers

Judy
Ellen
Dee
Traci
Brittany
Bella
Eladia
Rita

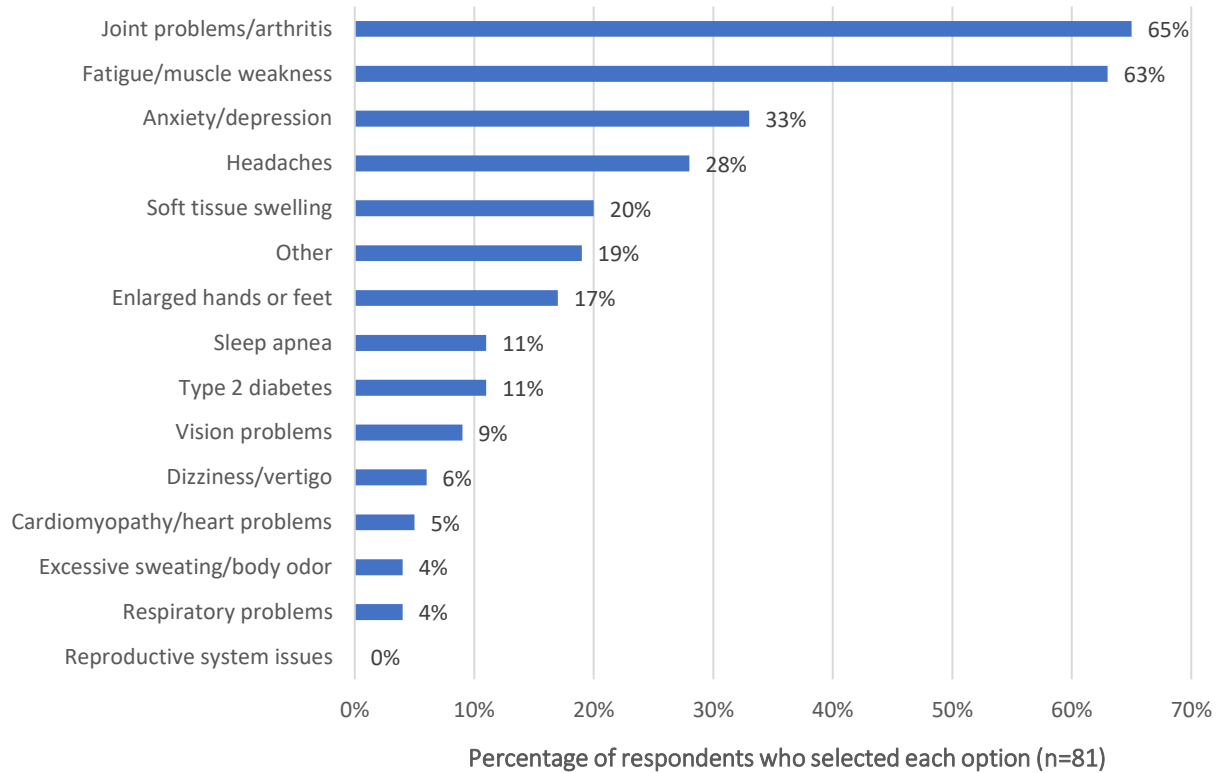
Appendix 5: Topic 1 Polling Results. Living with Acromegaly – Symptoms and Daily Impacts

These graphs include those attendees who chose to participate in online voting. The (n=x) on the X axis shows the number of patients who responded to each polling question.

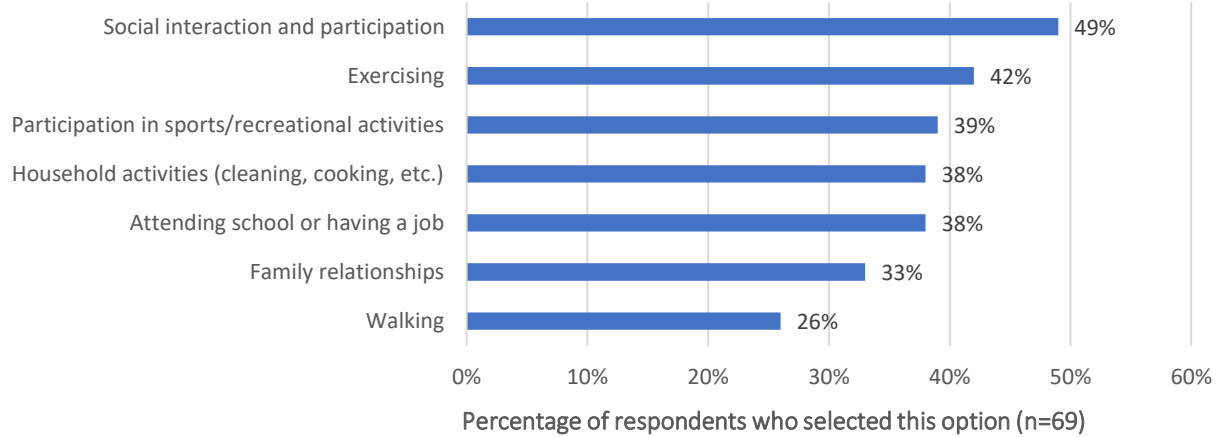
While the response rate data for these polling questions is not considered scientific data, it provides a snapshot of who participated in the EL-PFDD meeting and is intended to complement the live and pre-recorded comments throughout the meeting.



Q2. Select the TOP 3 most troublesome Acromegaly-related health concerns that you have



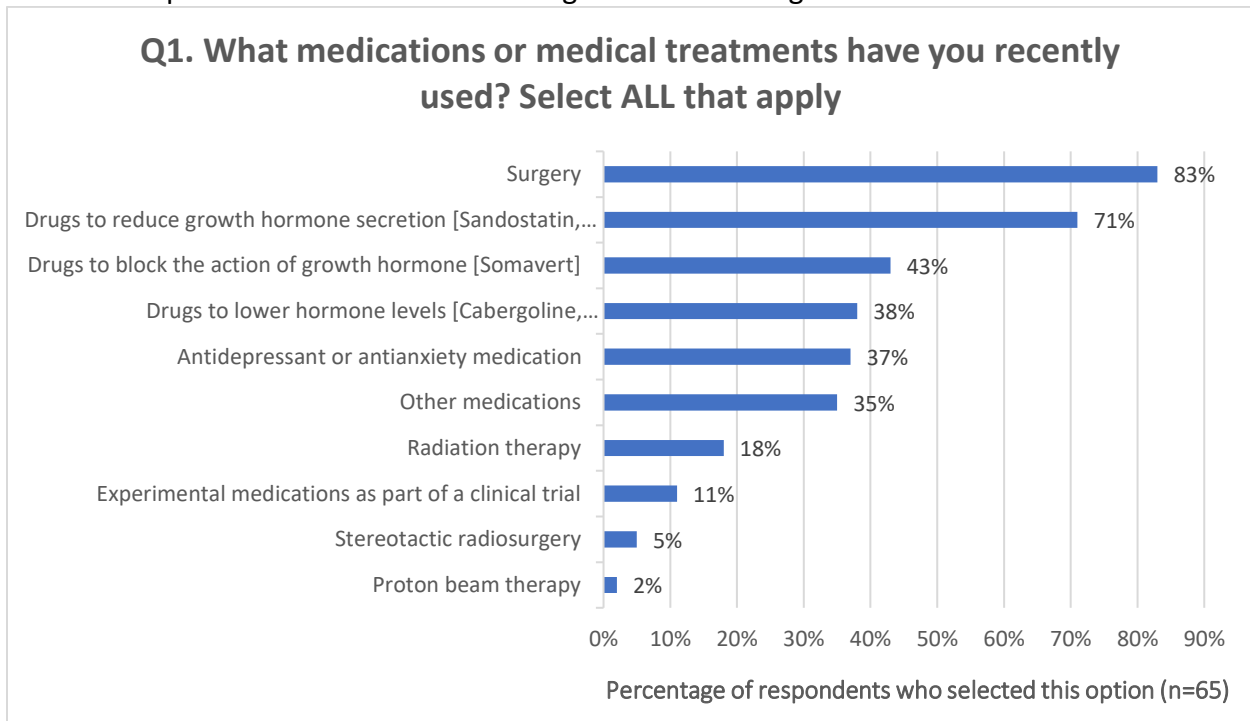
Q3. What specific activities of daily life are most important to you that you are NOT able to do due to Acromegaly? Select TOP 3

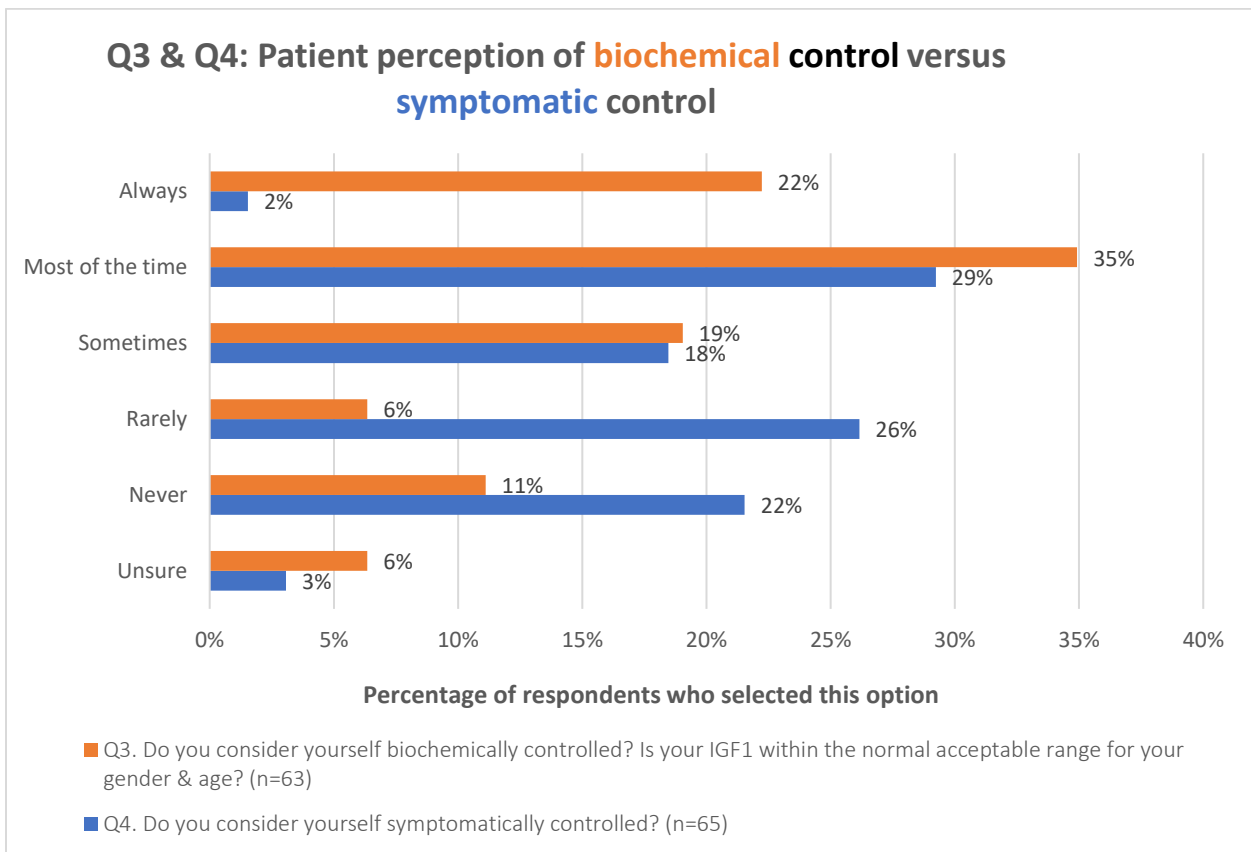
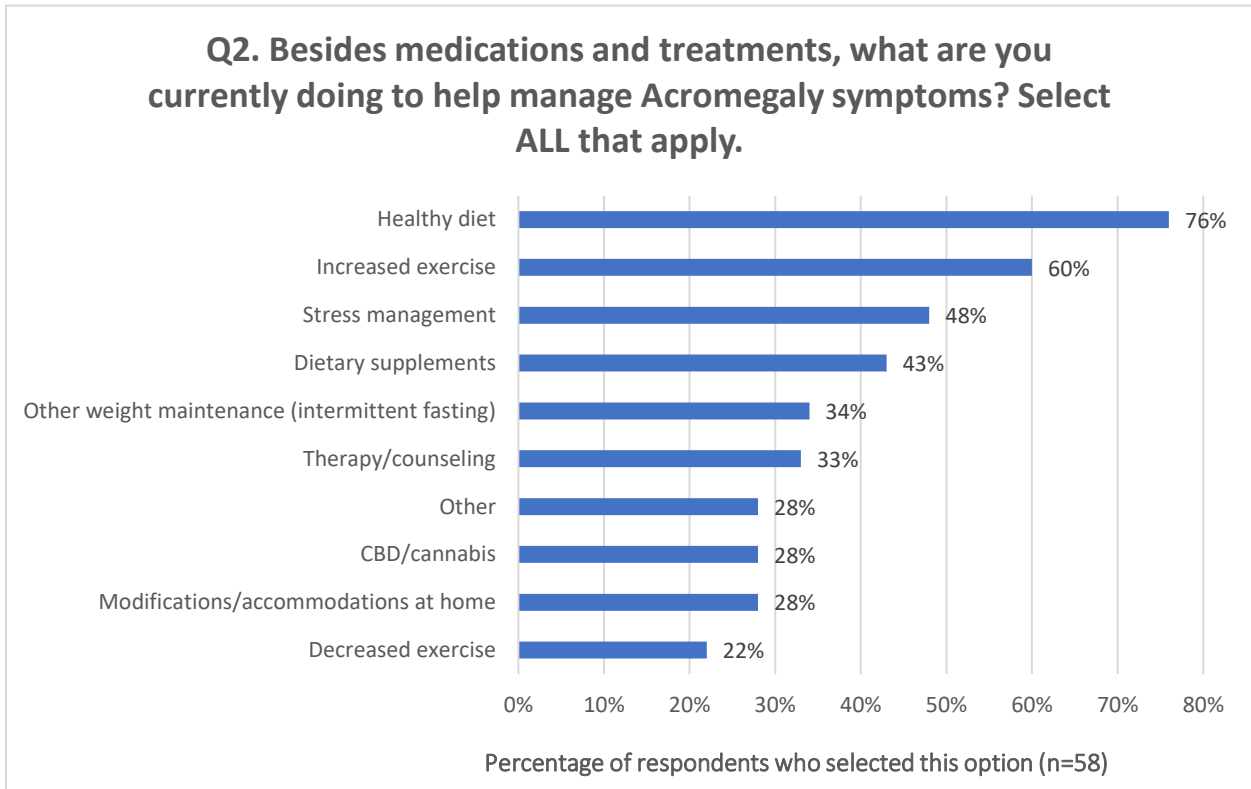


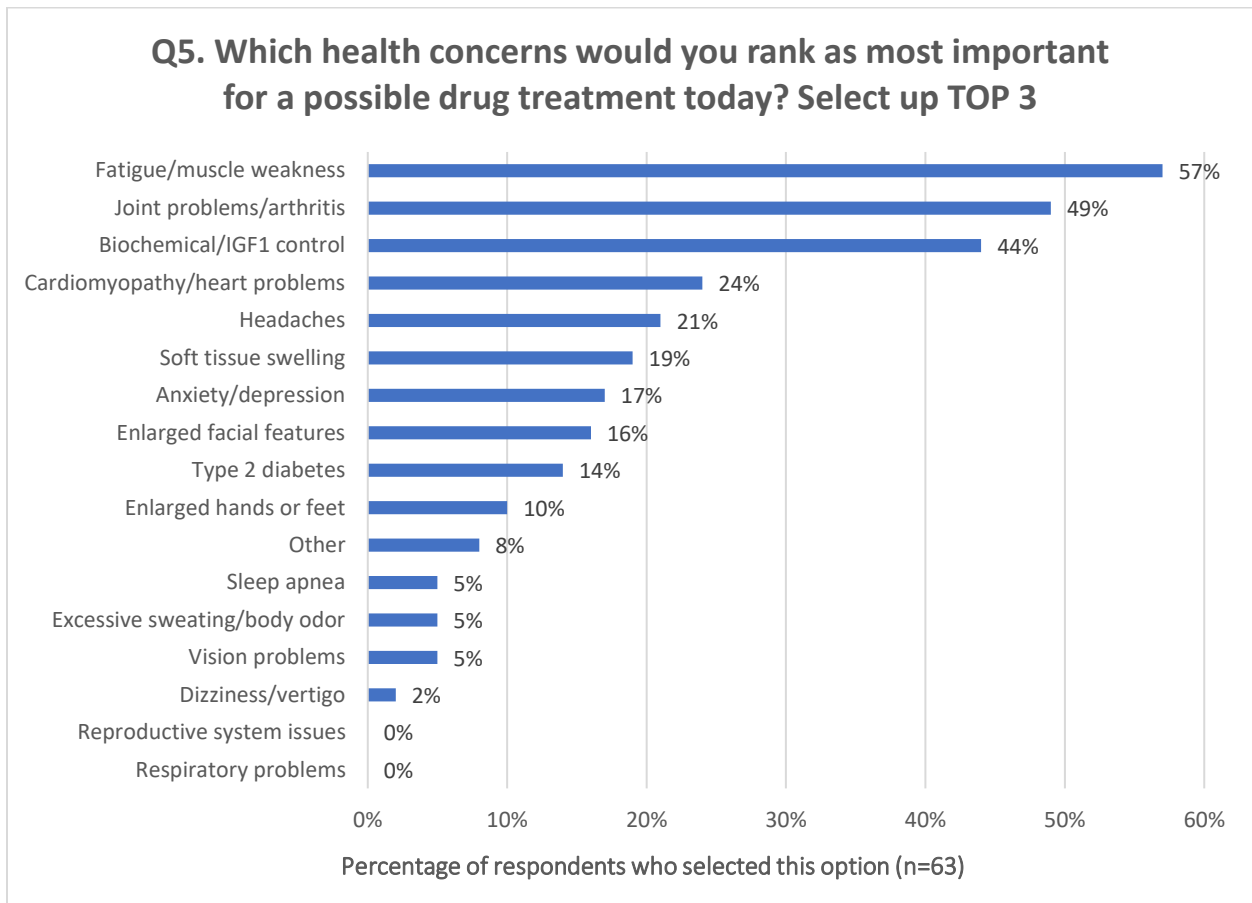
Appendix 6: Topic 2 Polling Results. Perspectives on Current and Future Approaches to Treatment

These graphs include those attendees who chose to participate in online voting. The (n=x) on the X axis shows the number of patients who responded to each polling question.

The response rate data for these polling questions are not considered scientific data but provide a snapshot of who participated in the EL-PFDD meeting and are meant to complement the live and pre-recorded comments throughout the meeting.







Appendix 7: Participant Written Comments Submitted Prior, During and After Meeting

Comments are presented in the order that they were submitted and edited slightly for grammar, spelling and punctuation. Respondents are identified by their initials only.

BM	<p>How acromegaly affects my life.</p> <p>Acromegaly has seriously impacted my mobility causing increased arthritis from head to toe. Since 2014, I have had 5 joint replacements, and have been seriously restricted due to pain and decreased motion - such as putting on a bra! I am in pain every day or am so stiff that I can barely move. I am on Somatuline Depot, and although it has successfully brought my IGF-1 down to almost a normal level, it does not do anything for my pain, discomfort, immobility, stiffness, or increased arthritis.</p>
SV	<p>What alternate therapies other than modern medicine have been tried with success to treat Acromegaly and Pituitary Adenoma?</p>
CG	<p>While my daughter's IGF-1 is just inside the normal range while she is on oral Octreotide (which she dislikes and will be returning to Somatuline soon) and injected Somavert, she is still experiencing symptoms. Her Endo will not increase the Somavert dosage. My daughter is on 30 mgs every other day. I have heard that some patients are as much as 30 mgs every day! Why is there such a discrepancy in Endo's prescribing parameters?</p>
IA	<p>I usually feel symptoms before my next dose. My joints ache and headaches are common usually a week prior to my next injection. I also struggle with stomach pain and diarrhea for the first week after injection, I am on Signifor LAR 20mg. I have been on this medication for 5 months and I was previously on Sandostatin 20 mg, but it caused elevated liver enzymes. I didn't seem to have as many stomach issues with the Sandostatin.</p>
IP	<p>I have recently been diagnosed, but always thought symptoms were due to other illnesses, which there is a long list of. After seeking my medical records, it turns out that I have had acromegaly since 2017 but it wasn't picked up on. Thinking back, the majority of my health issues became worse around 2-3 years ago.</p> <p>I've never been a well person, and after the birth of my son (in 2008) my periods didn't go back to normal. I didn't have any hormone testing, any MRI scans, nothing. They said it could be endometriosis even though I had no black spots. Things became so bad I needed a hysterectomy which I thought caused mood changes, osteopenia which caused broken bones, my mental breakdown which led to a diagnosis in cyclothymia. I also gained weight, my hands and feet got fatter. I have noticed changes in my face also. My body constantly aches but I thought this was due to my hypermobility, as well as my back which I had the MRI for in 2017. And I am constantly fatigued which has gotten worse over time. The only reason I got diagnosed is because I started expressing milk which I thought was due to me having a higher dosage of venlafaxine.</p> <p>I am now wondering if I've had acromegaly since the birth of my child in 2008 as the tumor hasn't grown since 2017. I am wondering if all my illnesses are because of what I thought or due to acromegaly. Furthermore, I wonder if I got diagnosed in 2017 and got treatment if I'd have osteopenia, if I'd have had my meltdown, if I would have put weight on so fast, and if I'd be so tired and sore constantly.</p>

<p>LP (continued)</p>	<p>I think acromegaly should be recognised within the medical professionals more. I will never know the answers to the questions but if there was more recognition then maybe all my symptoms could have been picked up in 2017, and maybe 2008 as I had a lot of symptoms then.</p> <p>Thinking back, I developed a heart murmur when I was 17, I am now 33, and have an irregular heartbeat which was picked up on at that age. I also gained regular headaches/migraines from puberty, so I could have had it since that age as before then I never got them. I have noticed now my son has started puberty he has started to get regular headaches/migraines as well, but it could just be a coincidence.</p> <p>I have never heard of acromegaly until a few weeks ago and no one I know has ever heard of it. This includes a biopsychology tutor at uni. So, this shows how little is known about it.</p>
<p>JK</p>	<p>While my IGF-1 is currently in the normal range, I suffer with many side effects of my acromegaly. They are largely bundled into 5 groups:</p> <ol style="list-style-type: none"> 1) Hormone replacement 2) Depression and anxiety. Was not on any medication prior to acromegaly 3) Medicine to help me sleep at night. I currently suffer from excessive daytime sleepiness am likely narcoleptic 4) Medicine to help me stay awake throughout the day. Unfortunately, we can not eliminate groups 3 and 4. 5) Pain medication <p>Together, I am on over 30 medications. While they do provide some help and relief, I am nowhere close to where I was before acromegaly. I need to see roughly 12 service providers regularly as there is no acromegaly doctor. This is incredibly difficult and frustrating and puts a significant strain on me and my entire family. How can we make this easier?</p>
<p>KH</p>	<p>Will Somavert be available as a monthly injection at any point?</p>
<p>KB</p>	<p>I have had acromegaly for 30 years. My endocrinologists have always been happy with IGF-1 levels barely within recommended levels and I have always felt fine. Two years ago, I began having debilitating arthritis in my back and hips. I know my jaw has grown from a slight under bite to 1/2 inch. It may be too late to help me, but should lower GH and IGF- 1 recommendations be considered?</p>
<p>CH</p>	<p>This disease takes away quality of life. I wonder if I was diagnosed earlier, if my old doc really listened and put symptoms together, would I have to deal with tissue damage...colon, heart, joints. I was diagnosed at age 62 and was told I had that tumor for at least 20 years!</p>
<p>BE</p>	<ol style="list-style-type: none"> 1. Living with the damage that was done and managing my pain control. Multiple surgeries on my cervical spine and lumbar spine. Chronic pain with IBS and digestive issues. And now Living with Chronic Pancreas issues. 2. The effect on me is that I feel I have to keep going even though I know I'm in so much pain some days. Best days I can get through my day and manage my pain with my nerve stimulator and be "normal ". Worst...I over do it and then need to just shut down and retreat with my pain. Hard to walk without hurting. Hard to hide my pain. 3. I lost my freedom to just be me... I look at my Grandchildren and wish I could do so many things with them. But because of my spine and the possibility of future damage and causing

<p>BE (continued)</p>	<p>more issues then already. My knees and shoulders are not good either. I just have had to adjust so many things. It affects my relationships when I don't feel well. Would love to do more with my Family without feeling pain or causing damage to myself. 4. Worries... It worries me if any of my children or grandchildren will have issues. If my tumor will return. If my insurance will continue to cover and what about once I reach retirement age? How will that work and I hear so many patients complain about getting medical attention and medication when they are not with a private health provider. Topic 2 My treatment now is taking the oral medication MyCapssa. 1. It has helped address my symptoms by keeping me feeling more controlled. And less afraid of a treatment that was so painful and complicated to do. 2. By being on a consistent dose instead of my past injection I do feel better that I don't have weeks that it felt like it wasn't working. And so much more convenient for me. My clients and friends say I look healthier. Much easier to take a pill with you when traveling or planning something than the whole process for an injection. 3. I can't at this time say I have downsides to my treatment at this time for my medication. The downside falls again with still trying to educate my medical Doctors in how my Acromegaly has damaged my body and that they all don't understand that and know how to treat an Acromegaly patient. So insurance certainly doesn't want to cover or understand why you have so many issues. 4.I would wish since Acromegaly is so rare, that there could be more of a national database of information. So any Doctor or medical person could look at and get the same latest information. It is almost crazy we as patients are having to bring information from our online support group to our medical team. And then we have some Doctors that don't like that or feel we are just looking up things on Google or something. We need to educate that just because a tumor is removed it doesn't mean you're done...and give patients a clean bill of health so they never recheck themselves. We constantly get patients who are devastated 6 months or longer after thinking they were cured finding out they were not. These Doctors need to be on board and have the knowledge to connect the dots. I shouldn't have to live with symptoms for over 30 years and no one ever scanned me for tumors. Thank you.</p>
<p>MC</p>	<p>Although my Acromegaly is under control now, I still feel like a time bomb. I take Somavert and wish the shots were in a pill form.</p>
<p>LB</p>	<p>The thing that concerns me most about my acromegaly is the lack of support & the 'not knowing' what it will affect & when. I have a 'permanent' headache, and it is permanent. There has been no development, that I know of, of a drug or treatment to manage this. It's debilitating & exhausting. There is still such a gap in awareness of this condition which naturally means there is little ongoing maintenance.</p>
<p>AA</p>	<p>Topic1: 1) Feeling fatigue 2) The change in facial features. ----- 2) A good side is that acro forced me to read about it ...so I got more knowledge... The change in features and people's comments are the worst as this made me withdraw from the network of old friends and relatives and try to find people who know nothing about this old history of mine.</p>

<p>AA (continued)</p>	<p>3) The worst of it is that I could not do activities or enjoy as others do, as I was always tired. I felt like a car that someone is pressing its brakes and it is trying to push itself. It affected me socially as I withdrew ...at work I was not affected but felt always super tired at the end.</p> <p>3) An activity that I will never do is hiking.</p> <p>4) I am worried if I don't find my medications one day or if I suddenly find the tumor out of control.</p> <p>-----</p> <p>Topic 2</p> <p>1) lowering IGF</p> <p>2) I started with bromocriptine but didn't work ..so I was switched to cabergoline.</p> <p>2) Diabetes stopped immediately even before IGF dropped.</p> <p>3)The most significant downside is that I think cabergoline causes some depression or angry feelings.</p> <p>4)I would look for a medication that stops me from feeling fatigue and helps my face features from getting worse.</p>
<p>TK</p>	<p>Discussion Questions</p> <p>TOPIC 1 – LIVING WITH ACROMEGALY: SYMPTOMS AND DAILY IMPACT</p> <p>1. Of all the symptoms of acromegaly, which 1- 3 symptoms have had the most significant impact on you or your child's life?</p> <p>1. Which symptoms most affect you or your child now?</p> <p>Headaches, joint pain, jaw and facial bones pain, memory issues</p> <p>2. Which symptoms were the most significant at other times in you or your child's life?</p> <p>Same symptoms: pain is worse, I also have issues with memory and cognitive abilities. How has acromegaly affected you or your child on best and on worst days? Describe your best days and your worst days.</p> <p>My best day is pain free. This happens only when my IGF-1 is in lower third of normal range and on my good days. If my IGF-1 is above lower third of normal range, I am constantly in pain. This also means that I have literally all acromegaly symptoms and very soon new changes are visible and measurable. If my IGF-1 is above lower third of normal range, I have no good days at all. With time acromegaly gets unbelievably painful.</p> <p>3. Are there specific activities that are important to you or your child that you or your child could not do at all or as fully as you would like because of acromegaly?</p> <p>I can't do sports as I used to, and I can't read books, something I really enjoyed in the past. I also like to learn new languages, but since I am so forgetful that has become very difficult...</p> <p>Pain, memory and cognitive issues affect every aspect of my life.</p> <p>1. How does this affect relationships/friendships with others?</p> <p>I prefer to spend more time alone, only with some members of my family and with acromegaly patients. They probably have the best understanding of how this disease impacts your life and relationships since we share the same problem.</p> <p>2. How does it affect life activities (school/work, abilities, relationships, self sufficiency, living situation, activities, etc.)?</p> <p>I am no longer able to work or live normal life like other healthy people. I have to divide my activities in many small tasks and then rest in between. I also had to accept that there are many activities that I simply can't do anymore.</p> <p>3. If you or your child could do one activity that you or your child currently are unable to, what would it be?</p>

TK (continued)	<p>I would like to be able to learn and read as I used to – fast, without constant errors, without having problems with concentration.</p> <p>4. What worries you most about your acromegaly? I constantly worry about medications and having the right dose. I worry that my IGF-1 will be higher than in the lower third of normal range and this would lead to constant pain and disease progression.</p> <p>TOPIC 2 – PERSPECTIVE ON CURRENT AND FUTURE APPROACHES TO TREATMENT</p> <p>1. What are you currently (or recently) doing to manage your acromegaly symptoms or your child’s symptoms? I take Somavert, I have regular blood checks and MRI.</p> <p>1. Which specific Acromegaly symptoms do the treatments address? Somavert helps me with all symptoms, but the dose needs to be high enough to maintain my IGF-1 is in lower third of normal range. I had Gamma Knife and my tumor is not visible anymore. I wish that Somavert would affect tumor, since I can’t take other meds (strong side effects) or other meds were not working for me (Bromocriptine).</p> <p>2. How has this treatment regime changed over time and why? I needed higher and higher dose. Currently, I have to take Somavert 50mg daily, so there must be still very active and aggressive tumor cells left.</p> <p>2. How well have these treatments treated the most significant symptoms of acromegaly? As I said, it all depends on the level of my IGF-1. All treatments help a lot, but IGF-1 just has to be in the lower third of normal range, otherwise my disease gets worse.</p> <p>1. How well do these treatments improve the ability to do specific activities that are important in daily life? Somavert helps me to reduce symptoms but it cannot reverse the damage that was already done. Without Somavert, the quality of my life would be miserable and I would die much sooner.</p> <p>3. What are the most significant downsides to you or your child’s acromegaly treatments and how do they affect daily life? (Examples of downsides may include bothersome side effects, going to the hospital for treatment, etc.) I have learned to live with side effects. I often feel many of them (the flu like symptoms are most common) but this is not a big problem for me. I hope that Somavert will be in form of pills too! This would help us a lot.</p> <p>4. Assuming there is no complete cure for your acromegaly, what specific things would you look for in an ideal treatment for your acromegaly? What factors do you consider when making decisions about selecting a course of treatment? I wish that normal range would change for acromegaly patients. The high third of normal range is set to high. Most of us feel best and most pain free when our IGF-1 levels are in the lower third of normal range. I hope that this will be soon part of official Guidelines for treating Acromegaly. I wish that patients would be more educated about diet and effect of different food on acromegaly. I have learned most facts about this on my own and by comparing experiences with other acromegaly patients in Acromegaly support group. I believe that we feel hungrier than other people and that this urge to eat must be one of important factors somehow related to our disease. Most of us struggle to maintain healthy weight. I hope that there will be further research on Ghrelin and other hormones which increase and/or control hunger. Also, I would like to add that for most acromegaly patient’s quality of life gets worse with hypopituitarism. Preserving pituitary functions should be the most important.</p>
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TK (cont)	I have learned the most about acromegaly in the Acromegaly Support group on FB. I would like to thank Jill Sisco, our admins and all other group members. They all taught me a lot and they constantly organize different events and post the latest articles about Acromegaly. All this knowledge helps us to make better decisions about selecting the best course of treatment.
DC	Having had surgery, drug therapy and radiotherapy my GH is now in normal range. I am still left with constant headaches, fatigue, weight issues, lack of sleep amongst other things but Doctors either don't know what to do or just don't believe me.
BH	I'm post op for almost 6 yrs. I've had surgery, radiation and Somatuline injection for 2 years. My IGF-1 runs about 54 for several months. Sometimes I feel systematic with a fat tongue and hands/feet. My biggest problem is fatigue and having arthritis in my bones. When I hurt, I stay home and rest and sometimes I cancel dance classes and don't do the normal things in my life that I'm used to doing. Anything I do I'll pay for it tomorrow. The weather changes, it makes me hurt so bad I spend the day in bed. My PCP put me on Celebrex, and it's helped but I still have my bad days. My endocrinologist is clueless on Acromegaly and I tell him things that I've learned. I think our providers need to study how to take care of an Acro patient. I had trouble getting medication in the mail through Prime. We need help getting our medication on time every month.
AG	<p>How does this affect relationships/friendships with others? Since being diagnosed with Acromegaly in 2017 I struggled to live a normal life before surgery. I was always in severe pain from headaches, body ache and fatigue. Life after surgery: I gained some control over my life with the headaches becoming less painful. Even with medication living a normal life that doesn't hold me back is very hard to do. Not only emotional stress but life after surgery has its own struggles. I became depressed and often think of suicidal thoughts. It's hard for me to even socialize with people I've known my whole life. I feel Acromegaly has taken over my whole life.</p> <p>It worries me to think about living with Acromegaly for the rest of my life. I'll never be able to live a normal life without worrying about my mental health, being too tired or feeling sick from the injections I receive every month. Somatuline depot has gained control of my numbers for the moment but I fear it will only be temporary.</p>
PD	<p>My son was diagnosed with Gigantism/Acromegaly 3-1/2 years ago at age 14. He missed out of playing football, which was a passion of his for 3 years. He was struggling with growing into his body, had much joint discomfort, and had 2 brain surgeries for tumor removal. Self-concept issues were also plaguing him. Dealing with side effects from injectable medication was also a struggle. He is currently 6'8" and wears size 18 shoes.</p> <p>Thankfully, his growth hormone has remained stable with all of his medications and MRIs have been fine. He is "trialing" MyCapssa at this time to, hopefully, remove one of his injections from his treatment protocol. Luckily, I am an RN and have been able to be his patient advocate and give him all of his injections.</p> <p>With all of that being said, my son has strong faith and determination. He was able to play football as a Senior in high school, has a GPA of 4.20 and has received a top academic scholarship to a reputable college AND will be playing football!</p> <p>As a Mom, though, I worry how he will do on his own going off to college this coming Fall. It is my hope for him in the future, that there will be more oral medications available that have low side effects and decreased frequency in the need to take them. Quality of life is so important to me and him.</p>

<p>PD (cont)</p>	<p>Thank you for letting me be a part of this discussion. We are grateful for the entire medical community and their passion for helping Acromegaly patients.</p>
<p>NS</p>	<p>The headaches and pain severely impact my daily life if I'm not on any treatment. I have 2 children and with each pregnancy I had to stop treatment. Those were the worst months of life. The pain and headaches were so bad I had to stop working. I lost a great deal of weight because the pain would take over and I wouldn't even feel hunger. I know many women with Acromegaly feel better when they are pregnant, but it was the complete opposite for me. I wish more could be done to help women with this condition that want to have kids.</p> <p>Acromegaly has completely changed my life. No one understands it and the ones that think they do tell me I don't have giant features... there's so much more to this disease & unfortunately it doesn't get the recognition it deserves.</p> <p>I'm so thankful that there is treatment that works for many patients, but I would be lying if I wasn't worried of the long-term side effects of many of these drugs. I often wonder if I'm trading temporarily feeling better for something worse later on.</p>
<p>WZ</p>	<p>TOPIC 1 – LIVING WITH ACROMEGALY: SYMPTOMS AND DAILY IMPACT</p> <p>1.Of all the symptoms of acromegaly, which 1- 3 symptoms have had the most significant impact on you or your child's life?</p> <p>1)Which symptoms most affect you or your child now? Joint pain</p> <p>2) Which symptoms were the most significant at other times in you or your child's life? Diabetes and hypertension</p> <p>2 How has acromegaly affected you or your child on best and on worst days? Describe your best days and your worst days. Best days: I cannot take part in sports with my son. Worst days: Sexual failures suck.</p> <p>3 Are there specific activities that are important to you or your child that you or your child could not do at all or as fully as you would like because of acromegaly?</p> <p>1) How does this affect relationships/friendships with others? Social activities reduce.</p> <p>2) How does it affect life activities (school/work, abilities, relationships, self sufficiency, living situation, activities, etc.)? Reducing work results in no promotion for years.</p> <p>3) If you or your child could do one activity that you or your child currently are unable to, what would it be? Take more sports with my son.</p> <p>4) What worries you most about your acromegaly? The side effects of taking cabergoline is unknown and seems to put bombs in my body.</p> <p>TOPIC 2 – PERSPECTIVE ON CURRENT AND FUTURE APPROACHES TO TREATMENT??</p> <p>1 What are you currently (or recently) doing to manage your acromegaly symptoms or your child's symptoms?</p> <p>1) Which specific Acromegaly symptoms do the treatments address? Lowing IGF-1.</p> <p>2) How has this treatment regime changed over time and why? The symptoms disappeared overnight due to sensitivity to cabergoline and SSA.</p>

WZ (cont.)	<p>2 How well have these treatments treated the most significant symptoms of acromegaly? How well do these treatments improve the ability to do specific activities that are important in daily life?</p> <p>Diabetes disappears right after taking cabergoline, I can eat as normally as people do.</p> <p>3 What are the most significant downsides to you or your child's acromegaly treatments and how do they affect daily life? (Examples of downsides may include bothersome side effects, going to the hospital for treatment, etc.)</p> <p>Always thinking myself as an acromegaly patient.</p> <p>4 Assuming there is no complete cure for your acromegaly, what specific things would you look for in an ideal treatment for your acromegaly? What factors do you consider when making decisions about selecting a course of treatment?</p> <p>Take natural treatments instead of taking pills which brings side effects.</p>
RW	<p>I must say that acromegaly has changed my life in so many ways. First diagnosed in 2009, when I finally found out what was going on with me, I thought it was a death sentence. A brain tumor, I wouldn't ever imagine it could cause all physical, mental and emotional changes I've been through. From an increased shoe size to hurting sometimes from head to toe, I've had my fair share of side effects. But thankfully with my 3x's a week dose of Somavert, things are staying within range. I once told my endo, that it's scary trying to get back to normal, but I'm determined to keep on living and trying!</p>
MA	<p>Topic 1, question 4:</p> <p>What worries me the most is that the tumor could come back and there's no way of knowing what causes the tumor. The fear I have EVERY TIME I feel a migraine, brain fog, blurred vision, fatigue, pure exhaustion, a new gap between my teeth, a snug ring, or a need for a bigger shoe size is unbearable.</p>
LHM	<p>I've had Acromegaly for 25 years. My surgeon said that once maintained my bones could actually decrease. That has been happening approximately 4 years now. My hands and feet originally were size 6.5. They grew to size 11. Now they're a size 9. Will this continue?</p>
LHM	<p>I'm always breaking ribs. My rib cage is highly visible. Regardless of if I fall, lean over something, lay on my stomach, or while exercising, my ribs crack. Is there anything to support them other than bubble wrap? Lol</p> <p>Also, I have a top denture. It keeps getting looser due to bone loss. Any recommendations?</p>
LHM	<p>A year ago, I was diagnosed with Kienbock's disease. This disease is avascular necrosis of the lunate bone due to no blood supply. When the surgeon removed the lunate bone, he was surprised that it was huge. I told him it was because of Acromegaly. Has anyone with Acromegaly reported Kienbock too?</p>
EE	<p>Topic 1;1 Headaches and Brain fog. Joint and muscle pain.</p> <p>Worst days. Had to stay in bed because of pain, and headaches.</p> <p>Loved going for long hikes...today hikes if at all are short, after a while the pain in my hips is too much and I give up.</p> <p>I have now stopped working at the advice (and mine) of my doctor...to try to have a better life.</p> <p>3:1 3:2 does not affect my relationship with others...do not allow it to do so, but had to quit my job.</p>

EE (cont.)	<p>3:4 Getting sick of something that acromegaly has triggered. Cancer or diabetes ... Topic 2, 1 Medication and massage 2; I can still take small walks and knit. 3; Living in Norway treatment is not costly and my doctor is just 10 min from my home so seeing my doctor is not bothersome but not so nice getting a needle in my butt cheeks each time. 4: In my case the doctors here in Norway did not want to risk an operation to remove my tumor...I wonder sometimes if that was the wrong choice to take. What would my health be like if I would have had the operation?</p>
NP	<p>Are there any new funds being set aside to fund grants for studies at medical schools or the federal government on 1) cause of Acromegaly (i.e., gene, defect in womb, environmental, sickness or meds of mother while pregnant, head injury of acromegalic patient); 2) development of an app that everyday people can use to find out if they may have Acromegaly based on a series of questions and answers. This may help in getting people an earlier diagnosis. New Question-Require Medical, Nursing, PA and osteopathic schools to cover Acromegaly as well as other diseases of the pituitary gland.</p>
IS	<p>1. Of all the symptoms, fatigue, headache, and joint aches have had the most impact on my life. 1.1 These symptoms still occur with medical therapy. 1.2 Other issues I have dealt with are swelling, sweating, joints locking, biliary issues leading to IBS symptoms and right upper abdominal pain, carpal tunnel, short term memory loss. 2. On my worst days, I am not productive at all. A best day, I'm able to work and do my tasks, then also be productive at night without falling asleep by 6:30 or 7 pm. 3. I'm 49 and would like to still be able to have the energy to travel and be productive. I don't want to always be mindful of my schedule and the fact that I will possibly crash after a taxing day. I wish for less pain and more energy. 3.1 I often just suffer through it rather than enjoying activities. I don't want my family to worry so I typically do not voice my maladies. I feel guilt when I do not live up to the expectations of others or if when I do say something, someone misses out because of me. 3.2 Sometimes I cannot work due to the headaches, the highs and lows I'm sure also make me a bear to live with. I try to keep my anger at bay, but acro-rage is real. I'm cognizant of this and try my best to keep it in check. 3.3 I wish I could travel more, see the world without feeling tied to a therapy. 4. My biggest concerns regarding my condition is the co-morbidities that it causes and the risk of premature death. I still have a lot of living that I would like to do and would prefer for it to be pain free and without being exhausted all of the time. 2.1. I take my acromegaly medication as per prescribed. I also take Excedrin migraine and Tylenol. If I can catch a headache early enough it can knock the headache out pretty easily. Tylenol helps with the joint aches and pains. But when I am well controlled, I typically don't have these symptoms. I have had to increase the doses of all. 2.2 When I was on the long-acting injections, I noticed the symptoms would be more common and intense 7-10 days prior to the next injection. When my injection was at the highest point of the bell curve, I was typically pain free and had energy. I felt like it was controlling the disease, rather than the disease controlling me. The daily injections are good, but who wants to be tied to injections for the rest of their life? Years ago, I participated in an implant study. I would love to see our medications use this form of administration. This study tested a 6-month implant and to be able to forget about medication for a while was wonderful. I would love for a therapy that was safe and effective that truly allows patients to forget that they are sick because they don't have to administer it daily, weekly or even every 28 days. Something that lasts until the next dose and has no breakthrough symptoms.</p>

DB	<p>When discussing the management of this Acromegaly you need to include the damage caused by the years of uncontrolled IGF-1 or the side effects of the medication. In the seven years since I was diagnosed: I have had to have my gallbladder removed due to the development of gallstone which are a side effect of the Somatuline Depot.</p> <p>I developed tympanosclerosis, a calcium build-up in my right ear, which encases the bones in my inner ear. This decreased my hearing to the point I was considering a hearing aid. I had surgery to chip out the calcium deposits. My ENT believes this was caused by the Acromegaly.</p> <p>I have developed osteoarthritis in both of my shoulders and had my first one replaced in 2020. My physical therapy protocol outlines 6 months of PT and full recovery in two years.</p> <p>I have developed a neuroma and had it excised in one foot and have a suspected one in the other foot.</p> <p>While I know these conditions do happen to people without acromegaly, the convergence of these in one otherwise healthy person seems unlikely that there is no connection.</p> <p>In 2013 I was diagnosed with two benign brain tumors, a meningioma on my brain stem and the pituitary macroadenoma. In fact, one surgeon stated that he believed that pituitary tumor was causing the meningioma to grow. Following transsphenoidal resection, I had a CSF leak leading to a week in the hospital with a spinal drain extracting spinal fluid every hour. The surgery also left me with diabetes insipidus leading to daily medication and fluid management issues. I did not achieve remission after transsphenoidal resection of the tumor. I was started on Somatuline Depot shortly after surgery. This required a monthly trip to my endocrinologist's office for an injection. Initially the side effects of the medication caused exhaustion for about 4-5 days, along with nausea and significant digestive disturbance. I found the best way to manage this was basically to limit my diet to crackers and tea for a few days. While the symptoms eventually became more manageable, they have never completely resolved.</p> <p>Between 2103 and 2018 my dose was adjusted based on my IGF-1 level. In 2018 I was on the maximum dose of Somatuline Depot and my IGF-1 level was not under control. Somavert was added to my treatment regimen. This is a daily sq injection that I do myself. The GI side effects were so severe that I contacted the pharmaceutical help line to see if it was an expected side effect. I seriously considered if I would continue the treatment. Luckily, they resolved after two weeks. Somavert requires refrigeration making traveling a challenge. The combination treatment did not provide control of my IGF-1 levels. I underwent 5 days of cyberknife radiation treatment. Starting on day 3, I developed a headache and had to be placed on steroids. The persistent headache led to a trip to the ER for evaluation. One year after treatment, the headaches returned for about 4 months. While my scans didn't show anything of concern, my neurosurgeon believed the headaches were related to the radiation treatment. Because it can take a minimum of two years for the radiation therapy to take effect, I continue taking the combination treatment of monthly Somatuline Depot and daily Somavert.</p>
DP	<p>Hello, I've been dealing with my acromegaly for over 12 years now and in that time I've reduced my medication to nearly zero now. I have no faith in big pharma. When I was taking full medication, my head was fuzzy. I could not focus or remember anything. Our bodies have a great way of repairing itself if you just give it time to heal. The main problem I have now is trusting what people say as I think they are lying to me as they don't understand what you've</p>

<p>DP (cont)</p>	<p>gone through. In the last year I've changed my diet to try and reverse my diabetic systems and it's been really good. My blood sugar is back to almost normal now and I'm able to do 3 kilometres a day on the exercise bike which keeps my circulation on my legs good. We are all individuals and react differently to meds and other treatments, so I don't let the doctor decide my life. I make my own decision on how I move forward. My worst moments are when my energy runs out and I get very fatigued. I take Tostran 2% gel, but it only lasts a short time; the full testosterone gel is too much for me and keeps me awake at night. My endocrine department is always there if I need any question answered but I control my acromegaly it doesn't control me. I have regular checks on most parts of my body every couple of years and my hospital has an app that allows me to check the results on any blood test or treatment I've had plus it compares previous results, so the doctor is alerted to any problems and so am I. Since I've had acromegaly, I keep to the one hospital so records don't get mislaid or lost which happens unfortunately. I urge everyone with acromegaly it is your life, not the doctors, you look after yourself not the doctor, he's only there to advise to eat well and be safe. I hope this helps the group. Best regards.</p>
<p>SA</p>	<p>Due to the disfigurement, increased size and crossbite resulting from this disorder, I was uncomfortable just being around other people. I was stunned to learn that the "medication" is done with a 16-gauge needle and that meant being tethered to my doctor's clinic. The positive event for me was that these injections eventually shrunk my adenoma, away from the carotid artery, so that I was able to have the only possible cure- surgery. Like most of us, I wasn't cured. I was very interested in obtaining the capsule form of the medication- conceivably, I would not need to plan my vacations with such concerns as being available and going to the clinic. Now I am ambivalent about switching, however. It took much effort and time to get the routine of ordering, making the appointments (with the limited number of nurses who knew how to inject), and making sure my insurance covers most of the cost. I've kept copious notes of my IGF-1 and vital signs. The cost, the procedures of getting more authorization, ordering from a specialty pharmacy and the change from monthly to twice daily, on an empty stomach are a few of my concerns. Additionally, I would not have the monthly data for my records. Going from filling out forms indicating "excellent" health, to needing to explain this rare chronic condition, and the aftermath of bradycardia side effects, which caused me to need a pacemaker, has also had infinite effects on my life. Any medical procedure (e.g., colonoscopy, which may also be related to polyps caused by this condition) now requires cardiac clearance; going through any metal detectors (airlines, court buildings- job related); these are constant reminders of my strange, systemic disorder. I've been fortunate, in maintaining employment despite periodic absences necessary for MRIs, evaluations and injections. I also consider myself fortunate in being able to navigate through the medical and insurance administrations in order to benefit from the treatment. But I wondered about others- less tech savvy, unable to attend appointments, uninsured/underinsured, or unable to avail themselves of treatment- even when the condition has been identified. This is an ongoing, serious disorder that requires tried and true treatments for the majority of us as long as we live. We have differing symptoms, some have total disabling issues- if we have choice of treatment, and the barriers in obtaining assistance- both health wise and financially, we are better able to deal with the emotional toll that which we are inevitably presented.</p>

<p>MV</p>	<p>I would like the panel to know that when a patient is diagnosed with acromegaly, sit them down and explain to them that this is a lifelong condition. Explain to the patient what COULD happen to them (example DM, liver, thyroid, headaches, etc.). My doctor made it sound like I was going to be "cured" with medicine. He stated I did NOT need surgery (my tumor was 2.6 cm x 1.8 cm that hemorrhaged) and I could be treated with meds. I learned ALL I know from this group. 9 doctors and 8 years it took to get to my diagnosis. Have the MD tell the patient about this wonderful group!</p>
<p>MD</p>	<p>Living with Acromegaly: The symptoms that affect me the most now eleven years after what is considered a surgical cure are sleep apnea, chronic hand pain and joint pain. The symptoms that were most significant at other times in my life include depression, sexual dysfunction, cognitive difficulties, rage, nausea and heart palpitations on top of the sleep apnea and chronic pain. I feel the hardest part of living with acromegaly is that it hits you from so many different angles that it is difficult to deal with life, treatments and symptoms all at once. That is why patient support is crucial along with a medical team approach. My best days living with acromegaly are pain free. The days that I don't think about acromegaly symptoms are few and far between. On the worst days, I worry about tumor regrowth, future treatments, procedures, tests and uncertainty about the unknown cause and cure of acromegaly. I wonder if any research is being done on acromegaly. There are many physical activities that I can no longer do because of acromegaly symptoms. It has affected my career, my body and my mind. If I could, I would hike the Appalachian trail. The thing that worries me the most is waiting for re-growth and what research is being done to save people's lives from this monster of a disease. Thanks for listening to the patients.</p>
<p>BR</p>	<p>My pituitary is not functioning right. What happens in my body when low growth hormone and low prolactin are present after macroadenoma is resected?</p>
<p>DS</p>	<p>Thank you for the opportunity to comment and for listening to what patients are saying about their personal experiences with Acromegaly. I am a patient and an advocate running a support group here in Ottawa. My experience is rare among the rare in that my tumour cannot be detected by MRI, yet bloodwork confirmed an acromegaly diagnosis in 2012. I was fortunate enough to be diagnosed very early when symptoms were minimal, and my health and life were not significantly impacted. My concerns are mainly focused on early diagnosis via public information on what this disease is and how it can be treated. Being rare may be a term that is not quite correct in that there may be many individuals who are suffering but have not been diagnosed. Early diagnosis could be the key to reducing the burden on our medical system both in terms of costs in dollars and negative health consequences to individuals. Health care professionals on all levels need to be educated on this disease that is more prevalent than once thought. When a patient presents with symptoms, the health care professional must think about the whole picture and not just focus on the pieces. The general public needs to understand what the symptoms are so they can have discussions with their medical team about acromegaly. Management of acromegaly for me has been medication by pills and shots of Sandostatin LAR every 4 weeks. Unfortunately, Sandostatin has caused an increase in my blood sugar and</p>

<p>DS (cont.)</p>	<p>I now have to be medicated with pills for diabetes. This disease causes me more concern than acromegaly. Although these treatments manage acromegaly and I am monitored every 6 months with my endocrinologist, it is still a concern that this condition could change at any time for me and have worsening effects on my health. Although the cost of medication is extremely expensive, I am fortunate to have insurance coverage for it but understand there are many who are not covered and this causes a financial burden for many. I would like to see the cost of the drugs for this disease and other rare diseases be regulated by our government. Also it would be seen as an improvement to have an oral medication available in Canada for Sandostatin LAR. Perhaps with help from large and respected organizations like the Federal Drug Administration this disease could be diagnosed earlier. The FDA could take an active role in education of acromegaly by teaming with advocate patients, groups and community leaders to provide funding for an ongoing campaign to make Acromegaly a household word that everyone understands. We don't want to remain in the dark any longer and our voices need to be heard. We respectfully ask for your help and know that this meeting is a wonderful forum to share our concerns and hopefully start a movement that will help patients.</p>
<p>BCR</p>	<p>Daily constant pain in my teenage son's joints have interrupted his life and playing sports.</p> <p>We worry about future symptoms and damage to his body and if the tumor will come back after surgery and will he be on lifelong medication.</p>
<p>LF</p>	<p>Hello</p> <p>I suffered undiagnosed for 15 to 20 years. My acromegaly caused much pain through my body but seemed to be different parts at different times. I was wrongly diagnosed with arthritis and menopause symptoms. I also lost my ability to taste. I can smell and have had smell tests to confirm it. These were not my biggest hurdles.</p> <p>My acromegaly had a huge negative impact on my mental health. I was diagnosed with Depression Bi-Polar II. Once diagnosed it seems the doctors stopped looking further. Mental illness tore apart my family and I now have irreparable damage to family and insofar as my daughters claim (and I believe them) they have scars because of me. I no longer have much of any relationship with them. I was prescribed horrible medications that seemed to help at the beginning but always fell short after a few months to a year. It was my pharmacist of all people that suggested I see a neurologist. When I did the neurologist seemed to know within about 7 minutes that I probably had acromegaly.</p> <p>After my surgery to remove the tumor, I felt like I walked out of a fog. It was incredible. Now 5 months after surgery I feel like I have brain damage. I cannot focus on business matters, find it hard to work through business problems. I have such low patience. It feels like I have been left with a personality disorder. I do not feel depressed or anxious. I was once very savvy in business and thrived. I no longer feel like I am thriving. The strange thing is that it's not because of depression or anxiety. I can only come to the conclusion that I have had some form of brain injury as a result of the tumour itself and the years of massive hormones. I do not get headaches. I do feel very angry. The anger is not warranted and there does not seem to be a cause for it. I do have a lot of fear. Fear that I can no longer be productive and fear that because of that my brain will get weak and stop thriving.</p> <p>I am not one who is a hypochondriac. In fact, maybe if I was a bit more that way inclined, I</p>

<p>LF (cont)</p>	<p>may have been diagnosed sooner. I just truly believe there is some brain damage and wish I could know for sure and then do whatever exercises possible to make the most of what I have left.</p> <p>That is my experience post surgery. Pre surgery I had every symptom except for significant eyesight issues. The tumour was not too close to my optic nerve.</p> <p>Many thanks, LF</p>
<p>KB</p>	<p>What are you currently (or recently) doing to manage your acromegaly symptoms or your child's symptoms? Currently on lanreotide injections and intermittent fasting, exercise and amitriptyline Which specific Acromegaly symptoms do the treatments address? Headaches and fluid retention and general bone/ joint pain How has this treatment regime changed over time and why? Added amitriptyline for headaches plus glucosamine and turmeric How well have these treatments treated the most significant symptoms of acromegaly? Very well - minimal joint pain. headaches -minimal and fluid retention is minimal How well do these treatments improve the ability to do specific activities that are important in daily life? Very well once controlling the symptoms that were my biggest concern everything else becomes much easier</p>
<p>SK</p>	<p>Topic 1: My leg strength continues to be weak and therefore I cannot do activities I used to enjoy. I no longer can go in the ocean without help because my legs are weak. If I fall near the shore, I won't be able to get up. I have problems going up stairs if there is no rail. I can't run. Any climbing is an issue. I feel ugly sometimes, hair loss.</p> <p>Topic2: I have been fortunate that my monthly shot of Sandostatin has kept my levels in the normal range. However, it is a once a month shot so I have to be at home during that time. Makes planning more difficult, it is not an easy shot to administer. It would be super if there was a daily pill that is as effective as my monthly shot. My endocrinologist does not feel that the current oral medication is very successful in lowering growth hormone levels.</p>
<p>SLK</p>	<p>Why are only a few medications being made, and most aren't close to 100% effective? Why do most patients have to take combo therapy and often on the max dose to be effective? We should have different drugs to better control and effectively lower IGF-1 in all types of tumors without the side effects of diabetes, cholelithiasis, etc. Medications should be improved substantially, so there's no need for radiation, which according to some studies, complicates disease management and increases morbidity and mortality years after the radiation therapy. If I could wish, I would like to have more options on medications that are far more effective, preferably well-tolerated, and non injectable.</p>
<p>AP</p>	<p>TOPIC 1 – LIVING WITH ACROMEGALY: SYMPTOMS AND DAILY IMPACT Of all the symptoms of acromegaly, which 1- 3 symptoms have had the most significant impact on you? 1) A trauma The diagnostic and treatment phases were a trauma. Having bad headaches (six months before the surgery) and gradually losing my vision (three months before the surgery) were a very brutal shock. Although the surgery was an effective treatment (we no longer see the tumor on the MRI); the month following the surgery without being able to use my CPAP was</p>

<p>AP (continued)</p>	<p>difficult; I had to go to the emergency room to have blood clots in my nose removed. My surgery took place in Montreal, Canada; I was 56 years old. Following my surgery, I was prescribed Somatuline, testosterone, and Synthroid. A year later, I was prescribed Somavert (30 mg twice per week). It is only this year, six years later, with 30 mg of Somavert per day, that my IGF-1 is below the upper limit of the standard (currently at 90% of the upper limit of the standard).</p> <p>2) Low energy / Lack of ability to move quickly I have low energy to the point where I have difficulty doing some of my daily activities (cleaning my house). I also usually take a nap during the afternoon. I am able to ride a bicycle but had to give up downhill skiing, running, tennis, etc.</p> <p>3) One comorbidity - Diabetes During my treatment, I gained about 60 pounds, but my weight has been stable for the last two years. Managing my diabetes, which started a year after my surgery, is a challenge despite the fact that I am taking more and more insulin. It seems that this deterioration is occurring more quickly than that seen in the general population, and general practitioners take too long to recognize / accept that fact.</p> <p>What worries you most about your acromegaly? I am physically different from others and I experience discrimination.</p> <p>Taking the decision to put an end to my relationship with my partner and her three children three years after my surgery was also a serious grief. This mourning was alleviated by a series of ten psychological consultations.</p> <p>Conclusion In conclusion, I consider that my physical health and physical look are poor, which has an impact on my social health (which is average). My poor physical health, poor physical look and my average social health do have an impact on my psychological health (which is average). Overall, my quality of life is seriously affected, but is not less to other individuals with cancer, Parkinson's or Alzheimer's. I am currently following a ten-week program to improve my quality of life.</p> <p>TOPIC 2 – PERSPECTIVE ON CURRENT AND FUTURE APPROACHES TO TREATMENT How well have these treatments treated the most significant symptoms of acromegaly?</p> <p>Surgery Symptoms related to the size of the tumor (headache and difficulty tolerating light or sun) disappeared after surgery.</p> <p>Medication Somatuline and Somavert brought IGF-1 back within the standard. My hypertension has stabilized at the appropriate level. My hands and feet have stopped growing and I'm sweating less. A colonoscopy performed five years after surgery confirmed the absence of new nodules.</p>
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AP (continued)	<p>However, the medication had no effect on my sleep apnea, the space between my teeth, the size of my tongue and the numerous calcium deposits on my gums. During the first six years after surgery, when my IGF-1 was 20 to 30% above the standard, my frontal bone grew, a cyst appeared behind the neck and a large number of skin tags appeared.</p> <p>Testosterone gave me more energy.</p> <p>My skin is less oily, but very dry on the knuckles and elbows.</p> <p>How well do these treatments improve the ability to do specific activities that are important in daily life?</p> <p>Without the surgery and the medication, I would not have survived.</p> <p>What are the most significant downsides to you or acromegaly treatments and how do they affect daily life? (Examples of downsides may include bothersome side effects, going to the hospital for treatment, etc.)</p> <p>Drugs are costly.</p> <p>Due to the guidelines for keeping the temperature of Somatuline and Somavert to a certain degree, it is difficult to travel by plane.</p> <p>I sometimes wonder about the ability of pharmacies to handle Somavert as it should; either when receiving products from their supplier, or during the many lengthy approval process where the product is out of the fridge before being handed over to me.</p> <p>Managing the blood tests that need to be done on a regular basis and the frequent adjustment to medication takes time and creates anxiety. I should have recorded relevant information in a detailed notebook about my health right after the surgery.</p> <p>Assuming there is no complete cure for your acromegaly, what specific things would you look for in an ideal treatment for your acromegaly? What factors do you consider when making decisions about selecting a course of treatment?</p> <p>My goal would be to regain the health that I had before the tumor appeared, regardless of the nature of the treatment. My decisions would be in line with the recommendations of my endocrinologist. Recently, I took standardized cognitive tests to identify cognitive strengths and weaknesses. I am able to focus on several things at the same time and quickly switch my focus from one activity to another. My hearing memory is okay, but my visual memory is not (e.g.: although I have the same grocery list from week to week, I sometimes have difficulty remembering which products are in which row). Also, my degree of coordination between the eye and the hand is poor (e.g.: I spill a lot of things while cooking). My ability to find a word in my vocabulary is poor (e.g.: I often search for my words when discussing with others). Finally, my speed to accomplish a cognitive task is not good (e.g.: I drive the car more slowly, especially when I am tired). Twice I was taken for a mentally retarded person and that irritates me the most. I don't know what caused those weaknesses; they have evolved slowly. I am doing exercises to strengthen those weaknesses.</p>
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AP (cont)	<p>The scientific community could look at the possibility to create a patient registry containing information about how the disease is evolving over time. We still have to learn about the disease. Quality of decisions is related to the quality of information we have to make those decisions.</p>
VS	<p>1. Main symptoms: fatigue, frequent flu-like days that disrupt my routine in all aspects, neuropathy. Symptoms in other times: swelling of facial features, hands and feet. 2. On the best days I feel normal, energetic, and in a good mood. On my worst days I feel sore, tired, low mood, just wanting to sleep, waking up tired. 4. What worries me most is how things will evolve in the future for me. Although I think I can be considered in remission, I hear about tumors that have grown again, symptoms that return, and I worry how my life will look in the future.</p> <p>Re: treatment I will just add that I was on Sandostatin LAR for 2 and half years and then had surgery, and although I have a residual tumor, I currently don't need any treatment as my values were so far in normal range.</p>
SA	<p>As a mental health professional, and a person with Acromegaly, mental health issues are at the forefront of my mind. What is being done to address the mental health needs, challenges, and problems of the Acromegaly community?</p>
LS	<p>Most significant symptom that causes me the most problems on a daily basis is excessive perspiration. It affects me every single day and is more debilitating than I had ever imagined. It makes it hard to do any physical activity, even light exercise like walking a few blocks. I have to change my clothes all the time and sometimes shower multiple times per day. Even emotions make me sweat. I wake up every night because of sweating. It's exhausting and embarrassing. It doesn't seem to matter what my IGF is, it has never gotten any better.</p> <p>I'm currently on Somavert 4x weekly. The frequent injections and the fact that it needs to be individually mixed and refrigerated is annoying and impractical. A depot or long-acting growth hormone receptor antagonist would be very freeing. If that's not realistic then a more stable form of the medication (like one that doesn't require refrigeration or can be given in a pen form rather than individual vials) would be nice. Or at the very least, can they stop packaging it in single dose boxes?! The amount of waste created by each dose is crazy. It's a medication that's designed to be given every day, why would you ever need an individual dose? We don't need 16 copies of the prescribing information every month.</p>
ML	<p>Is there any way to control the continued growth of the lower jaw? Tumor was removed five years ago, and has been on daily Somavert injection since, with only continuous jaw growth!! Thanks</p>
KH	<p>Of all the symptoms that you experience (or your loved one experiences) because of acromegaly, what are the 1-3 symptoms that have the most significant impact on quality of life? Growth in feet size Fatigue</p> <p>How do these symptoms impact specific activities that are important to you?</p> <p>These symptoms don't necessarily affect activities but comfort in my own body.</p>

<p>KH (cont)</p>	<p>What are you doing (or what is your loved one doing) to help treat acromegaly, and how well are those treatments working? We have had two surgeries. Tumor is back and we are pursuing Gamma knife radiation in a couple of weeks.</p> <p>What are the most significant downsides to those treatments? Possibility of monthly injections and side effects of them, medical expenses</p>
<p>DB</p>	<p>The symptoms that I experience are my medication weaning a week prior to the next shot (fatigue), brain fog & pain and lumps at my injection site.</p> <p>When my medication weans off, I feel like I am getting flu like symptoms and have to push myself through the week of feeling body aches, light headache, and body temperature going up slightly, I make sure that I don't make any plans, so I can stay home and rest, my husband takes over of making of meals and doing the chores that need to be done. But not all acromegaly people have partners to help them.</p> <p>With the brain fog I sometimes get, I make sure any written projects or interacting with people, I do before I know the brain fog is going to happen, usually when my medication wears off a week before next injection, and I stay home.</p> <p>When I have my injections, the area site is very sore and if touched will hurt a lot, and a lump will form at the site, and does not go away, to help with this, I use a heating pad to ease the pain and have now started having massage therapy to break down the lumps and relax the swollen muscles, which helps really well, and can use the area again for another injection and the injections go in smoother for the nurse.</p> <p>The symptoms impact me from spending quality time with my family and friends, spending time with my husband to be outside enjoying time in my garden or fishing or just going for a walk or going for dinner with friends, it impacts me with feeling down, incapable of being who I am. But it also lost me my professional career, which cost me a secure monthly income and not having a comfortable retirement with the security of having a pension for a comfortable retirement. For trying to stay on top of things from getting worse with my acromegaly, I eat a better balance diet, I try to go for walks everyday, I let my GP and Endocrinologist know of any changes happening in my body, I mentally and emotional work hard at keep a positive attitude about life, but have my moments of defeat.</p> <p>The most significant downside to living with acromegaly is that new medical problems show up, and that means more medication. But also having bone issues starting to show up, it slows me down, and I struggle with more pain, which leads to more surgeries in the future, which leads to a new specialized doctor that treats this certain problem.</p>
<p>NF</p>	<p>Not only am I an acromegaly warrior I am also a physician. My comment today is in regard to the seemingly commonplace practice of diagnosing patients with acromegaly with fibromyalgia as well. Medical literature defines fibromyalgia as “idiopathic widespread muscle pain”. Idiopathic refers to the fact that we don’t know the cause thus fibromyalgia is defined as muscle pain without a known cause. For those of us with active disease or acromegaly in remission we can all testify to the at times debilitating muscle pain we</p>

<p>NF (cont)</p>	<p>encounter. Pain which things like nerve meds and pain meds don't seem to help in the slightest. Widespread muscle pain is one of the most common symptoms of acromegaly. The thing is, we know the cause...it's the acromegaly, and therefore not idiopathic and cannot be diagnosed as such. To my physician colleagues on this panel- when you diagnose someone- whether you realize it or not you are reshaping their identity, some more than others. To tell a patient you don't know what's causing their muscle pain by diagnosing fibromyalgia when we know acromegaly causes widespread muscle pain is a disservice not only to your intelligence as a physician but to the patient and their illness. We have acromegaly, and acromegaly can be ugly and painful for many. We don't have fibromyalgia. We have widespread muscle pain due to excess GH and IGF-1 and its effect on muscle and connective tissues. If we can stop outsourcing every symptom of this condition to another rare or perhaps common condition, then we can develop better treatment strategies which will actually benefit people with acromegaly instead of filing them in an "idiopathic" filing cabinet. You see if we are saying we don't know the cause of something we are less likely to find a cure or an effective treatment. Patients with acromegaly have widespread muscle pain due to acromegaly. It's not fibromyalgia. It's not idiopathic. Thank you.</p>
<p>ZZS</p>	<p>Three symptoms that most affected my life are Constant fatigue Headaches and generalized body pains Acrorage</p>
<p>SK</p>	<p>I'd say the top three symptoms that have impacted my life the most are pain, fatigue and the mental issues (depression, short term memory, cognition). They have robbed me of my career.</p>
<p>BM</p>	<p>Symptoms / Health effects</p> <p>I can trace my first symptom back to 1996 - and was diagnosed in 2016. The symptoms that have the most significant impact on my life are an enlarged heart valve, excruciating joint pain and weight gain (constant hunger). Other very significant symptoms include, but are not limited to: osteoarthritis from head to toe, fatigue, apathy, mood swings, hypertension, depression, anxiety, lack of energy, no sex drive, gallstone, sleep apnea, swelling, blurred vision, carpal tunnel syndrome, digestive issues; constipation, colon polyps, sweating, increased body odor (cannot find a deodorant that works!), diabetes.</p> <p>QOL</p> <p>Acromegaly has seriously impacted my mobility, causing increased arthritis from head to toe. I can no longer hike like I used to, and I shy away from hiking most days because I am afraid I will be in too much pain to continue. I am in pain every day, or am so stiff that I can barely move. I used to love going dancing, hiking and bouldering, but that is too difficult now. I loved to socialize more, but find myself hiding instead because I cannot explain the fatigue and pain that I am in daily and get tired of being tired! In 2014, I had my first knee replacement. Since then, I have had 4 more joint replacements (right knee again, both hips, and right shoulder), with 3 more on the way (left shoulder, left and right thumbs). I have been seriously restricted due to pain and decreased motion - I can barely put on a bra or shirts with my shoulders being like they are.</p>

<p>BM (cont.)</p>	<p>Worries/fears for future: I am constantly worried that my IGF-1 is not controlled and maybe that is why I am experiencing symptoms 24/7/365. I worry that my tumor will come back any day since there is a 50/50 chance it could. I worry that my heart problems will get worse, and I will need heart surgery. I worry that my arthritis will get to the point where no more joints are available for replacement, but I am still in constant pain. I worry that all my hair will fall out, I worry that I will neve stop being hungry and will continue to gain weight. I worry about when I will need to have my gallbladder removed. I worry that my acrorage will come back. I worry that my endocrinologist thinks I am a hypochondriac and will refuse to help me. I worry that if I keep feeling like I do, I will become more reclusive by the day. I keep these all to myself, I rarely tell anyone, but I have these thoughts daily.</p> <p>Treatment successes While I was taking MyCapssa, I had less swelling, pain, irritability and anxiety. I felt happier. My hair was growing back in, my nails were less brittle. I did not have to have a stranger nurse come to my home to administer my medication nor did I need to schedule my life around my injection. But my IGF-1 never came into normal levels, so we switched back to 90mg Somatuline Depot injections. Now, my IGF-1 appears to be within normal range, but that’s the only good thing.</p> <p>Treatment failures/downsides MyCapssa did not bring my IGF-1 within normal limits unfortunately as it was much more convenient. My endocrinologist stated she could add pegvisomant to see if that would work, but we never did get to that during the Trial, then I was put back on Somatuline Depot injections. Somatuline Depot causes gallstones (which I have now), I feel that it has not controlled symptoms well at all, specifically increased arthritis, joint pain, mood swings, depression, anxiety, hair loss, brittle nails, weight gain, fatigue, apathy, irritability, to name a few. Insurance companies also make you jump through 100 hoops in order to get your medication, which causes you to be late with your dosage, which brings back all your symptoms tenfold. Other failures with Somatuline are 1) scheduling your life around a monthly injection, 2) finding a capable nurse who not only follows instructions (and watches the video) but listens to you when you tell her/him how to administer the shot and actually COUNTS the 20 seconds and injects SLOWLY and 3) having to take time off of work every 28 days to get a shot in your behind.</p> <p>Future Treatments I would love to see more pills on the market - less injections. Would be great to see pegvisomant in a pill form. More research on Ozempic and how it could potentially decrease the Ghrelin hormone. More research on Ghrelin. More research on how a Gastric Sleeve decreases Ghrelin and see endocrinologists learn more about this hormone and how they can tackle the issues that may arise from this. I would love to see any of the pharmaceutical companies tackle OTHER symptoms that we experience, and for me, that’s osteoarthritis, which is debilitating at times. Doctors and Pharma focus mostly on controlling IGF-1, but once we are on this crazy and painful emotional rollercoaster, the symptoms don’t all STOP, they keep tumbling like dominoes.</p>
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DS	<p>I am currently on Sandostatin Lar every 4 weeks. This medication has elevated my blood sugar levels and I must now have Type 2 Diabetes and must take 2 medications to control the sugar levels. I am as concerned about the long-term effects of diabetes as I am about the acromegaly.</p>
MF	<p>The most significant symptom I experience is extreme fatigue. Normal activities like just walking to the car to go somewhere or from the shower to my bedroom can exhaust me and take me 10-15 minutes to recover from.</p> <p>I have had two surgeries to resect my tumor, seen three endocrinologists, and tried five different medications to treat my Acromegaly before my doctor finally found a combination that seems to be working. For the first time since diagnosis my swelling has significantly improved, I'm not as tired, I can focus better, nor as moody or emotional. Just this year I required a significant amount of help just to complete daily tasks or chores, and now for the first time in almost ten years I can do normal things. I was so bad at one point my family was scared to let me drive.</p>
ER	<p>I am the husband of an Acromegaly sufferer.</p> <p>Outline of comments:</p> <ul style="list-style-type: none"> - Affect is on the whole family - Watching the daily pain and struggle, being support while having own worries, not being able to understand completely what it feels like - Perpetual roller coaster; no constants, no answers, no simple solutions, always hard choices and bad or worse options - Dealing with fallout of the neurological and emotional impacts - Kids don't get the mom they deserve, I don't get the wife I married - Financial impacts - Person suffering deals with guilt for all of the above, feeling like a burden - My wife is my hero
ET	<p>Acromegaly has made it hard for me to do things including gardening, walking a good distance, I have pain in my joints, I have a Sandostatin injection monthly and it is starting to lower IGF-1, but my issues don't seem to be changing.</p>
SS	<p>Fatigue has a massive impact on my son's life with acromegaly. Excessive growth has an impact with regards mobility and many other health issues, lack of all hormones and also the continuing elevation of IGF-1 which cannot be brought under control with surgeries, radiation or medication. My son was 24 and working when diagnosed and had many symptoms including terrible aches sweating, headaches, always tired, dark skin, weight gain. Since his treatments he has doubled in weight lost his eyesight through surgeries and is still growing. This illness has taken every part of his past and future away, we continue to fight for medication which may be able to lower his IGF-1 and give him some kind of normal. He takes pegvisomant 30 daily and lanreotide 120 every two weeks for the last two years.</p>
BN	<p>Treatment by medicine takes time to figure out what works best. For me it was 9 years. Starting out with cabergoline / Somatuline for 5+ years worked good until the breakthrough symptoms started during the 4th year and made it unbearable to continue.</p> <p>Switching to Somavert low dose took away those breakthrough symptoms for a year and then started coming back. That's when I was selected to conduct a one-year combo therapy</p>

BN (cont)	<p>study with Dr. Bonnert at Cedars Sinai. This became the greatest achievement in my treatment of Acromegaly and the horrific symptoms associated with it.</p> <p>Somatuline 60 + Somavert for six months gave me my life back. Energy and strength were most notable as I could do my favorite passion of Spring Turkey hunting again.</p> <p>This study taught me how to best treat my symptoms with which medication. Today I am on 30mg Somavert M, W, F, Sunday. My IGF-1 is in the 90's. Thank goodness for researchers such as Dr Bonnert & studies like Cedars Sinai conducts because now I live again.</p>
SK	<p>The three most impactful symptoms that affected my quality of life were the 24hr, 30-day headaches; photophobia and drastic change in both looks and personality. It is only thanks to treatment, a multidisciplinary medical team and strong family and friend support that I was able to accept the 'new' me and regain control of my life having a new purpose in my life. That of giving voice to those patients who don't have one to help them be diagnosed earlier and have access to treatment.</p>
JL	<p>I was diagnosed in 2010 after many doctors not listening to me about something being wrong. After being diagnosed, I had no idea what it was, never heard of it. So, I did what most people do, look it up on the internet. That was the wrong thing to do. I was a single mother of a 13-year-old boy. Not knowing whether my son would have to grow up without his mother, was the scariest part of it all.</p> <p>Even after having to have 2 surgeries & 6 weeks of radiation 10 years later, I still suffer on a daily basis with the damage that this condition has done to my body inside & out. Every time I go to the DR its something else. My biggest fear right now is what if something is wrong and no one catches it in time...What if they don't catch it at all & it ends up killing me because these doctors have no clue what to look for or what to do.</p>
RA	<p>Does the medicine help to shrink tumor?</p>
CF	<p>Change in features... Being a female I have always felt changes made me ugly. It has impacted daily how I feel about myself and my interactions with others. I will not go out at times and it is 29 years later after diagnosis. I feel people stare at me, I have been called a freak and a man... "Look at those hands". People who I grew up with do not recognize me. It is a shame that in today's society the females have to feel that our looks take such an important part in society</p>
KH	<p>Treatment for me is a monthly Somatuline depot injection as well as 3 times per week Somavert injection. It is very hard mentally and physically having to do these Somavert injections 3 days each week. Mixing the shot each time is time consuming. And not to mention pain of injection. To have an option for Somavert in a once-a-month dose would be wonderful.</p>
TY	<p>I was diagnosed with Acromegaly in 2013.</p> <p>My life has been changed forever. I don't recognize the person in the mirror. I am always hot and sweaty, extremely exhausted, morbidly obese, and in extreme joint pain. I take 22 pills a day along with 2 daily injections and 1 monthly injection. All of this medication is the only way I can function. Everyday is a struggle.</p>

<p style="text-align: center;">MK</p>	<p>Do you see Ghrelin tests coming into the narrative in the future? (For me the IGF-1 test is not the end all be all)</p> <p>(Although I am in remission and IGF-1 is currently in normal range off Octreotide medicine, I am still symptomatic at times.)</p> <p>Would it be possible to change the guidelines so that even though a patient is in remission that they could still have access to a low dose of octreotide to control symptoms?</p> <p>Do you think it is a possibility for patients to have the option to take a low dose of octreotide to control symptoms even if they are in remission and IGF-1 level is in normal range?</p> <p>What are the risks of trying? What would the benefits be?</p>
<p style="text-align: center;">SLK</p>	<p>I have arthralgia and arthritis in the cervical spine, knees, and hips, causing weakness and numbness of my extremities due to prolonged undiagnosed Acromegaly. I'm concerned about function, mobility, and possible future multiple surgeries as these joints worsen. I'm a very active and healthy conscious person. I want to continue living that lifestyle to continue to hike, attend gym classes, and travel. I had the surgery a year ago with 98% removal of the tumor. My symptoms improved and are being followed closely. I don't take any medications at the moment, and I declined the NS's recommendation to proceed a few months after surgery with GKS.</p>
<p style="text-align: center;">MK</p>	<p>What have you found over the years in regard to Acromegaly and pregnancy? How does the current medicine affect children born to mothers on octreotide at conception?</p> <p>In older women entering the perimenopause stage in life, are there any findings that give you knowledge in how to lessen their symptoms? For me they seem to be the same as acromegaly symptoms (water retention, mood swings for example) when I was on octreotide, I did not have these symptoms. Now, in remission, off octreotide I have horrible symptoms one week every month, like clockwork.</p> <p>Could Octreotide be used as a treatment for PMDD or PMS in patients?</p>
<p style="text-align: center;">CC</p>	<p>Of all of my symptoms, fatigue is perhaps the most prohibitive to daily life. Insomnia was one of my initial symptoms and even though I feel I sleep "well," I haven't felt rested in perhaps years. Someone under 30 shouldn't need to sleep >12 hours a day and yet be as exhaustingly tired as I currently am. Chronic pain is probably the symptom with the second largest impact on my life, as I deal with chronic soft tissue pain and joint dysfunction.</p> <p>As I consider possible treatment options, the American relationship between patient, insurer and doctor has been absurdly prohibitive to me starting treatment. I received non-curative surgery in September 2020 and my doctor prescribed medical management in October, yet here at the end of January I have yet to receive any sort of treatment because our insurer has been so prohibitive and has now changed due to pandemic-related job loss. I've now been on a low-dose of cabergoline for a month, but have yet to start a somatostatin analogue because of insurance related hang-ups.</p> <p>There has been virtually no change in my quality of life since diagnosis, besides experiencing less frequent headaches since surgical debulking. I'm far less physically active than I was previously (as a yoga teacher/fitness instructor who averaged teaching 15 classes a week in 2019) and my ability to make money has been significantly disrupted.</p>

JC	I was taking cabergoline made by PAR Pharma and had virtually no side effects. As of 2021 PAR Pharma no longer makes cabergoline. I just started taking cabergoline made by Greenstone Pharma and have severe side effects to the point I've had to cut the dose and may have to stop taking it. If all generic drugs are the same what could account for this?
DB	<p>My name is Dolores, I am 57 years old and have Acromegaly. While I was finally diagnosed in 2013, I believe the original onset was in 1994 when I was diagnosed with arthritis. Over the next 20 years I would have a myriad of symptoms that always seemed to be attributable to a "reasonable" diagnosis. The joint pain and swelling in my hand and feet was arthritis. The enlargement of my feet was arthritis and having two children. The hot flashes and sweating were perimenopause symptoms. The headaches (mostly mild) and exhaustion were attributed to a busy life of running a dental office and having two children. No one put it all together for the appropriate diagnosis. Doctors all along have told me that my issues aren't necessarily related to the acromegaly because other people have them as well.</p> <p>When you hear hoof beats you think horses, but I really had the zebra.</p>
SB	Constipation is currently my top symptom I struggle with on a daily basis. I have been trying so many treatments (i.e., fiber, digestive enzymes, laxatives, etc.) to try and figure out a long-term solution. I was told by my Endocrine that constipation was not connected to Acromegaly; that I just needed to eat some prunes which is not helpful.
CK	Other side effects - weight gain, fat hypertrophy, GI issues
LB	<p>I am 24 years in since my Acromegaly began to show. I was advised when I was diagnosed that it probably began approx. 8 years prior. I have had neurosurgery/medical therapy/radiotherapy. Last year my IGF-1 fell a good way into the 'normal' range.</p> <p>I still have a permanent headache & use subcutaneous octreotide to bring it back to a manageable level 3-5 times a day, the injections work in an average of 1 min 58 seconds, bringing the pain back to level 3 or 4 on a 1-10 scale, but the headache never goes away completely.</p> <p>I have tried many therapies for my headaches, but nothing 'cures' them.</p> <p>My first question is, are there any further developments on treatment of headaches in Acromegaly?</p> <p>My second question is, what are the key checks that I should be having and what frequency?</p> <p>Thanks</p>
DT	<p>My other is really two related things. I worry that the large amount of belly fat that I cannot seem to lose will harm organs. Difficulty losing weight even though IGF-1 is under control using Somavert 30mg/day is the other.</p> <p>Thank you for the conference.</p>
EK	Other symptoms that I did not see on the poll: acne, dental issues due to jaw growth, and memory/concentration issues
NB	My most frustrating issue is lack of concentration.
KP	The noise & the light are two things that bother me. I suddenly want light & suddenly I want dark. I suddenly want noise & I suddenly want quiet!!! Thank you for all this conference!!!
GK	I have trouble losing weight no matter what I do. I'm on Trulicity now. My diabetes levels are ok

DB	<p>My top concern is joint issues. I've had carpal tunnel surgery, my first shoulder replacement, enlargement of my hands requiring my rings to be enlarged and joint pain in my feet causing pain and numbness with exercise.</p>
HH	<p>What led to my diagnosis were skin issues. I had skin thickening particularly on my face (forehead and nose) I was misdiagnosed for rosacea. Also, I had many skin tags.</p>
LF	<p>My tumour was removed this past Aug 25th. I did have all systems of Acromegaly. While I feel that Anxiety and Depression has been alleviated by the tumour removal, however it feels like I have been left with some form of brain damage in so far as I feel I have a personality disorder. I have no patience and my ability to reason and exercise logic seems to be broken. Anger is quick and easy to come. I have exercised CBT techniques, but I would like to know more. I have also lost my taste completely. So, it feels logical that if the parts of my brain that help with taste are affected, that other parts of my brain have been damaged. I do have chronic pain returning in my neck and back. It had been gone for months since my surgery. So, I am on watch to see where and how it goes moving forward.</p>
AD	<p>I was diagnosed nearly 10 years ago and have been in various levels of disease since initial surgery. My biggest issues now are pain due to arthritis and disc compression in my spine as well as in my hands and feet depending on what I do. Secondary to this are issues with my lungs. I have a large number of lung nodules and a barrel chest. Even though my oxygen saturation is ok, I feel like I can not get a full breath on any given day despite the level of activity. I do not understand fully how the respiratory issues are related to Acromegaly so I feel like I can't have an intelligent conversation with my doctor on it.</p>
AM	<p>Headache and fatigue are most troublesome because they are with me constantly and impact what, and how much, I can do every day. I also have to think about it all the time because of the need to plan ahead and pace myself. I sometimes need to tell people "I'll let you know how I feel on the day" or I have to cancel things at the last minute. It doesn't make me feel good. It makes me feel unreliable and lazy when actually I'm trying to do as much as I can. Thankfully the situation has improved as my condition is better controlled but at their worst, I felt like I had ground to a halt - didn't go anywhere, do anything, meet up with friends or family.</p>
JK	<p>I wanted to expand on some of the "Other" Symptoms that I experience. For context, I was diagnosed a little over 4 years ago and am currently in surgical remission:</p> <ul style="list-style-type: none"> - Memory Loss - Tremors - Extreme fatigue. I use a CPAP which has controlled my sleep apnea, but I still sleep close to 16 hours per day - Pain. It's constant and everywhere. It impacts my ability to move around and function <p>As a result of all this, I am no longer independent and have become a burden on my family. It is awful. I need to see a myriad of doctors and am on over 30 medications. It is exhausting to manage all this.</p> <p>And after listening to some of the panelists, I am even more afraid of the future and what it holds</p>

RD	<p>Although joint pain, fatigue and anxiety are limiting factors in my quality of life I have been significantly impacted by the "mental fog" that many of us experience but has yet to be recognized as a symptom of acromegaly.</p> <p>Our current treatment options do not address the issues that present as obstacles to a "normal" life</p>
ME	<p>My wife, who has acromegaly, was a participant in a clinical trial for an oral octreotide. I would like to encourage others with acro to participate in the clinical trials. This a way for patients to become part of finding a treatment and also to benefit from the research that is being performed.</p>
HH	<p>Social Interaction - due to anxiety and also low self esteem due to physical changes (changes to appearance).</p>
GK	<p>I feel more confident while wearing a mask because it covers my jawline. One of the benefits of Covid. I didn't realize how much I was self conscious I was until I noticed the difference wearing the mask.</p> <p>Second question: I was just diagnosed with Paget's disease of the bone, anyone else?</p>
KM	<p>The unpredictability. That is one of the biggest challenges. After surgery, radiation, and finally after a decade of trying to find the right drug regimen to almost normalize me, I decided to go back to school. I feel so beyond grateful to have this opportunity, but acromegaly is making it even more challenging than I originally thought due to the breakthrough symptoms of migraines and extreme fatigue which can cause me to sleep over 11 hours at night if I don't fit a nap into the day. I'm not giving up, but I wish my meds would be more predictable and consistent in their symptom control so that I can be there for my family and my career.</p>
RH	<p>I agree with the caller regarding weight gain after surgery. It's well known in the Acro Community. But when you go to the doctor they don't know anything about this weight gain & lack of fat metabolism. You just get told to diet & exercise.</p> <p>However, if you read the Symptoms of patients with GH deficiency, they read just like the symptoms Treated Acro patients are having. There needs to be NEW treatments developed that don't take away all the good benefits of GH while still helping the Acro. Most days I question whether taking my Acro shot is worth it. Thank you!</p>
EP	<p>I'm concerned with building tolerance or antibodies to the medical treatments. I'd like to see the rate of absorption monitored to determine treatment frequency/dosage.</p>
PS	<p>By the time I was diagnosed, my doctor believed that I had acromegaly for at least 15 years. I was 59-years-old at the time. My pre-diagnosis symptoms included incapacitating fatigue, apathy, uterine fibroids, weight gain, enlarged feet, hands and jaw, a deepened voice, hypertension and sleep apnea.</p> <p>I'm almost two years post-neurosurgery, and I still have mild fatigue some days. After adverse reactions to several medications, I'm now successfully being treated on oral octreotide.</p> <p>One of my biggest challenges is living with the self-consciousness about my physical changes, particularly my face — and the impact on my mental health.</p>

PS (cont)	<p>Most of my professional life was spent working in healthcare administration in psychiatry. I realized early on that there was a paucity of information regarding the psychological impact of having acromegaly. There are mentions of depression or quality of life issues but nothing substantive.</p> <p>For me, living with acromegaly isn't just about the path to recovery from the medical complications caused by the disorder; it's also about surviving the accompanying emotional turbulence that one may weather. Despair, depression, grief, anxiety and impaired quality of life issues are not uncommon.</p>
AM	<p>The worst part is that I didn't do things I wanted to do with my son as he was growing up - activities, travel, even having friends visit, organise a birthday party.</p> <p>However, I also think if I didn't have Acromegaly, I would probably have stayed in a career that was no longer satisfying and lived a life I wasn't really enjoying. Instead, I now prioritise so I do what's really important and gives me pleasure. As a result, I now volunteer for charities that mean a great deal to me and have a new hobby that has brought me such joy, a wonderful set of amazing new friends and a great social life (pre-Covid - all social life is now online!)</p>
HH	<p>Fears for the future:</p> <p>I had transsphenoidal surgery in Sept 2020 and the doctors were confident that they got all of the tumour however my IGF-1 is still very high (the same as it was at diagnosis). The MRI shows complete resection and no visible tumour which means at this point my only option for controlling IGF-1 is medication.</p> <p>I'm 38 and the thought of being on medication for life, and particularly having to do daily injections is daunting!</p>
JC	<p>Haven't heard any discussion of cancer or visual migraines. I've had 2 forms of cancer and get visual migraines regularly. I've also had a "severe complex migraine" that temporarily and intermittently paralyzed the right side of my body and left me unable to speak. Wondering of anyone else has had this?</p>
WB	<p>I've had surgery and, shortly after, started Somatuline 120mg injections. Decreased IGF-1 significantly, but with side effects. Now, after 1 year of treatment, my IGF-1 is on an upward trend, now out of range. My endo is recommending Radiosurgery. Says combination drugs are expensive. My neurosurgeon says to radiate while the tumor is small(<1cm³). Tumor is abutting pituitary but not covering it. I'm scared of developing adrenal insufficiency or replacing one medicine with another if I choose radiation. I don't have enough data to make a decision I'm confident about.</p>
CT	<p>I have developed a fear of doctors over the past 30 years. I had 3 decades of being misdiagnosed or being told I had depression from age 20 when I had my first ocular migraine to the age of 46 where I was finally diagnosed and had my tumor removed. I'm sure the depression came from seeing my face and body change and not understanding why I looked and felt so different than my peers. Now that I am in remission and I continue to have break through symptoms mainly chronic joint and tendon pain, headaches and weight gain regardless of exercise and diet; I continue to hear the same excuses doctors gave me in my 20s 30s and most of my 40s- "Women get headaches", "your life is too stressful", "you sound depressed you need to talk to a psychologist." The dismissal is devastating, time-consuming and expensive! I have combined other treatments into my care including acupuncture, massage and meditation to work through the pain and exhaustion this disease causes -</p>

<p>CT (cont)</p>	<p>during COVID I can't get these treatments and don't feel safe, so I stopped and I feel horrible. I think that doctors and dentists need to be more open to qualitative data and not just the quantitative data like our IGF levels etc. Doctors didn't connect the dots and even my current specialists have a tendency to dismiss my symptoms as psych or gender related! I am in tune with my body and when I was pregnant, I had never felt better, after delivery of my first my symptoms came back fiercely: de Quervain's tendonitis, locking joints, hearing loss, migraines and jaw issues. I have stepped back from many relationships because it's hard to be dismissed as being a hypochondriac or too much of a liability. I have voice, body and face dysmorphia and hate how I look and sound. I visited doctors from age 20 with symptoms and was not diagnosed by a doctor (I connected the dots and self-diagnosed via the internet) until I was 46 and even then, I was told I didn't LOOK like I had acromegaly! I have become apathetic and changed my job, I have a small group of people I trust- I hope I can add my medical experts to that list. I save up my energy for my 2 wonderful children and just go day by day and hope for the best.</p>
<p>MK</p>	<p>Hello and thank you for hosting this virtual PFDD meeting today.</p> <p>I saw questions that you are looking for responses to and one question below I feel I have knowledge as a patient for the past 18 years and now in remission.</p> <p>What are specific downsides to current treatments?</p> <p>Current treatments are a blessing as they are better than 25 years ago. With that being said, change is a good thing if you find a treatment that becomes available to you.</p> <p>Are the current treatments given to patients based on IGF-1 tests?</p> <p>What IF the IGF-1 test is not catching those with mild acromegaly?</p> <p>What if there was a test to diagnose people even earlier before symptoms cause irreversible damage?</p> <p>Do you see any future tests to diagnose acromegaly? Could one diagnose Acromegaly on symptoms alone? Why or why not?</p> <p>Could someone in remission be treated with an octreotide medicine based on symptoms to improve their quality of life? Why or why not?</p>
<p>JK</p>	<p>It's great to hear about all these medications that treat Acromegaly and lower IGF-1. However, this is only a small part of the issue. There are many ongoing symptoms, even after achieving remission, that these medications do not address.</p>
<p>PD</p>	<p>My son takes CBD - has brain neuro-protective mechanisms. Also helps provide calmness.</p>
<p>MF</p>	<p>I have tried two different combo therapies: Octreotide with Somavert then lanreotide with Somavert, and both were unsuccessful in lowering my IGF-1. Octreotide caused such severe diarrhea that I had to be hospitalized for dehydration. Sometimes my doctor is not up to date on the current standard of care on prescribing these medications. Traveling with these</p>

MF (cont)	<p>medications is also very difficult, even a short road trip with an overnight stay, I have to make sure I can keep the medication refrigerated and if the medicine upsets my stomach that there's a bathroom nearby. It's yet another way Acromegaly controls my life.</p>
HE	<p>WISH FOR THE FUTURE OF TREATMENT:</p> <p>I was diagnosed with acromegaly in 2012. I have had several surgeries and am currently on long-acting octreotide and pegvisomant. Most of my tumour cannot be removed because it took years to get diagnosed and during that time the tumour grew so large that it wrapped around my carotid artery.</p> <p>My tumour was found exploring the cause of my infertility (though I had been seeking medical treatment for other acromegaly symptoms for years prior). After my first surgery, when it was clear that I would need to be on medication to control my IGF-1 and GH, I had very little information on how these medications would impact pregnancy. I was started on bromocriptine because it had the most pregnancy safety data, but it did nothing to help. I then started octreotide, which eventually worked enough that my endo gave me the green light to try to get pregnant. Thankfully, we were successful, but because of the large residual tumour and the risk of the tumour growing while I was pregnant, my doctor and I made the decision to go back on the lowest dose of octreotide during my second and third semesters. We also decided to continue on octreotide while I breastfed for one year.</p> <p>Now six years old, my son is in perfect health. My own health suffered, however, from not being on the optimal level of medication for over two years. I also had to make the heartbreaking decision not to have a second child, as the octreotide was not sufficiently lowering my IGF-1 level and there was not enough information on pegvisomant and pregnancy for me to feel confident in taking it while trying to get pregnant again...and I needed to get my acro under control to be an active parent to my son.</p> <p>I would love to see more research on the effects on these medications on pregnancy and their safety and efficacy during breastfeeding. Making a decision that could impact your unborn child or infant is agonizing. If we knew what was safe, we would not have to reduce or delay taking medications that are vital to getting and keeping our acromegaly under control.</p>
CK	<p>I find it very difficult to wade through the side effects of gamma-knife radiation (which I had) and Somavert (which I take daily) vs. the symptoms of the acromegaly disease itself. It seems my endocrinologist does as well. Any guidance here? Thanks so much.</p>
AA	<p>Topic 1: a) Drug therapy for GH gives me serious side effects b) Mental Health c) Emotional dysregulation.</p> <p>Topic2: The side effects of the medication makes it impossible to have a consistent routine and schedule life events as necessary because I always have to plan around the week before the shot and the week after. If I have PMS during that month, I probably only have a few days (4-5days) of 'normal' symptom free functioning. One of the main side effects is fatigue. This impacts my mental health contributing to depression and anxiety and contributes to low productivity and loss of social interactions and financial stability. Emotional dysregulation due to skyrocketing hormone levels affects every aspect of my life, but it especially affects my ability to communicate effectively. If trauma and stress happen (as they do) it becomes very difficult for me to lead a healthy life, unburdened by my circumstances.</p>

AA (cont.)	<p>Topic3: I have been on medication for it for most of my life, since age 3. I had Gigantism as a child. I'm now medication free because I'm taking a breather. My family and friends have been very supportive of me for the most part but less supportive of my mother who single handedly spearheaded my diagnosis process by actively seeking the best doctors in the country. She moved our family from Romania to Canada hoping that I would be able to get better medical care and start on Sandostatin LAR. After years of doing Sandostatin I started on Somatuline when it became available because I wanted the freedom to inject it myself. The only thing that wasn't offered to me was mental health support and I really needed it / need it atm as well, I will likely always need it. Another thing that wasn't offered was a transition program from paediatric care to adult care. Once I turned 19, I was left to my own devices and my mom was told by my doctors that she can't join me at my medical appointments anymore. This was a very difficult and confusing time for me because at that time, my mom had all of the details of my health, while I only thought that I knew — I did not, and I had to start from scratch working with doctors who expected me to know more, who did not properly explain my health conditions and how Acromegaly plays a part. I have McCune Albright Syndrome and Acromegaly is a comorbidity. I am now a patient advocate, on my way to becoming a general rare disease Expert Patient with a secondary focus on Acromegaly, MAS, FD, Prolactinoma and can advocate for myself and for my community.</p>
DT	<p>Warm water arthritis exercise classes help with constant joint pain.</p>
CT	<p>When I asked my endocrinologist to look into this I was reprimanded and told to stop looking at the internet and to see a psychiatrist.</p>
JC	<p>Somavert worked to normalize my IGF-1 but my GH is 17 or higher. Doctor says it's possible Somavert can cause GH level to increase. My MRI is stable, so it doesn't look like the residual tumor is growing. Does anyone know what effect high GH has if IGF-1 is normal?</p>
CP	<p>I feel this disease is a roller coaster ride. I have gone from managing to not so much. I am a fighter! But that being said, I can go from exercise to not being able to function. It is hard to navigate! I try to manage my symptoms based on how I feel. 9 years in, I am still up and down! I think hormones being askew is hard to manage. I think the drugs used to manage IGF-1 have a huge impact on other hormones.</p>
DD	<p>Since switching to pegvisomant in late 2013, my IGF levels and overall feelings dramatically improved. I use this in conjunction with a cabergoline dosage as well. I still feel some fatigue but believe it is due to the meds, but otherwise feel well controlled. I do still take meds for blood pressure, thyroid, HRT and triglycerides.</p>
ZZS	<p>I would just like to point out that IGF-1 levels can be normal in some cases and normal level of the IGF-1 is not exclusion for the diagnosis. IGF-1 concentrations are decreased by several factors, including advancing age, female sex, estrogen deficiency, chronic illness and acute illness, because it is a negative acute phase reactant. Take care</p>
SD	<p>The treatment for acro has been worse than the symptoms, as my tumor was diagnosed as a microadenoma. The 2 endoscopic endonasal TSH surgeries have left me with chronic sinusitis/laryngitis due to removal of my bony nasal septum and resection of several nasal turbinates; this is with the most experienced neurosurgeon in the U.S. With Octreotide I developed severe pancreatic insufficiency and malabsorption. I'm now on Somavert, which has normalized my IGF-1 and improved fatigue, but I still experience joint pain (both peripheral in hands/feet/knees and centrally in the entire spine), pain/swelling in hands/feet with just minimal walking and cooking. Gardening and sewing are no longer possible, and</p>

SD (cont)	<p>biking/aerobic exercise is out. I've been able to transition to full time telework, but would have had to lose my job if not possible. Having to refrigerate my Somavert is problematic with travel.</p> <p>An ideal treatment would be an oral analog of Somavert that improves the arthralgia/ arthritis, which was the most troublesome symptom according to today's poll.</p>
EP	<p>Symptoms resulting from medication not being identified as such. Causes increase in medical debt while seeking diagnosis of the symptoms. Example- GI issues with Sandostatin.</p> <p>Malabsorption due to medication causes other medications to not be as effective. This isn't recognized so medications aren't dosed appropriately. Leaves pain significantly undertreated.</p>
AC	<p>As an acromegaly patient, I would love for our community to have more oral medication options so that we can move away from injection-based therapies. Injections are very painful and caused me to develop lumps under the skin at the injection sites. Breakthrough symptoms have also been a huge issue for me - I have known it is time for my injection because I could feel it in my knees (and I'm only in my early 30s!). Especially during COVID, I have been very concerned about going into my doctor's office on a monthly basis just to get my injection. I recently switched to MyCapssa, and so far it has helped to control my breakthrough symptoms. I appreciate that I no longer have to go into the doctor's office every month to get the painful injections.</p>
JL	<p>One of the issues I had with Sandostatin was getting someone to follow the directions. It's hard to educate a nurse when you're not one. At least 50% of the medication was following the needle out of my body and ended up on the exam room floor. The 8th or 9th dose caused my liver to fail but my igf-1 was below normal, so the doctor took me off of it. My liver function has returned.</p>
BE	<p>It's very challenging to educate people what Acromegaly is. Sometimes even some of our medical team just don't know what it really is. The tumor wasn't just a little thing that was removed and done. People think you look great so what could be the problem?? I think it is such a hard disease to have when no one knows what it is, and you feel so alone. The references we see are mostly shown as "monster type" People in the movies. Myself my levels have been within range however that doesn't mean some of the symptoms from damage still aren't there. I still have struggles daily.</p>
EK	<p>One of my medications is Sandostatin LAR, an intramuscular injection, taken on a three-week cycle. After cycling between the four approved injection sites for over a decade, I've developed scar tissue which more and more often makes it difficult to inject the medication - it's like trying to inject into a cork versus injecting into normal muscle tissue. If the medication won't go in, the only thing to do is to pull the needle out, put on a fresh needle and try a new site, and sometimes I've had three injections before the medication is delivered. At this point, I move the injection site all over beyond the four approved locations because I'm afraid of hitting scar tissue. Also, my chiropractor thinks the scar tissue could be a contributing factor to muscle weakness in the area.</p>
LB	<p>Hi, I have tried to call but can't get through.</p> <p>I have had a headache for 19 years. Everyday, all day. It peaks several times a day & I have to abate it using Octreotide subcutaneous injections.</p>

LB (cont)	<p>I can cope up to level 6 (on a 1 to 10 scale) but beyond that is extremely distressing.</p> <p>Are there any developments in medicines for headaches in Acromegaly?</p>
TT	<p>The administration of medications can be complex as well. For example, Somavert is delicate and requires specific storing, handling and mixing. This is time consuming and can also be a struggle for storage and transport for travel or shift work.</p>
KM	<p>For future treatment, something more long acting (I'm currently on Sando LAR and biweekly Somavert) that could help eliminate the breakthrough symptoms and the cyclical nature of my good days. Something to help with hunger and weight gain would be lovely too!</p>
DD	<p>As treatments have progressed from monthly injection to an easier daily injection, it would be great if a daily oral medication were developed. That would be awesome especially if it came in multiple dosage levels just as a number of the injectable prescriptions already do. It would also be important to get a standard IGF-1 level test. I have heard too often that each lab does it differently so across the board it seems to be difficult to be doing a comparison of apples to apples.</p>
AP	<p>Reducing growth hormone via radiotherapy in a SAFE way (improve research and / or training given to those performing the radiotherapy). Assessing the best type of radiotherapy.</p>
LF	<p>I would dearly love them to include a focus on ways to help manage the inner anger. Why do we have to live with and why do our loved ones have to live with the anger that so many think we are able to control. We are not necessarily depressed or have anxiety. What is going on in the brain to cause these fits of anger by otherwise loving people.</p>
PS	<p>I had successful transsphenoidal surgery in April 2019. My IGF-1 level was still higher than normal. I was placed on cabergoline but had an adverse reaction.</p> <p>I was then placed on Somavert. Unfortunately, I also had serious side effects to that medication.</p> <p>In October 2020, I began oral octreotide (60 mg/day), which has been effective in lowering my IGF-1 though I do have some side effects (mild GI distress). Because of this side effect, there are days that I skip my morning dose in order to be able to attend appointments scheduled outside of my home.</p> <p>Other ways I manage living with acromegaly are with nutrition/diet, daily yoga and Zoloft.</p>
JR	<p>Many of us have other hormonal issues such as hypothyroidism, hypoparathyroidism, testosterone issues, etc. Is there research in ways to avoid those effects from acromegaly?</p>
JE	<p>Hi from NZ</p> <p>A few snippets! Diagnosed end 2017, surgery early 2018...symptoms in retrospect a good 10 years</p> <p>I have had one surgery but can't have a second as the balance of my tumor is right next to an artery and too risky, so now on medication. Constant colonoscopies etc....</p> <p>It's so easy to ramble about Acro because there's SO much to it! I think that's it; it is not like having a single disease, it's a disease of many things. You often cut the conversation short so as not to bore people or sound like you are complaining or a hypochondriac.</p>

<p>JE (cont)</p>	<p>Waking up with a headache/migraine more often than not. Yes to the rage/mood swings, thanks Jill for talking about this...I am on medication to keep me "even". Yes short term memory, "brain fog", headaches and cognitive issues, I run my own full-time business. I keep going because I need to but it's such a real challenge. Once people know you have had surgery, common comment so "you're fixed" Yes keeping the "I'm fine" face on. There's so much more... 😊 Thanks for reading</p>
<p>AM</p>	<p>Re future treatments, the method of delivery is less important to me than the effectiveness. A daily injection is really no problem at all if it's having the desired effect of improving IGF-1 and symptoms. I was happy to take subcutaneous Octreotide 3 times a day rather than a monthly lanreotide or Octreotide injection because the subcutaneous injections gave me instant relief from excruciating head pain. It helped me manage my pain better because I knew that for 90-120 mins after the injection, I'd be able to "get things done". Then I could use painkillers in between injections. A recognition by endocrinologists that subcutaneous Octreotide can relieve head pain in some patients would be welcome.</p>
<p>CK</p>	<p>THANK YOU SO MUCH!</p>
<p>BE</p>	<p>I was part of the MyCapssa trial for the past five years. Being so honored to be a part of something that could possibly help so many patients like myself. There were challenges being in a study. Mine being in another state and flying back and forth sometimes not feeling so well. But I was all in no matter what. Having it now approved is so wonderful. I would express to anyone that could take part in a study to do it. I have grown so much from doing something like this for myself and hopefully for others.</p>
<p>CE</p>	<p>As an African American woman in my 30s, Acromegaly has altered my daily life. After injections and surgery, I am still left with joint pain and fatigue. I thank you for this meeting and I look forward to finding ways to aid in the effects Acromegaly has disrupted my life.</p>
<p>JD</p>	<p>I am recently diagnosed with acro (Jan 2020) but have been managing other neuroendocrine tumors for 5 years. My acro was caught by accident, and my symptoms are much less severe than those who were sick for a long time. My pituitary surgery was in Feb 2020, and so far, my hormone levels are ok, high end of normal. I am not on medication. But, I have still had symptoms that needed to be addressed (e.g.: fast nighttime heart rate) or accepted (e.g.: my hand bone has grown).</p> <p>A future treatment from a drug that wasn't listed in the final survey was tumor growth control. The control needed would be for the pituitary tumor, but quite a few of us with acro have or grow other tumors. There are a number of patients who have genetically tested negative for various types of MEN (MEN-1, MEN-4, etc.); however, we still have multiple unexplained MEN-like tumors. A drug controlling tumor growth is a priority.</p> <p>Also, I am willing to do whatever is within my control to benefit my health. Eating right, sleeping, exercise, etc. Having a tool to monitor my hormone would be very useful. Recently I changed my diet, eliminating sugar, salt, caffeine, and eating quite low carb. The changes in</p>

<p>JD (cont)</p>	<p>my joint pains and my nighttime heart rate were immediate. But I had to figure that all out on my own with my own research. If I had a hormone monitor (especially during my monthly cycle when some symptoms seem to be worse), I could better understand how my behaviors contribute to my hormone function and I could HELP MYSELF BETTER which would increase my feeling of control about this disease.</p> <p>Thank you for taking the time to listen to our acro community. We are grateful for any support you can provide.</p>
<p>ND</p>	<p>One missing focus is Physical Therapy specifically developed for those with Acromegaly.</p> <p>What happens...</p> <ul style="list-style-type: none"> -Structural and functional changes to the musculoskeletal system -Accelerated wear and tear on the joints along with inflammation. -Bone scrapes on bone. -The way the joints sit in the joints, articulate, and hinge change -The tendons move differently around the bones -Muscle pain, fatigue, nerve changes -The bones no longer stack properly from hip to toes which puts pressure on the joints <p>Physical Therapy is needed in every Pituitary Center, covered by Insurance. And ideally, subsidized.</p> <p>Thank you so much for your help towards our community!</p>
<p>AA</p>	<p>Hello,</p> <p>I'd just like to write a bit more and be more specific because I wasn't clear on what was asked of me the first time I commented.</p> <p>My history with Acromegaly is that I have McCune Albright Syndrome and Acromegaly is a comorbidity. I had Gigantism as a child, so I started on medication at 3yrs old. I took medication (thyroxin) to regulate my thyroid gland and used diet as well. Diet worked better because I didn't have to worry about side effects. After a few years, the secondary hyperthyroidism resolved itself with the help of diet. I have flare ups here and there if I don't eat a high nutritional and light plant-based diet.</p> <p>I also have Prolactinoma and that was also controlled with cabergoline (I think). By the time I was in my mid 20's I had become intolerant of cabergoline and had to get off because it gave me sexual dysfunction in the form of acute pain in my clitoris due to the effects of the cabergoline constricting the blood vessels in that area. That dysfunction healed but I can still feel the psychological and emotional effects of it.</p> <p>Growing up and having Gigantism had a massive impact on my development as a child, teen and young adult. I desperately would have needed access to mental health resources, but no one thought about providing those to me. I feel like the mentality 25yrs ago when I was 7yrs old was that children do not understand what is happening to them, and that is very unfortunate. The trauma persists until an individual is able to work through it in therapy or self therapy, and if left untreated it can lead to major depression and anxiety disorders. So there's a big mental health component to Acromegaly that needs to be acknowledged. I</p>

AA (cont)	<p>didn't have access to resources then, and unfortunately, I don't know either because mental health support for the most part isn't free or affordable.</p> <p>The Sandostatin LAR 2 gave me some serious side effects, much like everyone else says — GI issues, heart disease, gallbladder, chronic fatigue, cognitive issues, blood sugar issues. I was on it for many years, until I switched to Somatuline because I wanted the convenience to self inject. Having a nurse come to my place was a pleasure and a luxury but I quickly noticed that my life started to revolve around that date and I needed more freedom. I'm a young adult, or an adult at 32, and my life doesn't revolve around medication and medical appointments and for that reason it is impossible for me to keep up. Seeing that I have McCune Albright Syndrome, Fibrous Dysplasia and other degenerative diseases it is practically impossible for me to keep up with all of it.</p> <p>I've become a patient advocate to anchor myself in the community in order to try to keep track of my medical records and procedures. If it wasn't for the patient community and specifically for patient advocates, I wouldn't have any support.</p> <p>My care team of doctors does not treat symptoms, and they don't care about my standard of living because they only check the test results. I go to them for that and only that, and they often get it wrong and I need to correct them which is unfortunate, but this is what happens when you have one or more rare diseases. I'm constantly looking for new doctors and nurses who can assist me better.</p> <p>I am off medication for the first time in my life just to see what it is like, and my hormones are really high if I don't eat properly. Stress can also amplify them.</p> <p>I'm not sure if not this disease is better than treating it as it relates to my standard of living. I've felt better than ever being off medication.</p> <p>Granted, I have an encyclopaedia of symptoms so it's hard to tell sometimes which disease causes what.</p> <p>Definitely exercise and a plant based, gluten and sugar free diet works for me really well. If I don't exercise, I notice difficulty with my heart, I get tired very easily and sometimes I can't speak properly because I need to catch my breath — this is in part due to the effects of acromegaly and in part due to the Sandostatin.</p> <p>The side effects of the drugs on young children and teens are confusing because they are given before the child can form a sense of self, before they can understand and identify their emotions, feelings and bodily sensations and it takes a while to know what sensation is real and what is caused by the side effects of medication or disease. This affects their sense of worth, of self, how they perceive others and how their behavioral patterns that make up their personality form. If the child/ teen comes from an abusive household, the effects of stress and trauma can severely amplify the physical and mental health issues as it happened to me.</p> <p>I'm not sure if I will get back on medication any time soon. I feel like I need to be on something that is specifically designed for Acromegaly instead of taking repurposed drugs.</p>
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<p>AA (cont.)</p>	<p>I just wanted to weigh in because only about 20% of people with Acromegaly have MAS, so I have a totally different patient journey to 80% of the people in the Acromegaly Community. The effects of being diagnosed early are tremendous but I'm proof that even if that were to happen, there are still challenges. We focus on discovering the diagnosis early, but the earlier we do, the more dependent we are on our family, on society and on the system at large to provide us with the guidance and resources that we need to be able to live a good life. There's also no transition period from paediatric care to adult care; once a child is 18 or 19yrs old they are considered 'adult' and their parents aren't allowed into doctor's offices anymore. The adult doctors speak to the teenager as if they expect them to know everything however, it most often happens that the teenager needs to start from close to zero because their parents held all of the information throughout the process, because the parents are responsible for the teenager's care and well being. Once that system breaks, the teenager needs to be their own caretaker and unfortunately no one teaches them how to do it, so they spend years getting adjusted to the new normal. That is what happened to me and so many others in the rare disease community that typically only focuses on children. When those children grow up, they find that nobody really cares anymore and that they need to fight for themselves and advocate for themselves, and many don't want to do that because they don't know how to. The challenges that a 5yr old with Acromegaly faces are different than what a teen with Acro faces and different still to what a 30yr old faces and so on — most people with Acromegaly get diagnosed in their late 40's and 50's sometimes 60's and they have a totally different set of needs and requirements for treatment and care. For a hormonal degenerative disease such as Acromegaly, the age of patient population is extremely important.</p> <p>One thing I noticed being off medication compared to being on it is that I tend to get emotionally dysregulated more easily and I find it harder to self soothe. It never used to happen to me back when I was taking medication. I'm not sure if this is related because I've also been under a lot of stress. Just something to consider.</p> <p>Thanks so much for taking the time to read this, and I appreciate your effort in putting this together! Please don't hesitate to reach out if you have any questions, I'll be happy to answer. As I said I am a patient advocate, on my way to getting accreditation as an expert so I'll try to get to resources on my end if you need anything. In my experience I am the only one (aside from one patient from California) who has Acromegaly due to MAS, and we are underrepresented. Not even support group leaders know about us. That needs to change and I'd be happy to lend a helping hand.</p> <p>Many thanks, A</p>
<p>NJ</p>	<p>For me, the constant drain on my QOL (joint pain, migraines, fatigue) has been the greatest impact. There are non-stop medical visits to more specialists than I ever knew existed This speaks to the multi-system monitoring and associated worry of "what's next". Depression sets in!!</p> <p>My story began with a surprise diagnosis and surgery soon after. I continued with Lanreotide and cabergoline, but I had to stop using Lanreotide due to the dramatic drop in heart rate.</p> <p>Started on pegvisomant but within 6 months IGF-1 levels climbed to pre-surgical levels due to tumor remnants. Underwent fractionated stereotactic radiation treatments. Six years</p>

<p>NJ (cont)</p>	<p>later, I have started to deal with initial loss of hormones due to hypopituitarism.</p> <p>I have partial vision loss in one eye, and developed migraines since radiation treatments. Still on pegvisomant injections (just check in the larger fridge I had to purchase to store the meds.</p>
<p>LP</p>	<p>Provide more training for all GP's so that they can recognise initial symptoms of Acromegaly in the initial stages. Therefore. avoiding numerous years that a patient is left undiagnosed and feeling so helpless whilst damage is being done to our bodies. Also, no-one wants to be labeled a hypochondriac.</p> <p>In my case I was told I was just getting old.</p> <p>It would be great to have a list of key issues that send doctors to think that they should investigate further and "now".</p> <p>Further research on the causes of the adenomas.</p>
<p>MK</p>	<p>I watched the Acromegaly Meeting in the days following the live presentation. Thank you for providing this opportunity to share my experience. I am a 64-year-old Caucasian woman from Portland, Oregon. I was diagnosed with acromegaly at age 61 in 2017. In early 2018 I had transsphenoidal surgery, and in June of 2018 began monthly octreotide injections, 30 mg, which have kept my IGF-1 in the normal range.</p> <p>My initial diagnosis was almost incidental. I had many of the symptoms, but no one had connected the dots. I have had low thyroid for about 20 years prior, and familial high cholesterol for which I had developed statin intolerance. Shortness of breath and a carotid artery ultrasound discovered carotid artery disease, so my endocrinologist referred me to Dr Purnell at OHSU to be evaluated for Repatha - a different cholesterol lowering medication. My coronary calcium score was found to be over 500, so I was approved for the medication. At the same time, Dr Purnell asked me a few key questions about my shoe size, and he noticed the indentation on my finger where I had recently had my wedding ring cut off because it was too tight, and the gap in my teeth - which I have always had. The simple blood test gave me the shocking diagnosis, but I am so glad it was discovered relatively early.</p> <p>I have not had the debilitating headaches described by many, nor the vision changes or severe arthritis yet. That said, I will list the symptoms I do have: Coronary artery disease, arthritis in several joints, and anxiety are my top three problems. I also have enlarged hands and feet, osteoporosis, and fatigue.</p> <p>I did have rising blood pressure, excess weight gain, excessive skin tags all over my body, and snoring - but those symptoms have gotten better since treatment and some weight loss.</p> <p>Activities in my daily life that are affected: I continue to walk and hike for exercise. The large bone spur on one of my big toes makes it difficult to find supportive shoes, as my feet are size 11 extra wide, (used to be 8.5 medium), plus even more room for the bone spur. Joint pain sometimes limits how far I can go, and I need more recovery time than I used to. I have pain in my sacro-iliac joint which sometimes makes sitting and lying down/sleeping difficult. I feel embarrassed by my changed appearance - that affects some of my social activity.</p> <p>I am comfortable with my monthly injections. I get them from the same nurse team each</p>

<p style="text-align: center;">MK (cont.)</p>	<p>month, and I do not experience the pain and anxiety I hear from many in our community. I do have to schedule my life around the injections, which is not a problem during lockdown.</p> <p>My husband has recently retired, and we hope to travel widely, but will have to schedule around the medication schedule. I am considering the Mycapssa, but not sure how it will fit, as I have two other medications that are required to be taken on an empty stomach - levothyroxine, and alendronate for osteoporosis.</p> <p>Before this diagnosis and treatment, I found it impossible to lose weight, despite eating a healthy diet and regular exercise. I was developing type II diabetes, with an A1C creeping into the 6 range. With help from a nutritionist, I adopted a diabetic eating plan, monitoring carb consumption and adding more lean protein and healthy fats to what had been a more vegetarian diet. I have lost 30 pounds, my BMI is in the normal range, my A1C is now 5.9, and I feel very comfortable with eating this way. Before my acromegaly treatment I always felt hungry, and it was difficult to stay on an eating plan. My blood pressure has also returned to the normal range after the weight loss. In general, I feel very healthy, but I always have the lingering anxiety that the tumor will grow back or the acromegaly medication will stop working.</p> <p>Going forward, the symptoms I most worry about are increased joint problems, and possible increased coronary artery disease. I hope I can take an oral medication in the future. The other concern I have, which was not mentioned at all in the seminar, is anxiety about the cost of treatment. My insurance has covered it so far, with fairly large copays, but as I move into Medicare next year, I am uncertain how well Medicare will pay for the treatment. The monthly injections are billed to the hospital at more than \$16,000 per month. I hear stories of different patients getting on a variety of programs to help with these expenses, but it seems wrong to me that in addition to the burden of the disease is the burden of the expensive treatments. I hope you keep that in mind as you help create new treatments for those of us with this rare disease.</p>
<p style="text-align: center;">NS</p>	<p>I had an endocrinologist that wasn't listening to me regarding how my monthly shot of Sandostatin LAR was making me feel. She said, "It's not the shot! You must have something else wrong with you!" I read the package insert for Sandostatin LAR and it clearly stated that upon rare occasions, people have allergic reactions. It listed EVERY symptom I was experiencing. She hadn't done ANY research, much less read the insert information included with the shot. I wasn't able to drive the entire time she had me on Sandostatin. I found a different endocrinologist, one who listens to me and works WITH me. I have my independence back and can drive again. My treatments don't interfere with my life anymore. Having a doctor that listens, researches what they don't know, and works with you is crucial to having a good patient experience.</p>
<p style="text-align: center;">SCS</p>	<p>1 - Arthritis, fatigue, Brain fog 2 - my career, my hobby motorcycles, mobility loved walking the hills 3 - Sandostatin four weekly injection 4 - side effects like chronic constipation ++ and have a high week so on overdrive, then a week of chronic fatigue, so hard to do regular activities.</p>

<p>IP</p>	<p>as of right now the emotional stress in conjunction with the terrifying and nightmarish health conditions caused by acromegaly life changing for lack of better words, even though I complained, explained, begged, and pleaded ... My diagnosis took more than 10 years. the suffering is real ... even though I had the tumor removed the damage is done I am suffering every day ... and even if sickness puts me to bed in the evening and sickness wakes me up every morning, I will continue to push... pills are the new norm for me... I am disabled due to having compounding medical conditions ... wishing someone would listen a little closer, typical mechanic hands, was my diagnosis a decade ago ... now I can't work ... today is someone then year anniversary wondering why they feel OFF thinking its on their head, hurting, emotional distress, mutating into something else ... I would still have my life if found sooner...</p> <p>I am not a drug user, never in trouble with the law, don't sleep around to be blamed for having STD's, 20-year professional career over ten years of damage did me in ... help is needed.... my life could have been saved over ten years of damage ... TYPICAL MECHANICS HANDS they say ...</p> <p>early detection fails miserably and there are no second chances</p>
<p>JC</p>	<p>Significant Symptoms</p> <ol style="list-style-type: none"> 1. Changes to body: face, big hands and feet. 2. Clumsy: seem to drop things and walk into things. 3. feeling sluggish: fatigued and bowel functions slow I take hydrocortisone which I think has changed my blood and made it thinner, I've noticed I bleed more. The biggest problem I have had is some of the medical professionals do not know about my condition and have failed to provide a good level of care. I have had after surgery complications from internal bleeding and had an adrenal crisis whilst in hospital. I would like medics to know more about this condition. I always feel like I'm teaching them and they sometimes let their ego get in the way so don't act. I think if we could give them a leaflet pre-op, that they recognise as official it would take away the awkwardness of being told by a non-medical and they might avoid serious complications. I have felt like I've not been listened to about many things around my health. I was even told that the new tablets I was given should be fine for me even though I felt rubbish and the leaflet said they were not recommended for adults with Addison's disease. I don't trust what medical professionals say to me unless it is their specialist field.
<p>RL</p>	<p>I wanted to comment that doctors do not understand the longevity of this disease. Just because you had two surgeries and levels (according to blood work) are within range... the effects this has had on your life, relationships, etc. is horrific. Doctors do not take the after effects into the appointment. I hate being laughed at. I hate seeing rolled eyes from the "expert". I feel alone as it is. Then to have doctors discard you and make a joke when you bring an issue up.</p>