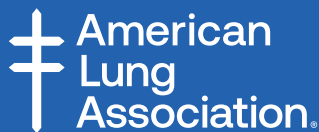


# Little Airways Big Voices

## Voice of the Patient Report on Asthma in Childhood



Little Airways, Big Voices is an initiative led by the following organizations:



[littleairwaysbigvoices.org](http://littleairwaysbigvoices.org)

# Asthma in Children

Asthma is the most common chronic respiratory condition in children. It affects approximately 6 million children (ages 0-17) in the United States.<sup>1</sup> Asthma causes episodes of coughing, wheezing, chest tightness, and shortness of breath. Symptoms may vary from child to child. These symptoms can be mild or severe, and sometimes life-threatening.

Asthma in children can be especially serious. This is because children have smaller airways than adults. It is a leading cause of emergency department visits. Plus, it is one of the top indications for hospitalization in children. Asthma impacts children's ability to participate in physical activities, go on vacation or travel, take part in social engagements or events, and attend school or daycare.

Although treatment options have increased, they are not effective for or accessible to all patients.

Learn more about asthma in childhood on page 9.

## Initiative Overview

The Allergy & Asthma Network (AAN), American Lung Association (Lung Association), American Partnership for Eosinophilic Disorders (APFED), and Asthma and Allergy Foundation of America (AAFA) are collaborators on the Little Airways, Big Voices initiative. To learn more about asthma in childhood, these nonprofit patient organizations hosted a virtual externally-led patient-focused drug development (EL-PFDD) meeting, conducted a survey, and solicited written comments from people affected by asthma in childhood. This Voice of the Patient report summarizes the findings of this initiative. It aims to help inform new treatment strategies and regulatory decisions for children living with asthma.



Voice of the Patient Report on  
Asthma in Childhood

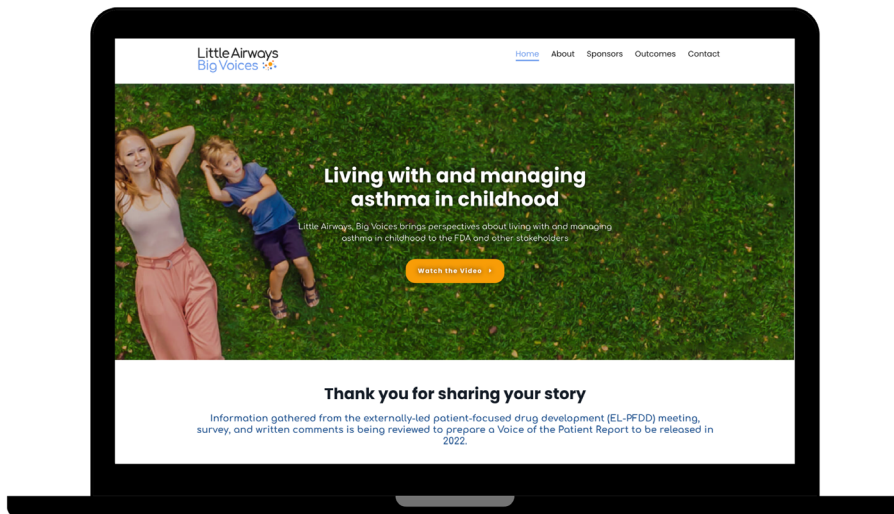
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Published September 2022.

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# Initiative Team

The organizations involved in the Little Airways, Big Voices project have a history of providing support for people with asthma and their caregivers. The organizations also have a history of documenting patient perspectives and elevating them for research and drug development. Together, the organizations bring significant expertise, experience, and influence.



The **Allergy & Asthma Network** is the leading nonprofit patient education and advocacy organization for people with asthma, allergies, and related conditions. The patient-centered network unites individuals, families, healthcare professionals, industry, and government decision makers to improve health and quality of life for Americans with asthma and allergies. The organization specializes in making accurate medical information relevant and understandable to all while promoting evidence-based standards of care.

Learn more: [allergyasthmanetwork.org](http://allergyasthmanetwork.org)



The **American Lung Association** is the leading organization working to save lives by improving lung health and preventing lung disease, through research, education, and advocacy. Their work is focused on four strategic imperatives: to defeat lung cancer, champion clean air for all, improve the quality of life for those with lung disease and their families, and create a tobacco-free future.

Learn more: [lung.org](http://lung.org)



The **American Partnership for Eosinophilic Disorders (APFED)** is a non-profit organization whose mission is to passionately embrace, support, and improve the lives of patients and families affected by eosinophil-associated diseases through education and awareness, research, support, and advocacy.

Learn more: [apfed.org](http://apfed.org)



Founded in 1953, the **Asthma and Allergy Foundation of America (AAFA)** is the oldest and largest non-profit patient organization dedicated to saving lives and reducing the burden of disease for people with asthma, allergies and related conditions through research, education, advocacy, and support. AAFA offers extensive support for individuals and families affected by asthma and allergic diseases, such as food allergies and atopic dermatitis (eczema). Through its online patient support communities, network of local chapters and affiliated support groups, AAFA empowers patients and their families by providing practical, evidence-based information, and community programs and services.

Learn more: [aaafa.org](http://aaafa.org)

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# Executive Summary

Asthma is the most common chronic respiratory condition in children. It affects approximately 6 million children (ages 0-17) in the United States.<sup>2</sup> Asthma causes episodes of coughing, wheezing, chest tightness, and shortness of breath. Symptoms may vary from child to child. These symptoms can be mild or severe, and sometimes life-threatening. Although there are treatment options, they are not effective or accessible for all.

This report summarizes the findings from the Little Airways, Big Voices initiative. The report includes input from the virtual externally-led patient-focused drug development meeting on September 20, 2021. It also features insights gathered through a survey about asthma in childhood, and incorporates written comments submitted by people affected by asthma in childhood.

The report identifies outcomes and burdens that matter most to those affected by asthma in childhood. It also illustrates unmet needs. The U.S. Food and Drug Administration (FDA) will use this report as they consider new treatment options. The report will also be a resource for drug developers designing clinical trials. The project team, meeting, and report aim to generate awareness and engagement within the patient community.

Beginning in 2020, the Allergy & Asthma Network (AAN), American Lung Association (Lung Association), American Partnership for Eosinophilic Disorders (APFED), and Asthma and Allergy Foundation of America (AAFA) worked together to plan and implement the Little Airways, Big Voices initiative.

Survey data collection and written comment collection began in August 2021. The Little Airways, Big Voices meeting held in September 2021 included representatives from each collaborating organization, people living with asthma in childhood, as well as caregivers. Representatives from the FDA, researchers, and health care providers also participated. Written comment collection closed in October 2021. The survey closed in January 2022.

The Little Airways, Big Voices meeting began with presentations on the drug development process, the role of externally-led patient-focused drug development meetings, and a clinical overview of asthma in children.

The September 2021 virtual meeting consisted of two main sessions. The first session focused on the patient experience. This included symptoms and disease burden. The second focused on treatment options. Each session began with personal statements from people who experienced asthma in childhood. A live, moderated discussion followed. Throughout the meeting, participants completed polls and submitted written comments. They were also invited to call in to contribute to the discussion. Moderators highlighted a selection of the written comments by reading them during the meeting.

Predominant themes about asthma expressed by initiative participants included shortness of breath or trouble breathing. There were discussions about how these breathing difficulties can make it challenging to go to school, deal with sickness, and take part in exercise or social activities. As a result, there are significant feelings of isolation, fears, and worries. This included a well-founded fear of dying.

While there are many treatment options available, there are still unmet needs. There are unmet needs in prevention, diagnosis, treatment, and progression of the disease. There is a need for more research to understand the development and progression of asthma, and the connection between asthma and other allergic conditions. Health care coverage is also an important issue, but not one that the Little Airways, Big Voices initiative aimed to address.

More education can help people correctly administer medications. It can also help people avoid or reduce exposure to asthma triggers.

More research is needed to understand the subtypes of asthma. Plus, how to identify them, and which treatments work best for different subtypes. This identification has the potential to improve the effectiveness of treatments.

More research is needed to identify treatments to reduce side effects. Many people rely on oral corticosteroids when asthma episodes don't respond to other medicines. Yet, these have undesirable and detrimental side effects. This can include mood and sleep disturbance, weight gain, bone loss, high blood pressure, osteoporosis, and more. Finally, research can explore treatments with other methods of administration, such as additional alternatives to inhalers and injections.

People living with asthma in childhood desire treatments that reduce asthma symptoms, with fewer side effects. They want to worry less about asthma and to improve their quality of life, including taking part in more activities.



Little Airways  
Big Voices

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**Little Airways, Big Voices aims to bring the voice of patients and families impacted by asthma in childhood to the forefront of drug development and research.**



### About the Initiative

The [Allergy & Asthma Network \(AAN\)](#), [American Lung Association \(ALA\)](#), [American Partnership for Eosinophilic Disorders \(APFED\)](#), and [Asthma and Allergy Foundation of America \(Aafa\)](#) are collaborating on this initiative. Together they hosted a virtual externally led patient-focused drug development (EL-PFDD) meeting on September 20, 2021.

# Introduction

More than 25 million Americans have asthma, including approximately 6 million children (ages 0-17).<sup>3</sup> It is a chronic respiratory condition. While there are many treatment options available, there are still unmet needs. This includes prevention, diagnosis, and treatment. To collect feedback from those affected by asthma in childhood, the Allergy & Asthma Network (AAN), American Lung Association (Lung Association), American Partnership for Eosinophilic Disorders (APFED), and Asthma and Allergy Foundation of America (AAFA) collaborated on the Little Airways, Big Voices initiative.

There were many ways for patients and families to take part in the initiative. This included:



completing an online survey



attending a virtual meeting



submitting written comments

These three tactics allowed patients and families to share their perspectives on symptoms, daily impacts, and burdens of asthma in childhood. They also shared their thoughts on currently available treatment options and hopes for future treatments.

## Patient-focused Drug Development Meetings

The FDA established the Patient-focused Drug Development (PFDD) initiative in 2006 to collect patient insights on specific diseases, evaluate the impact of those diseases on daily life, and learn about the patient experience with available treatment options. PFDD meetings connect patients and families with the FDA, as well as drug researchers and developers. To gather information about more conditions, the FDA encourages patient advocacy organizations to host externally-led patient-focused drug development meetings (EL-PFDD). **Voice of the Patient reports summarize the findings to help the FDA identify what is important to patients, and what treatment options people want.**

This Voice of the Patient Report details the perspectives shared through the Little Airways, Big Voices survey, meeting, and written comments. This includes suggestions for future research and drug development to improve health outcomes. Some quotes from participants, contributors, and speakers have been edited for length and clarity.

The goal of the report is to share experiences of people living with and managing asthma in childhood with the U.S. Food and Drug Administration (FDA) and other stakeholders – including researchers, medical product manufacturers, health care providers, and federal partners.

## By the Numbers Overview

4

partner organizations

142

live virtual attendees

40

polling responses

248

patient insight survey responses

4

corporate sponsors

385

views of meeting recording

20

written comments

11,642

words in open text survey responses

In August 2021, to gather insights in advance of the Little Airways, Big Voices meeting the initiative collaborators launched a survey on asthma in childhood. Written comment collection also began in August 2021 and ran through October 2021. The survey remained open through January 2022. Detailed results from the survey are available in the appendix of this report (see page 67). Key findings from the survey and written comments mirrored the discussions at the meeting.

The Little Airways, Big Voices meeting was on September 20, 2021. Participants gathered virtually. It was the 52nd EL-PFDD meeting and the 18th fully virtual meeting of its kind. Sanaz Eftekhari, Vice President of Research at AAFA, and James Valentine, JD, MHS, an associate at Hyman, Phelps & McNamara moderated the meeting. After welcoming everyone to the virtual meeting, they introduced Kenneth Mendez, MBA, President and CEO of AAFA. He provided opening remarks about asthma and childhood.



*Sanaz Eftekhari and James Valentine, JD, MHS moderated the Little Airways, Big Voices meeting*



*Will Mendez at 18 months climbing on his HEPA air filter, another tool in his journey with asthma as a toddler*

“Our goal in this is to bring patient insights through this initiative to help inform new treatment strategies and regulatory decisions as it relates to families and caregivers in the asthma community,” said Mendez. “This reminds me of when my son, Will, was 9 months old and had his first asthma attack. I watched him being treated by a nebulizer and then the many episodes after that, where he, as a toddler and as a child, had to be on medication for his asthma.”

Dr. Stacy Chin, Clinical Team Leader, Division of Pulmonary, Allergy, and Critical Care, Center for Drug Evaluation and Research at the FDA, then presented information about the role of PFDD meetings and the subsequent Voice of the Patient reports.

“Your input today can help us develop better patient-reported outcomes and further the development of additional targets for childhood asthma,” said

Dr. Chin. “The input we have heard has been very valuable in informing the decisions we make in our regulatory review process.”

Dr. Chin also provided background information on asthma in childhood. She shared details about the drug development process and the role of the FDA in that process.

“To date, all of the drug approvals have been based on signs and symptoms of asthma — primarily improvements in lung function ... improvements in the frequency of asthma exacerbations, or patient-reported outcomes such as asthma control or symptoms,” shared Dr. Chin. “Unfortunately, to date, we don’t have any drugs that are available to stop the progression of disease or for prevention of asthma.”



*Dr. Stacy Chin presented background information about asthma in childhood*



# Asthma in Children

## Overview

Dr. Albert Rizzo, the Chief Medical Officer for the American Lung Association, presented a clinical and treatment overview of asthma in children. It provided helpful background and context for the discussions that followed.

Asthma is a chronic lung disease. It is the most common chronic respiratory condition in children. It causes episodes of coughing, wheezing, chest tightness, and shortness of breath. Increased mucus and inflammation in the airways can cause spasms of the bronchial tubes, making it difficult to breathe. Symptoms can be mild or severe, and sometimes life-threatening.

**“Every person with asthma will not have the same signs and symptoms as another person and a key component to proper asthma management is understanding your signs and symptoms.”**

**Dr. Albert Rizzo**  
American Lung Association



Asthma symptoms may vary from child to child. Common signs and symptoms of asthma in children include:

- Fast, shallow breathing
- Panting with normal activities, such as playing
- Wheezing (a whistling, squeaky sound when you breathe)
- Feeling winded (shortness of breath)
- Chest tightness or pain
- Persistent coughing
- Difficulty sucking or eating
- Tiredness, not interested in normal or favorite activities
- Flaring nostrils
- Frequent colds that settle in the chest

### Asthma in Children: U.S. Based Statistics

More than 25 million Americans have asthma, including 6.1 million children (age 0-17).<sup>4</sup>

Asthma is more common in male children than female children.<sup>5 6</sup>

Asthma is the third leading cause of hospitalization among children under age 15.<sup>7</sup>

Asthma is one of the leading causes of missed school days for children ages 5 to 17<sup>8</sup>; in 2013, it accounted for an estimated 13.8 million missed school days.<sup>9 10</sup>

Black children are nearly three times more likely to have asthma compared to white children<sup>11</sup> and 10 times more likely to die from asthma in the U.S.<sup>12</sup>

20% of Puerto Rican children have asthma.<sup>13</sup>

In 2019, 44.3% of children age 18 and younger who had asthma reported having one or more asthma attacks in the past year.<sup>14</sup>

In 2018, asthma accounted for 1.6 million emergency department visits.<sup>15 16</sup>



When considering an asthma diagnosis, health care providers take a detailed medical history and perform a physical exam of the patient. Health care providers also conduct testing to look for airflow obstruction and inflammation. Testing may include breathing function or spirometry, as well as chest x-rays and other tests. Unfortunately, breathing tests are not currently reliable in infants and young children. This can make diagnosis challenging, resulting in a longer path to proper treatment.

While there is no cure for asthma, a combination of long-term control or maintenance medications, and quick-relief medications can help manage asthma. (See page 25 for more details about current treatments for asthma in childhood.)

It is also important to identify and avoid asthma triggers. Respiratory infections, allergens, exercise, cold weather, strong emotions, smoke, tobacco products, and more can trigger asthma in children. Health care providers often encourage keeping a diary of asthma symptoms to help identify triggers.

“By keeping a journal or a detailed diary tracking symptoms, you and your health care provider can find patterns in your behavior or exposures that point to a specific trigger that could help management,” shared Dr. Rizzo.

Children have smaller airways than adults. Children and their caregivers may not always understand or recognize asthma and its symptoms. This may contribute to asthma being:

- a leading cause of emergency department visits,
- one of the top reasons for hospitalization in children, and
- a leading cause of missed school days for children and work days for caregivers.

“Besides impacting the quality of life of the individuals with asthma, **caregivers can also be impacted** as in the case of a child that needs to be home due to illness.”

**Dr. Albert Rizzo**  
American Lung Association



## Risk Factors for Developing Asthma

We do not know what causes people to develop asthma. Some risk factors include:

- Genetics (having a parent with asthma)
- Outdoor allergens
- Occupational (workplace) sensitizers
- Tobacco smoke and e-cigarette emissions
- Air pollution
- Respiratory infections
- Socioeconomic factors (location, finances)
- Family size associations
- Diet and drugs
- Hygiene hypothesis (childhood exposure to germs and certain infections helps the immune system develop)

# Living With Asthma

## Symptoms and Daily Impact

“Now that we’ve heard a clinical overview from a disease expert, we turn to **the core of today’s meeting, which is to hear from you, individuals living with childhood asthma**, those of you who have lived with childhood asthma, as well as the direct caregivers of those persons living with childhood asthma that can speak to the experience of those individuals.”

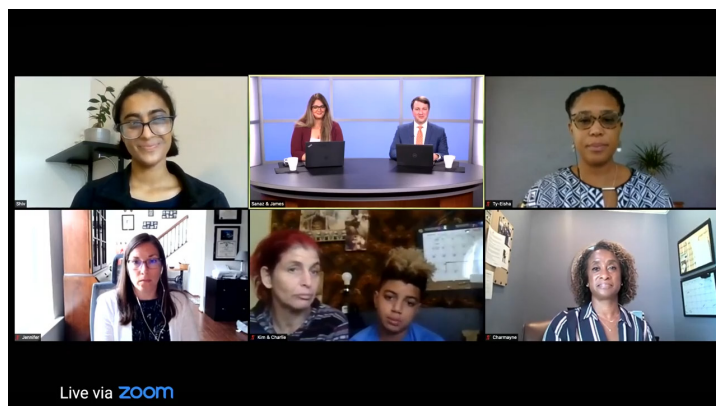
**James Valentine, JD, MHS**  
Moderator



The first discussion session of the Little Airways, Big Voices meeting looked at what it is like to live with childhood asthma.

The moderators led participants through a series of polls and discussion questions. They talked about the most significant symptoms of asthma in childhood. They discussed activities affected by asthma, and fears and worries.

There were many ways to participate. Panelists provided pre-recorded video statements. Discussion starters answered questions live via video stream. Other participants shared feedback by calling in or providing written comments.



*Participants discussing living with asthma in childhood*

## Panelists

The “Living With Asthma” session began with presentations by five panelists who presented statements about their personal experiences with asthma as a patient and/or caregiver.

**Javan Allison and Monique Cooper**  
13-year-old living with asthma, and his mother  
Miami, FL

**Regan Lloyd**  
17-year-old living with asthma  
Fairfax, VA

**Nicole Sutton**  
parent of 5-year-old living with asthma  
Tampa, FL

**Larry, Anne Marie, and Adrianna Del Principe**  
parents and sister of Alessandra Del Principe who died following an asthma attack in 2021 at the age of 26  
Bridgewater, NJ

**Esther, Chidiogo, and Chidubem Igboerika**  
parent and her two children (ages 10 and 8) who both have asthma  
Fresno, CA

## Biggest Concern: Shortness of Breath/Trouble Breathing

“That day, February 17, 2018, changed our lives when Javan wrote on the bathroom fogged mirror, ‘Help me.’ **He didn’t have the strength to yell out to me** while I was in the shower. We rushed him to the hospital, barely making it. That day, **it took everything in him to breathe.**”

### Monique Cooper

parent of a child living with asthma

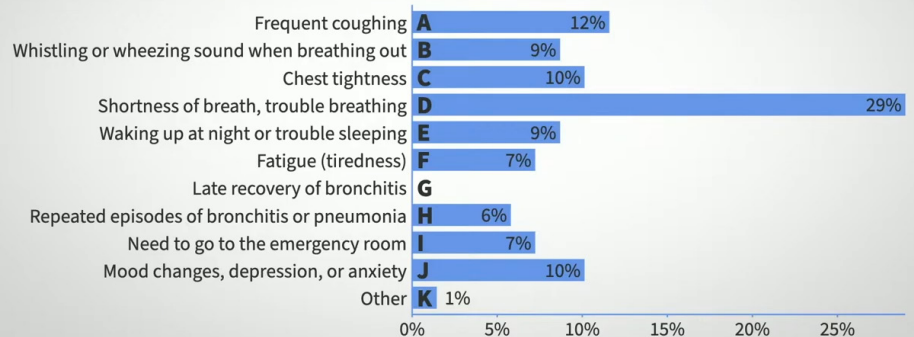
(Pictured right: Monique with her son Javan Allison)



The top asthma-related concern was shortness of breath or trouble breathing. This was clear from the comments and polling responses from the meeting participants, as well as the survey responses.

“One of the main symptoms that I experienced is shortness of breath ... if I’m walking up the stairs or going on a walk outside, if the pollen is too great, or if there’s too much dust, the main symptom I feel is a shortness of breath ... It often causes stress and me to take my inhaler,” shared Shiv Sewlal from South Africa, a 20-year-old living with asthma. She makes sure to always carry her inhaler in case her asthma gets triggered and she needs help breathing.

### 2. Select the TOP 3 biggest asthma-related health concerns that you have (for you/your child).



*Poll conducted during the Little Airways, Big Voices meeting*

Others reiterated these concerns, including Charmayne Anderson from Maryland. She has two children, now in college, living with asthma, and had asthma in childhood herself. “As a young person, all you know is, “I can’t breathe and I want to be able to breathe,” she shared. “The anxiety kicks in: ‘Oh my goodness, I can’t breathe. And if I continue to not be able to breathe, then I might not last that much longer.’”

Nicole Sutton from Florida, another parent of a young child with asthma recounted a harrowing experience with her son. “My child was really gasping for air and he was exhausted trying to breathe,” she shared. Due to his continued difficulties with asthma, she and her family made substantial changes to their home to remove asthma triggers. This included removing all carpet and stuffed animals.

Chidubem Igboerika, an 8-year-old living with asthma, also shared, “My worst symptom is coughing and trouble breathing. It makes me feel uncomfortable and scared.” Some nights are good and some nights are bad. Bad nights are when I cannot sleep because of my cough.”

## Challenging Trigger: Respiratory Infections

“My mom used to sleep in my room to listen to me breathe when I got sick, just in case, it sounded like I was struggling. **Sometimes I would have to go to the [emergency room] when I got really bad.**”

**Regan Lloyd**

17-year-old living with asthma



What can be a simple cold or respiratory infection for some children can result in worsening asthma for many children.

“My children are 5 and 7, and by far their asthma is the worst when they get sick,” shared Jennifer Roeder from Maryland. “I know that pretty much, as soon as they get the smallest cold and snuffle, we are preparing to get out the nebulizer and have it quickly turn into an upper respiratory infection.” Her youngest daughter was hospitalized twice after getting respiratory syncytial virus (RSV) at 4 months and 16 months old.

Nicole Sutton expressed similar experiences with her son. “Each time there was an illness ... there was an asthma reaction even while we were adhering to his treatment plan,” she said.

The frustration these parents experience as a result of their children’s asthma was clear.

# 12%

of poll respondents indicated illness (e.g., colds, flu) was a trigger for your/your child’s asthma



Meeting participants discussing challenging triggers of asthma in childhood

“[My asthma makes] every simple cold turn into an asthma attack.”

**Shreaya Madireddy**

18-year-old living with asthma

(Pictured right. Shreaya with her mother)



## Asthma Peak Week in September

Asthma symptoms tend to get worse in September. In fact, the third week of September is known as “Asthma Peak Week” as many more people have asthma-related episodes, attacks, and hospital stays than any other time of the year.

Around 25% of asthma-related hospital stays in children happen in September, shortly after school starts.<sup>17</sup> The number of asthma-related hospital stays peaks for school-age children first, followed by preschool children, and then adults.<sup>18</sup>

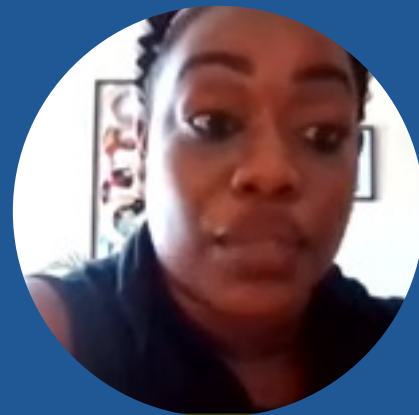
Asthma worsens in September because both adults and children with asthma are exposed to more asthma and allergy triggers, such as ragweed pollen, respiratory infections, and dust and mold in school buildings.

### 09 – September

S	M	T	W	T	F	S
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	

“Something about September, it brings on those colds and **usually she’s a lot worse.**”

**LaJoy Johnson-Law**  
parent of a child living with asthma



“Every year up until he reached middle school, Javan would have a good first week of school, attending every day. **When we reach that second to third week, the complications would start.** He would get sick with asthma, and either be in the hospital and or home for days to weeks at a time, delaying him in his education. While in the hospital we wouldn’t know if he’s getting better up until the very last hour of being discharged because of our villain (what we like to call asthma) that likes to come and sneak back into Javan’s lungs.”

**Monique Cooper**  
parent of a child living with asthma  
*(Pictured left: Monique’s son Javan Allison)*



## Exercise or Recreational Activities

**“I do not enjoy having asthma symptoms, especially when I play soccer. My symptoms start with coughing and may get worse. I have to stop playing when I cannot catch my breath. I don’t want my symptoms to get worse, so I use my rescue inhaler before playing soccer.”**

### **Chidiogo Igboerika**

10-year-old living with asthma



Some children with asthma have to take medication before exercising or participating in sports. Others are not able to take part in certain activities at all.

Esther Igboerika’s daughter, Chidiogo, has asthma. Physical activities are a trigger for her asthma. She uses her quick-relief (rescue) inhaler before sports practices, but still experiences symptoms. Esther shared one example. “She had to immediately stop soccer practice and I took her home. She was sad that she could not practice with her friends.” Over time, Chidiogo discovered that tennis and wakeboarding are easier on her asthma than some other sports. Chidiogo shared, “My mom encourages me to participate in sports, to know my limits, when to rest, and use my rescue inhaler.”

# 40%

of survey respondents indicated that asthma prevents their child from participating in sports or other activities

Some physical activities are less likely to trigger asthma than others. Exercise that requires shorter bursts of activity (like volleyball or tennis) may be an option for some individuals. “You kind of figure out what you can do to allow you some level of exercise activity,” shared Charmayne Anderson.





Not being able to take part in sports and other physical activities as a result of asthma can be emotionally difficult for children. And it is not always easy for children to transition to other activities.

“[Charles is] very angry that he had to give up playing with his friends,” K.A. Hoskinson from California shared about her son’s need to quit football. After repeatedly having asthma attacks during practices and games, they had to make a hard decision. “We had to pull him because the coaches weren’t looking out for his best interest ... they don’t understand.”

Others shared similar experiences, including Amanda from Texas. “My son loves sports and playing outside, but is often unable to do these things because it is hard to get through without using his inhaler,” she shared. “He gets depressed when his asthma flares up and he’s unable to attend school, field trips, school activities, sports, etc.”

“My daughter wanted to run on the track team at school, but couldn’t because it triggers her asthma,” commented Lauren from Michigan. “She won’t ice skate at the outdoor rink because it may trigger her asthma.”

Regan Lloyd from Virginia quit gymnastics as a result of her asthma, as well. “Because of the medication I’m on for my asthma, I’ve had fractures and cysts develop on my wrists and I have to see an orthopedist and endocrinologist. This forced me to quit gymnastics after 10 years of doing it,” she shared. “I’m grateful that I am okay for now, but asthma is incurable. And I worry that someday I might not be able to get my medication or that it might start not working again.”



*Javan Allison takes his quick-relief inhaler before and after his football practices and games to help manage his asthma*



*Nic, 5-year-old living with asthma; His mom Nicole Sutton participated in the Little Airways, Big Voices meeting*



“Asthma truly has impacted, not just my life and the way I live every day, but my family’s life and who I am as a person today.”

**Regan Lloyd**  
17-year-old living with asthma

## Social Activities

“Within the past three years, **[Alessandra]** had at least **one [asthma] attack per year**. One attack when she was visiting a family with cats, another was during a family vacation in Aruba, and the last was during a New York Rangers hockey game. Each time she was provided steroids and sent home.”

### Larry Del Principe

parent who lost a child to asthma



Larry and Anne Marie  
Del Principe

Simple pleasures, such as visiting a friend’s house or attending a birthday party, may be difficult for families living with asthma. It can be harder to avoid asthma triggers away from home.

Amanda from Tennessee commented that “my child chooses not to attend social gatherings out of fear of catching a virus and having her asthma get bad.” Sickness is a significant trigger for her child’s asthma (see page 13 for more about this trigger).

Ty-Eisha Rivera from Rhode Island is both a parent of a child living with asthma and grew up with asthma. During the meeting she shared, “I remember ... as a child, I had a particular friend that always wanted me to come over to her house, but I’ve always had this really bad allergy to cats ... They had cats in the house along with a few dogs ... Every time I would go to her house with the plans of being able to stay the night, I would only be there for a couple of hours before I would have to leave.” The cat allergy would trigger her asthma making it difficult to breathe. It is often hard for her to go places because of her asthma.

The challenge of sleepovers came up a few times. Shiv Sewlal shared how this resonated with her, particularly if the family had pets that could trigger her asthma. “If I’m staying the night, I will have to take antihistamines, but still, I will wake up puffy. I’ll wake up [in a flare] and most times I’ll just have to go home because it’d be too irritable and not really comfortable for me to stay.” Shiv shared that it was hard because she didn’t want to insult anyone or insinuate that their homes weren’t clean.



# 53%

of survey respondents indicated that **asthma prevents their child from visiting certain people’s houses** because it will trigger their asthma

# 20%

of survey respondents indicated that **asthma prevents their child from attending events, parties, or other social activities**

## Attending School or Daycare

“My asthma is truly uncontrollable. I **missed 46 days of school this year** ... I was worried I would never be able to get good grades if I wasn't in school or even have any kind of life.”

**Regan Lloyd**

17-year-old living with asthma



Asthma is one of the top causes of missed school days among children ages 5 to 7.<sup>19</sup> A study conducted in 2013 indicated that asthma accounted for an estimated 13.8 million lost school days in school-aged children with an asthma flare-up.<sup>20</sup> The discussion at the Little Airways, Big Voices meeting illustrated the challenges children with asthma have with both attending and missing days at school or daycare.

Monique Cooper's son Javan Allison has missed a lot of school due to his asthma.

“On his worst days, we take off from work and he's home from school due to being hospitalized after having attacks,” she shared. “Every year up until we reached middle school, Javan would have a good first week of school, attending every day. Then when we reached the second to third week, the complications would start. He would get sick with asthma and either be in the hospital and/or home for days to weeks at a time, delaying his education.” (See information about Asthma Peak Week on page 14.)

Nearly

**60%**

of survey respondents indicated that **asthma causes their child to miss days from school or work**



Becky from Oregon can relate. She commented, “During cold and flu season, when my daughter gets sick it means she misses out on a lot of things since she takes longer to recover [due to her asthma]. She misses school, birthday parties, swimming, etc. [It] makes her really upset.”

Esther Igboerika has a unique perspective on children with asthma in school. She is both a school nurse and a parent of two school-aged children with asthma. “As a school nurse, I manage students with asthma and I see these students daily,” she shared. “My greatest worries for my kids and other kids with asthma are a safe environment, safe physical activities, self-advocacy, and identifying symptoms before it gets worse.”

***Pictured left:** Esther Igboerika with her children Chidiogo and Chiubem who are both living with asthma*

## Feelings of Isolation

As a result of missing social activities and school due to asthma, many people expressed feelings of isolation.

“My time in the hospital was often boring, scary, and filled with sleepless nights. However, the hardest part of this was not feeling ill and getting poked by needles and on the medication, but feeling isolated, watching my friends continue to live their lives from our phone screen while I just sat in the hospital bed.”

Regan Lloyd, 17-year-old living with asthma

“I can only remember two family reunions in which I was not coughing, wheezing or blowing through two tissue boxes in just one day. Being bedridden and alone with nebulizer treatments in your bedroom, while you hear your whole family laughing about card games or the dogs, can make for a very depressing and lonely atmosphere on the holidays.”

Shreaya Madireddy, 18-year-old living with asthma

“So it’s something that’s always had an effect on my life. And it’s something that I know that I’m going to always have to deal with and think about.”

Shiv Sewlal, 20-year-old living with asthma

## Fears and Worries

“I think anyone who has asthma and has had serious complications or a really bad attack ... [has a] fear about dying. And so that’s a long-standing thought ... **will I die from asthma?**”

**Charmayne Anderson**

parent of a child living with asthma who also grew up with asthma



The final discussion topic of the “Living With Asthma” session was about worries and concerns for the future. The biggest fears families reported were asthma progression and death.

On a daily basis, children with asthma and their caregivers manage fears about not being able to breathe. “You’re always thinking about your asthma, you’re always preparing for it,” shared Ty-Eisha Rivera.

The fears are very well-founded. On average, 11 Americans die from asthma each day.<sup>21</sup>

11

people die each day from asthma, on average

On May 2, 2021, Alessandra Del Principe died at the age of 26 from a severe asthma attack while at her twin sister’s wedding. “One of the happiest days of our lives turned into a parent’s worst nightmare,” shared Alessandra’s father, Larry Del Principe of New Jersey.

“Shortly after I had a dance with Alessandra, she felt ill and was having trouble breathing. Her boyfriend escorted her out of the reception to get some space and use her albuterol. Unfortunately, she passed out in the hallway,” recalled Larry while choking back tears. “Alessandra never regained consciousness and passed away during the early morning hours of May 2. [The] official cause of death was cardiac arrest caused by a severe asthma attack, which also caused loss of oxygen to her brain for over 40 minutes ... The pain, the agony, and the loss of Alessandra for our family has been excruciating, which no parent or sister should endure.”

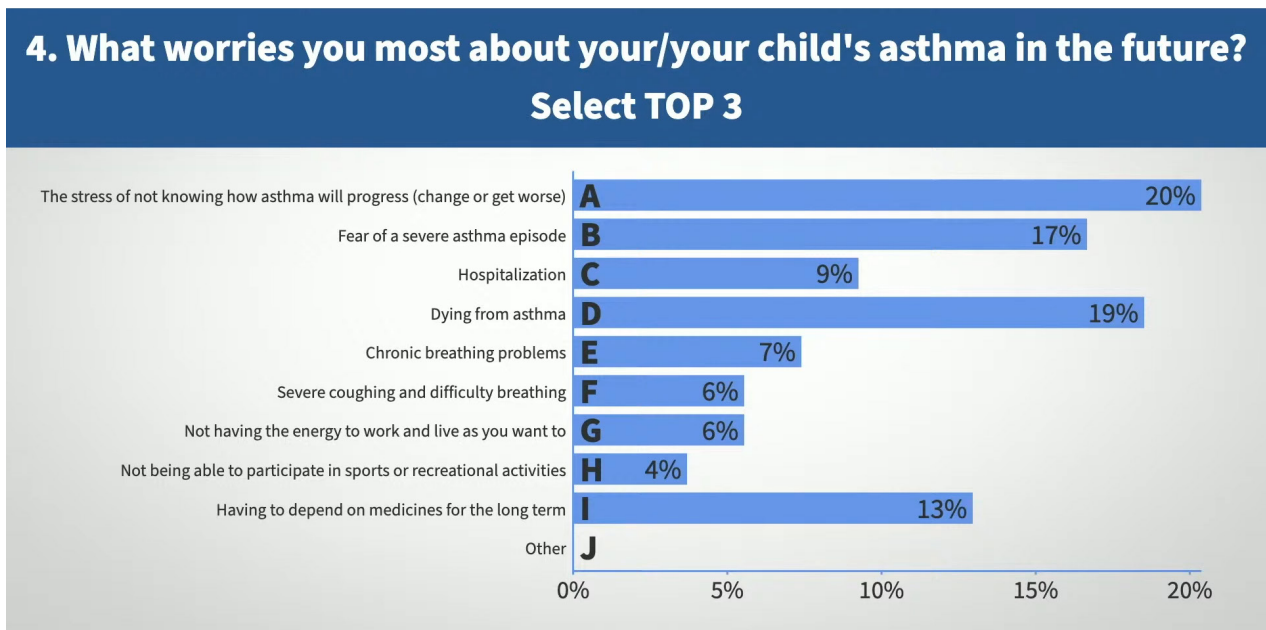


*Del Principe family at Adrianna’s wedding, shortly before Alessandra died*

Alessandra’s mother, Anne Marie, shared, “We were not fully aware of the severity of asthma, that it can actually make you die. We just didn’t know that. We just thought you just take your nebulizer and you move on.” Alessandra’s family hopes that by sharing her story, others will become more educated about the seriousness of asthma.

Javan Allison and his mother Monique Cooper also used their experiences with asthma as an opportunity to educate others. Javan was diagnosed with asthma at age 2. At 10-years-old, Javan spent a week in the Intensive Care Unit to treat an asthma attack. Afterward, Javan and his mom co-authored a series of children’s books, “The Adventures of Javan and the 3 A’s”. The books are about asthma, ADHD, and anxiety. Then at age 13, he took part in the Little Airways, Big Voices meeting. He told the FDA, researchers, and other stakeholders what it is like for kids to live with asthma.

“Javan plays sports and is always at fear with the what-ifs. What if it’s too hot and he gets exhausted and can’t breathe? What if the activities are too much for him to handle?” shared Monique. He has experienced those what-ifs on several occasions. “Javan has had over 50 hospital visits due to asthma, and several overnight ICU stays,” she recalled. “Some families may not know how serious it is.”



*Poll conducted during the Little Airways, Big Voices meeting*

## Fears of Treatments and Side Effects

Participants of the Little Airways, Big Voices initiative expressed fears of treatments and side effects. There was additional discussion about this in the second session about current and future approaches to asthma (see page 24).

Charles' health care team encouraged him to try a biologic treatment given by injection, but he has refused. "He's so afraid of [the shot]," shared his mother, K.A. Hoskinson. While sharing these concerns during the Little Airways, Big Voices meeting, Charles was having an asthma attack. "He went to bed with it and he's waking up with it," K.A. shared. "And it's hard, it's mind-blowing and it's extremely scary." She feels that if Charles were to receive the injectable medicine, it would help control his symptoms and lessen his risk for a severe asthma attack.

Corticosteroids are a common treatment for asthma flare-ups. This includes inhaled corticosteroids and oral corticosteroids. Unfortunately, oral corticosteroids can have significant side effects and risks. These make children living with asthma and their caregivers uneasy.

"It is an extreme worry to administer steroids to my young children," commented Vanessa from Maine. "But I also don't know what else to do when they are having trouble breathing." Her former husband had hip surgery due to prednisone usage for asthma and allergies. She is fearful of something similar happening to their children.

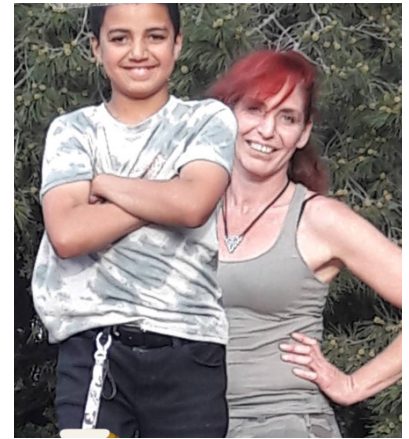
Ty-Eisha Rivera shared similar concerns about potential future side effects of treatments her children take. "I'm just worried about if the asthma is not well managed, if there's any other long-term lung damage or airway remodeling that could happen to any of us," she said. She also shared that her son has been on inhaled steroids since age 5. She is concerned about the long-term effects of this treatment, as well as the oral steroids he has taken.

## The Role of Strong Emotions

Beyond fears about the progression of the disease, dying, and side effects of treatments, there were also comments about how fear along with other strong emotions, as a trigger, can accompany or bring on asthma attacks.

Jason from Seattle, Washington commented, "I remember not being able to breathe and gasping. Each breath was a struggle and no one knew how to stop it. My mom could only tell me to be still, but I couldn't stay still in the midst of a panic attack that always [accompanied] the asthma."

Ty-Eisha Rivera shared how her teenage daughter's asthma gets triggered by stress and anxiety. Plus, how her son's asthma gets triggered by laughter, especially when he was younger. "So we were always trying to keep him calm and not so animated because he was a very, very happy child and wanted to laugh. But unfortunately, at times, that was something that would cause his shortness of breath and trigger his asthma episodes."



*Charles, 11 year-old living with asthma, and his mom, K.A. Hoskinson*



*Ty-Eisha Rivera and her two children, all three are living with asthma*

## Transitioning to Adulthood or Self-Management

Going off to college or moving away from home is a huge milestone in a child's life. During this time, parents are less involved in the management of their children's health. Parents and caregivers invest significant time and energy into preparing their children to take care of themselves. But it doesn't stop them from worrying; instead, the worries increase. Particularly about a chronic medical condition like asthma. Parents and caregivers worry about whether their children will continue taking their medications and avoid their asthma triggers. They worry about transitioning to new health care providers, as their children age out of pediatrics. And they worry their children will need emergency care and they won't be close enough to help.

"As a teenager, Kaleb had well-managed asthma. Then he went to college and I'll never forget getting that call of him being in a flare-up in the middle of the night and not knowing if he should go to the ER [Emergency Room]. And he was two and a half hours away from me. For the first time, I realized how little control I have as a mom, as a caregiver of a child with asthma. And I think that this speaks to kind of that understanding of the chronic disease, but also ... [needing] better solutions and treatments. And we need that awareness and education around this."

**Tonya Winders**, parent of a child living with asthma

"One of my concerns is just the stress of not knowing how asthma will progress. And we're in that stage now that we're transitioning into adulthood. And the doctors that have followed my children for their whole lives, they now have to say goodbye, and it's like starting over. So just making sure that my kids understand that it's not me any longer that's going to be taking care of their asthma. And now they have to really take responsibility and have that communication with the provider if they feel like something's not right."

**Ty-Eisha Rivera**, parent of a child living with asthma, who also grew up with asthma

"My three adult children have allergies and asthma. After 12 hospitalizations and two ICUs for asthma when they were younger, I still worry that one of my adult kids will die from asthma. Even after taking controller meds, having years of allergy shots, and making sure their apartments are allergy- and asthma-friendly, I still worry for them."

**Andrea Jensen**, parent of a child living with asthma, who also has asthma

Individuals living with asthma at any age need a support system. They need people who understand the symptoms and health effects of asthma. As children age and become more independent with their health, they may need new support systems.



*Kaleb Winders, an 18-year-old living with asthma, at his high school graduation*



## Approaches to Asthma Treatment

The second session of the Little Airways, Big Voices meeting focused on current and future approaches to treatment. This included:

- Treatments that are currently available
- Impact of treatments on asthma symptoms
- Challenges, downsides, and side effects of current treatments
- Factors important for new or future treatments

The moderators led participants through a series of polls and discussion questions. The discussion, written comments, and survey responses reinforced that **the same treatments don't work for everyone**. Plus, they highlighted a need for **more treatment options with fewer side effects**.

### Managing Asthma Symptoms and Current Treatments

There are a variety of treatments available to manage asthma in children (see page 25). From quick-relief to control medicines, inhaled, oral or intravenous steroids to biologic agents, antihistamines to allergy shots, and even holistic approaches. There is not a one size fits all approach to treating asthma in children. Treatments work with a common goal of improving the quality of life for children with asthma.

### Panelists

The second session began with presentations by four panelists who shared their personal experiences with asthma treatments as a patient and/or caregiver.

#### Jolene MacDonald

parent of 12-year-old living with asthma  
South Portland, ME

#### Shreaya Madireddy

18-year-old living with asthma  
Dayton, OH

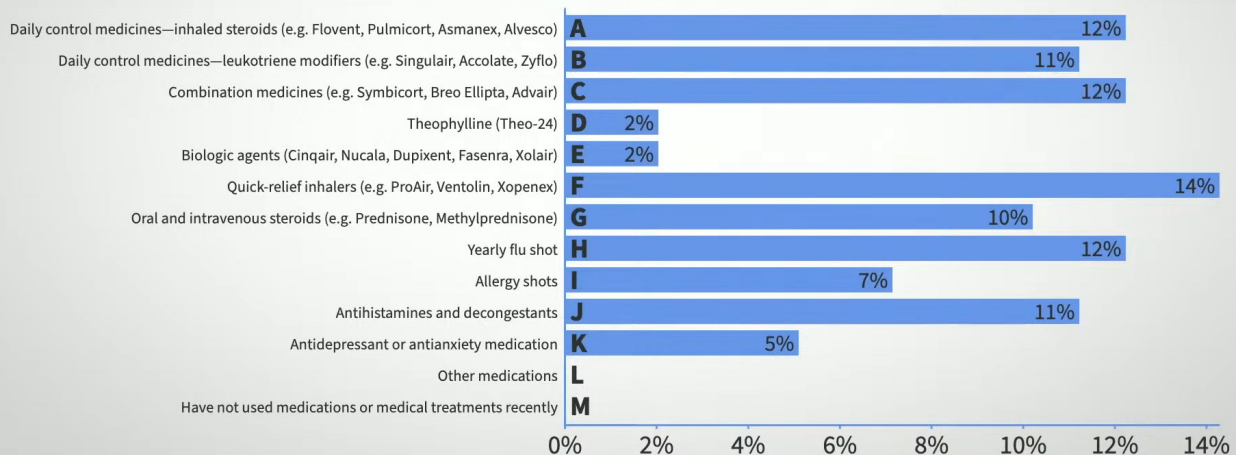
#### Ryan Piansky

21-year-old living with asthma  
Atlanta, GA

#### Colleen and KE Plunkett

parent and 18-year-old living with asthma  
Woodside, NY

### 1. What medicines or medical treatments have you/your child used to treat or manage asthma? Select ALL that apply



*Poll conducted during the Little Airways, Big Voices meeting*



# Current Asthma Medications

Managing asthma during childhood involves ongoing assessment of asthma control, monitoring symptoms, taking medications as prescribed, and avoiding asthma triggers. A combination of control/maintenance medications and quick-relief/rescue medications helps manage asthma in children.

Different types of medications address a variety of challenges, such as inflammation (swelling), bronchoconstriction (tightening of the smooth muscle airways), and excessive mucus in the airways. There are also multiple methods to deliver the medications. They can be inhaled (e.g., pressurized metered-dose inhaler, dry powder inhaler, soft mist), administered by a nebulizer, taken orally, or given as an injection.



**Control (maintenance) medications** address inflammation in the airways to prevent symptoms. There are many forms of maintenance control medications. This includes inhaled corticosteroids, long-acting beta-agonists (bronchodilators), a combination of inhaled corticosteroids (ICS) and long-acting beta-agonists, and long-acting muscarinic antagonists. Some of these medications are inhaled (e.g., fluticasone propionate), while others are taken orally (e.g., montelukast).



**Quick-relief (rescue) medications** (e.g., albuterol) are taken as needed when symptoms arise. They are also known as short-acting bronchodilators (SABA) and can be administered as inhalers with a propellant, breath-actuated, and through a nebulizer. They work for approximately four to six hours. SABAs relax the smooth muscles within the airways that tighten and result in symptoms. This helps open the airways and may keep an asthma episode from getting worse. For those with exercise-triggered asthma, taking quick-relief medications before exercise is a strategy to help prevent or manage symptoms.



**Single Maintenance and Reliever Therapies (SMART)** or combination inhalers are a new preferred method that incorporates the use of rescue and controller therapies to manage moderate to severe asthma that is not well controlled. SMART allows people to use the same medication daily to prevent asthma symptoms and for quick relief when asthma symptoms occur. SMART was not discussed as part of the Little Airways, Big Voices initiative and is not yet approved to be used this way by the FDA. SMART is recommended in the 2020 Focused Updates to the Asthma Management Guidelines.



**Oral corticosteroids (OCS)** (e.g., prednisone, prednisolone, methylprednisolone, dexamethasone) may be prescribed as a rescue treatment as part of a flare, or in some cases as a control therapy, for difficult-to-control or severe asthma episodes. OCS have serious long-term side effects. This can include mood swings, weight gain, high blood pressure, cataracts, osteoporosis, and infections.

*It is important to note that the short- and long-term side effects of OCS differ from ICS. Also, OCS doses are milligrams, while ICS doses are micrograms.*



**Biologics (monoclonal antibodies)** are an emerging category of medications used to treat some cases of moderate-to-severe asthma to improve control and reduce repeated use of OCS. An example of an asthma biologic therapy is omalizumab. Biologics help control immune responses and target the specific cytokines and pathways that cause inflammation related to severe asthma; these are sometimes referred to as “targeted therapies”. Biologics are a category of newer treatments that are effective for several different phenotypes of asthma. These “types” of asthma currently include allergic, eosinophilic, or OCS-dependent asthma. Some biologics are given as subcutaneous injections and others are given as intravenous infusions. Some are only available in clinical settings while others are available for at-home self-administration.

The 2020 Focused Updates to the Asthma Management Guidelines did not include biologics, but they are mentioned as a possible consideration.

The effectiveness of most medications is dependent on adherence and correct technique of administration. As Dr. Rizzo shared during his opening remarks on asthma in childhood, “a study from the Baylor College of Medicine showed that 70% to 90% of people with asthma make mistakes in using their medication devices, thereby limiting the medication’s ability to reach the lungs and relieve their symptoms.”

Incorrect use of medications can lead to uncontrolled asthma. Using a valved holding chamber, also commonly referred to as a spacer, can improve the delivery and effectiveness of pressurized metered-dose inhaler medications (also called MDIs, inhalers, press-and-breathe inhalers, puffers, or pumps). In general, an MDI administered with a spacer/chamber is as effective as a nebulizer, but the doses are not equal. However, for some children, a nebulizer or breathing machine may improve medicine delivery.

Just as asthma symptoms for all individuals vary (including children), the treatments used to control it may vary. In particular, asthma treatments are defined, prescribed, and continuously adjusted through asthma management clinical practice guidelines according to three separate age ranges for children (ages 0-4, 5-11, and 12 or older) and a stepwise approach. These guidelines are the current state of evidence on what works best for most people (including children). There is a need for more research and guidelines to understand and manage new medication categories, the underlying mechanisms, and the genetics of asthma in children.

“My asthma typically affects me in one of three ways, from my negligence to take my daily dose of my inhaler, from a sinus infection, or by just weakening my overall immune system. Currently **taking one inhalation a day from my inhaler relaxes my lung’s airways and allows me to pursue my day-to-day activities or even a rigorous exercise.** However, once I contract a mild cold or sinus infection, the last step of that mucus-filled pathway is wheezing, chest tightness, and nightly asthma attacks.

To combat these unsettling side effects of an infection or a cold, **I utilize a nebulizer treatment with albuterol medication at least once a day.** After said treatment, immediate relief relaxes my lung’s rigid airways, and my breathing can come back to an ease. However, after just about four to six hours, my breathing will revert back to an irregular breathing rate. **Aside from the nebulizer treatment, I also take prednisone in these circumstances so as to also control my breathing by lessening my airway’s inflammations.**

Overall, combining a daily dose of prednisone with one or two nebulizer treatments can result in a stable, yet somewhat fragile, breathing rate, ultimately resulting in several restrictions in daily activities.”

**Shreaya Madireddy**  
18-year-old living with asthma



## Control Medications

“My children’s control medications, their inhalers, **allow them to better stave off asthma attacks** from illnesses and allergens.”

Parent from New Jersey

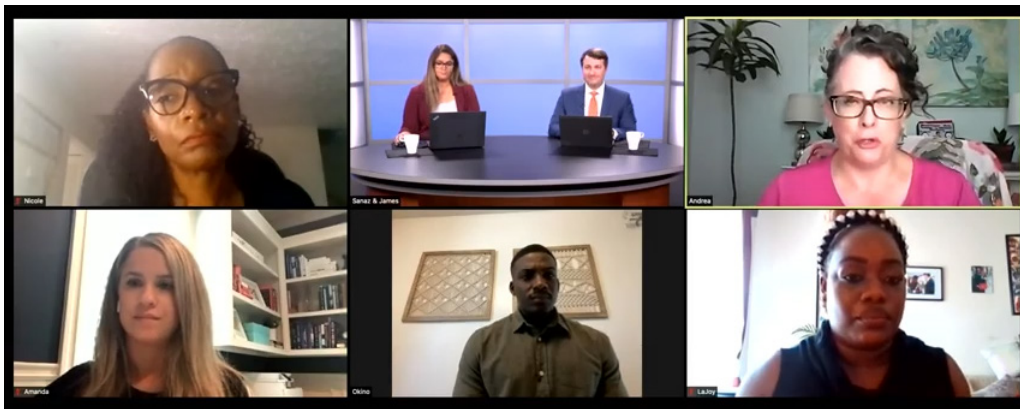
Control medications continue to be important to manage asthma. They help prevent asthma attacks or flare-ups through reducing the overall sources of inflammation that lead to symptoms. There are a variety of control medications available. Children may try multiple medications before they find the best choice or combination to control their asthma. Treatment plans may need to adjust or change over time.

“My children take Singulair®,” shared Jeanette from Pennsylvania. “And when they were younger, they used an inhaled corticosteroid. They carry a short-acting bronchodilator in case they need it, but rarely do they need it.”

Andrea Jensen from Utah and her three children have asthma. Their experience is an example of how different people, even within the same family, may need different treatments. “We’ve tried pretty much everything on the market. When my kids were diagnosed 21 years ago, doctors didn’t know as much about the different phenotypes and endotypes, so the different types of asthma.” shared Andrea. “It can be really hard to get the right medication for the right person. So, for my three kids that are all adults now, all four of us, including myself, we’re on different treatments.”

Colleen Plunkett’s son KE has eosinophilic asthma. “I take my inhaler every day to breathe easier,” shared KE. Colleen added, “KE has tried lots of different combinations to get the right success for his treatment ... he now is on a good treatment plan that works well for him ... Currently, his plan is to use a Symbicort® puffer and azelastine nasal spray twice a day. And once a day also uses the Flonase® nasal spray and takes a levocetirizine pill at night. He takes the Pulmicort® or budesonide steroid to control his eosinophil counts.”

LaJoy Johnson-Law from Washington, D.C., shared her frustrations with treatment experiences for her daughter. “We’ve just kind of been through it all: outpatient, inpatient, hospitalization, Pulmicort®, Flovent®, and she’s currently on ADVAIR®,” she said. “Everything doesn’t work for everybody. The Pulmicort® wasn’t working, the Flovent® wasn’t working. And so now she’s on ADVAIR®, which seems to be really mellowing her symptoms out.”



*Meeting participants discussing control medications for asthma in childhood*

## Quick-relief Medications

“If you have a really severe asthma attack, [the] nebulizer is the only thing that’s going to cut it because you literally can’t inhale to use your inhaler. You just can’t do it. You’re not strong enough.”

### Andrea Jensen

parent of children living with asthma, who also has asthma



Children with asthma need access to quick-relief medications, such as a propellant driven, breath actuated, or nebulized format. Many people commented about relying on nebulized treatments during asthma attacks and flare-ups.

“If my asthma is really bad, I take the nebulizer,” shared KE Plunkett from New York. “The nebulizer helps me breathe better when near smoke, or in cold weather. It also helps me do more physical activities.”

“We are pretty much on nebulizers around the clock when she gets sick ... when her lungs are inflamed, and she’s having asthma issues,” shared Amanda Eisen from Connecticut, whose daughter has asthma.

A survey respondent answering on behalf of her daughter shared: “When she has an attack she has to make sure she has her nebulizer with her. She has to take it every few hours. The nebulizer is big and difficult to use on the go. We have gotten a hook up for the car to make it easier, but it does force us to be by an [electrical] outlet.”

Unfortunately, at-home treatments are sometimes not enough to stop the progression of asthma symptoms. More or different treatments may be necessary. “I just found it kind of heartbreaking that even with three medications, around the clock, and this nebulizer, it still didn’t seem to be enough. It had to take a trip to the hospital or the doctor in order to give her some relief,” shared LaJoy Johnson.

## Biologics

Biologics are the newest category of asthma treatments mentioned as a possible consideration in the 2020 Focused Updates to the Asthma Management Guidelines. Biologics may be an option for severe asthma that is not well controlled with other medications. They target a cell or protein in your immune system to prevent airway swelling. Several participants shared their positive experiences with biologics.



*KE Plunkett using a nebulizer at the hospital to help manage his asthma*



*Javan Allison receiving a XOLAIR® injection to help manage his asthma*

“These XOLAIR® shots that he gets are really great for him,” shared Monique Cooper from Florida, whose son has asthma. “We haven’t had any hospital stays or ICU stays due to getting those shots. And we still maintain his regular inhaler in the mornings and at night.”

Biologics are proving particularly helpful for several phenotypes of asthma including those with allergic and eosinophilic asthma. This includes Ryan Pianksy from Georgia. “On benralizumab, my eosinophil blood count levels went from high to normal, which greatly improved my eosinophilic asthma after the first couple of doses.” The treatment has worked so well for Ryan that he indicated he is now able to do things he couldn’t do before. “For example, I started running,” he said “Just six months after starting this new medicine, I was able to compete in a 5K obstacle course. I’ve been able to work out regularly, running in the Georgia heat in the summers, traveling, taking up weight lifting, and swimming. Since I’ve been on benralizumab, I haven’t needed to use my rescue inhaler. Though of course I still carry it on me, just in case.”

## Avoiding or Reducing Triggers

“We had many medication adjustments and after one particularly difficult period, **I felt I needed to do something to get more control over what might be triggering the asthma.** So I found some information that was not previously provided to me by his medical provider. And I removed every stitch of carpeting in our house and replaced it with laminate. I re-homed our pets, I removed all stuffed animals, and we also got into a routine of washing all beddings, sofa coverings, area rugs, changing air conditioning filters, and cleaning vents. Just a very strict schedule of doing those things. And we did notice improvements in the frequency of his asthma symptoms.”

### Nicole Sutton

parent of a child living with asthma



Unfortunately taking medication alone is not always enough to manage asthma in childhood. Individuals with asthma must also avoid or reduce exposure to their asthma triggers (see page 10 for more information about triggers). Some people’s asthma is triggered by cats or dogs, others by dustmites or mold. There is great variability in asthma triggers.

“Medication can only do so much. If there are still triggers at home, asthma will still be a challenge,” shared Okino Thompson from Texas.

“We did a lot for our home to make it allergy and asthma friendly,” shared Andrea Jensen. “We ripped out all the carpet, re-finished with wood floors, all sorts of things. Standing air purifiers, mattress tight covers, pillowcase covers, all sorts of things like that to make it allergy and asthma friendly. It’s been quite a ride.”

Monique Cooper also commented on the importance of avoiding triggers to manage her son’s asthma. “It’s just kind of keeping him away from what can trigger his asthma, and keeping him on his medications that can allow him to do certain things,” she shared.

## Holistic or Alternative Treatments

“Accessing **non-steroidal treatment options for asthma** therapy over the past five years has brought him health and brought us hope.”

**Jolene MacDonald**  
parent of a child living with asthma



Some caregivers turn to holistic or alternatives to medications to supplement traditional asthma treatments.

Okino Thompson found swimming to be helpful in improving his asthma. “I think my mom got me enrolled in swimming. The doctor told her it’s good for breathing to help strengthen the lungs,” he shared. “And then I noticed, maybe two years afterward, I wasn’t going to the doctor as much, or I didn’t need the inhalers as much ... the controller one or the quick relief ones.”

Jolene MacDonald from Maine uses several approaches to help manage her son’s asthma and seasonal allergies. This includes working with an integrative dermatologist to help manage skin rashes, seeing an osteopath for acupuncture, and a counselor to learn how to cope and manage stress from a chronic health condition. Plus, allergy testing empowered her to manage her son’s environmental allergies. In his bedroom, she uses trigger mitigation strategies such as putting dust mite protectors on his mattress and pillows, and using an air purifier or dehumidifier. She shared that “the asthma treatments that benefited Max the most ... supported and strengthened his immune system and lowered stress.”



*Okino Thompson, a 28-year-old living with asthma*

## Complementary Health Approaches

Patients and caregivers expressed a clear interest in integrating non-pharmacological treatments into their asthma care plan.

At this time, it is recommended to use holistic or alternative treatments to complement traditional asthma treatments, but not replace them. It is important to talk to your doctor about any supplemental treatments you or your child are considering. They may interact with your other treatments.

To learn more about asthma and complementary health approaches, visit <https://www.nccih.nih.gov/health/asthma-and-complementary-health-approaches-what-you-need-to-know>.

## How Well Treatments Address Most Significant Impacts of Asthma

In addition to gathering feedback about what types of treatments people are currently using to manage asthma in children, information was also collected about how well treatments help the most significant impacts of asthma.

The majority of survey respondents were either very satisfied or somewhat satisfied with the ability of their or their child's current asthma medications ability to help manage asthma.

Many factors play into the effectiveness of medications. This includes adherence to treatment schedules, medication confusion, and correct techniques. Using an inhaler or nebulizer incorrectly can keep medication from getting to a child's lungs.

How satisfied are you that your child's current asthma medicines are helping to manage their asthma?

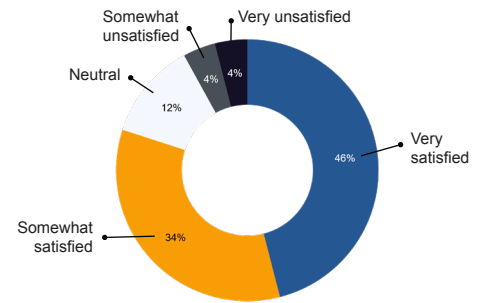


Chart represents responses to Little Airways, Big Voices survey

### Incorrect Technique

Health care providers, patients, and caregivers need more education about how to correctly use inhalers and nebulizers, the difference between medications and their side effects, and more. The majority of children with asthma do not use their inhalers correctly, which can lead to poor management of asthma symptoms. Multiple studies have looked at inhaler techniques.

< 50%

of children properly use inhalers

Reported in a 2019 study in the *Journal of Allergy and Clinical Immunology*

12%

of inhalers are used correctly

Reported in a 2017 study in the *Journal of Aerosol Medicine and Pulmonary Drug Review*

92%

of people with asthma use their device incorrectly

Reported in a 2015 study in the *Annals of Allergy, Asthma & Immunology*

The Little Airways, Big Voices survey respondents generally felt the current treatments reduced asthma symptoms. But, approximately 25% felt they caused negative side effects, which was concerning.

Treatments can only do so much; education and avoiding asthma triggers are also essential.

**“Providing as much education and training to students, educators, and parents can help reduce poor asthma outcomes.** I remember the last time that my son had an asthma attack, I was talking to the nurse and she said that I did the right thing by having him use his rescue inhaler. She also stated that sometimes parents administer the wrong inhaler to their children during an asthma attack.”

**Esther Igboerika**

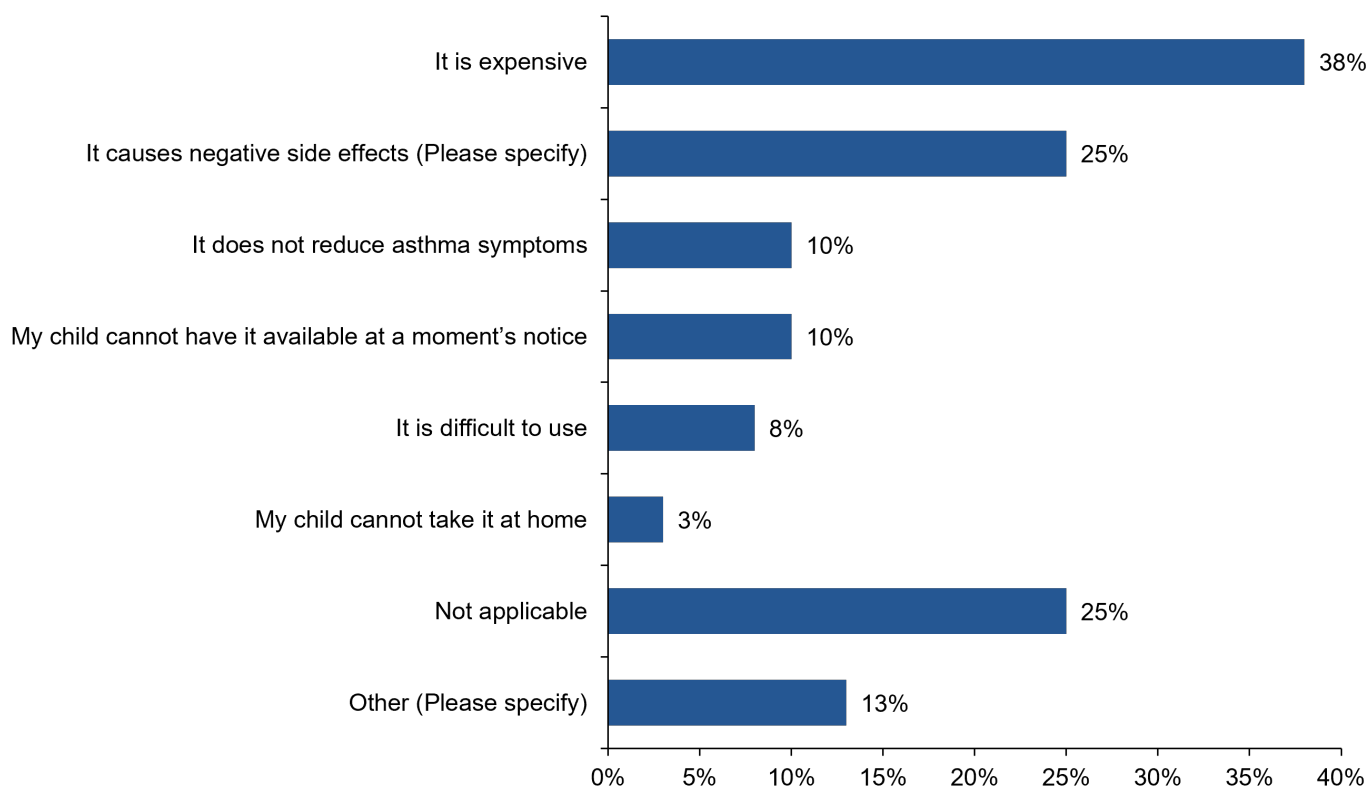
school nurse and parent of two children living with asthma



## Most Significant Downsides/Biggest Drawbacks of Current Treatments and How They Affect Daily Life

While there are many treatments available to manage asthma in children, there are many concerns about the treatments. A top concern was side effects. Concerns about the expense of the treatments and access to quality health care were also expressed, but are outside of the scope of this report.

Regarding your child's current asthma medication(s), what don't you like about it?



Sample Size = 248

Chart represents responses to Little Airways, Big Voices survey

## Side Effects

Side effects of steroid treatments for asthma in children were particularly concerning. At times, oral corticosteroids (OCS) may be necessary to control asthma symptoms. OCS can have serious long-term side effects such as mood swings, weight gain, high blood pressure, cataracts, osteoporosis, and infections.

Contributors shared that OCS treatments make children shaky, anxious, unable to focus, and cause difficulty sleeping. This can impact academic success. Concerns were also expressed about long-term effects such as stunted growth and bone issues.



Word cloud from answers to survey question about negative side effects of current treatments for asthma in childhood



"I just kind of wished that [my daughter] didn't have so many steroids because one of the side effects was making her a little bit sluggish at school. It was kind of like just affecting her attention span at school."

**LaJoy Johnson-Law**  
parent of a child living with asthma

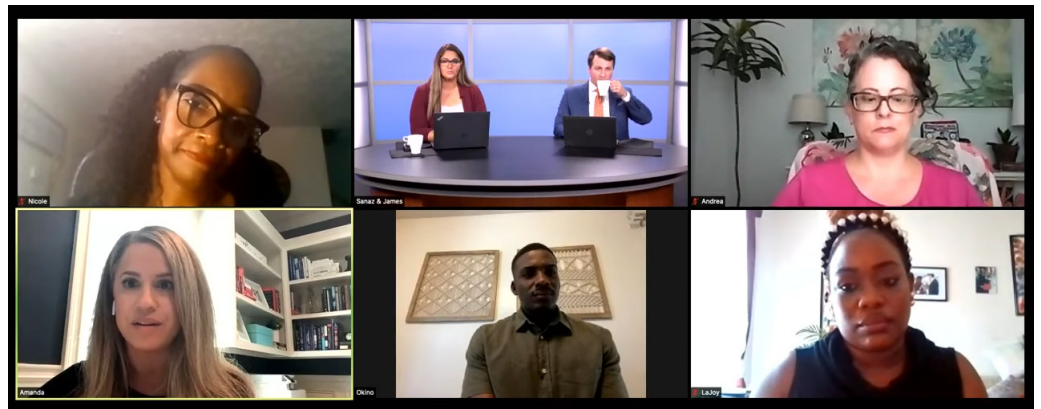


*Ryan Piansky in the hospital at age 2 for issues related to his chronic illnesses*

Ryan Piansky from Georgia was first diagnosed with asthma at age 2. Today he is thriving in college. But, he has had a long journey. He has tried various treatment approaches and experienced many side effects. "The most effective option for much of my teenage years was steroids but that came with a host of problems," he shared. "I became dependent on these medicines so transitioning to new treatment options became extremely difficult. Most attempts to wean off my steroids left me very ill, sometimes resulting in hospitalization. I would lose all my energy, have muscle pain, and be prone to illnesses resulting in coughing fits that lasted for weeks. The dependency on steroids left me without energy and weak any day when I didn't take them. I have long-lasting effects attributed to chronic steroid usage in childhood, such as short stature and permanent bone loss. Due to chronic steroids, I developed osteoporosis, something my doctors are still trying to figure out how to manage today."

Nicole Gyimah of Maryland also shared concerns about her son's growth and height as a result of taking steroids. "I just want him to be whatever he was intended to be, whoever he's supposed to be. And I'm hoping that these medicines are not keeping him from growing and being taller or anything else," she commented. "I get concerned about the things that I can't see, that are going on inside of him ... what is it doing to him overall, physically?" These are important questions to address.

Colleen Plunkett from New York, whose son KE has eosinophilic asthma, also expressed concerns about steroids. "The downside to his treatments are steroids," she said. "They make him very anxious and very panicky. He's full of energy, pacing, and jumping ... At school, he's often unable to focus and falls behind [on] his classwork."



*Meeting participants discussing side effects of treatments for asthma in childhood*

Survey contributors shared similar concerns about medication impact as well. Kathie, a caregiver to a teenage daughter with asthma, shared, “She does not feel well after taking it. Breathing improves but then she must contend with a headache and/or stomach issues.”

Stopping steroid treatments can also cause significant issues, such as withdrawal.

Max MacDonald’s mom Jolene attended the Little Airways, Big Voices meeting to share his experiences with asthma in childhood. Following an acute respiratory issue at 7 years old that required a stay at the hospital, Max started taking beclomethasone (QVAR RediHaler®). “The first week on the steroid inhaler, Max experienced intermittent shortness of breath and felt rattley, dizzy, and not so right. It took him three hours to fall asleep each night after each p.m. dose,” Jolene recalled. After two weeks, Max’s lung tests looked good and his doctor recommended stopping the beclomethasone. Unfortunately, he had a debilitating adverse reaction and experienced significant withdrawal issues.



*Max MacDonald using a peak flow meter, his inhaler with a spacer, and a pulse oximeter*

“We stopped QVAR® and the following day at the same time of day his dose had been administered, Max’s neck swelled to the size of two tennis balls,” shared Jolene. They went to urgent care and learned he was experiencing a rebound from the steroid inhaler. “The weeks after Max’s rebound reaction were intense as the swelling subsided,” she continued. “He experienced trouble swallowing, eating, breathing, felt frequently sick, dizzy, and had stomach pain.” Five years later, Max is managing his asthma without steroid treatments. “Accessing nonsteroidal treatment options for asthma therapy over the past 5 years has brought him health and brought us hope,” shared Jolene.

## Convenience and Lack of Knowledge

It can be burdensome and cumbersome to manage the various treatments for asthma in children. And the treatments can be challenging to administer.

Correctly and regularly administering asthma medications is critical to managing asthma in children. Different formats and delivery methods can be off putting. Nebulizers can be scary to young children due to the sound and the face mask used to administer the medicine.

“There’s a lot of medications to keep track of. I have reminder alarms in every device, my iPhone, and the Alexa.”

### Colleen Plunkett

parent of a child living with asthma  
(Pictured right: KE Plunkett with his mother, Colleen)



Other children are afraid of shots (see page 22). And there is a lot of confusion around inhaler techniques (see page 31). These issues can reduce medication effectiveness.

“It takes time to learn to use the inhaler properly and needs to be monitored by an adult,” shared Vanessa from Maine.

Unfortunately, even health care providers don’t all provide the same advice on how to administer inhalers. “Bless their hearts, not all pharmacists or doctors and nurses know how to use them correctly. So head to the [manufacturer’s] website and make sure you’re using it right,” shared Andrea Jensen. In addition to having asthma, and having children with asthma, she is also an asthma educator. Inhaler and spacer manufacturers often offer videos with instructions for use.

“My son Jamie hated his breathing treatments. He would scream and thrash each time I held the spacer to his face. Even though I noticed significant progress by adhering to his treatment plan, **I began purposely forgetting and skipping his treatments just to not hear him cry.** Because of my neglect to keep his treatments consistent, his lung health began dissipating once again.”

**Jennifer Hobbs Folkenroth**  
parent of a child living with asthma

It is important to surround children with asthma with people who understand how to manage it. Professional training and Asthma Self-Management Education (ASME) programs for children and caregivers can help. Several contributors made comments about coaches, teachers, and others not understanding asthma.

“Folks not knowing and really understanding and myself too, when he was first diagnosed, my knowledge on asthma was to our detriment. And so I think that’s definitely a downside. Maybe if the schools could implement some programs or something where folks can learn, the educators and everybody just learn as much as they can about this condition, that would be great.”

**Nicole Gyimah**, parent of a child living with asthma

“I have to constantly inform most teachers and school nurses, but the older he got, they don’t always understand.”

**Colleen Plunkett**, parent of a child living with asthma

“Growing up as a young person, living with asthma and really having to rely on your parents and, or those around you, i.e the adults or the teachers to help understand your condition, and help you manage your condition can oftentimes be very difficult.”

**Charmayne Anderson**, parent of a child living with asthma who also grew up with asthma

“Most people think asthma isn’t severe. So sometimes it was a bit hard for them to understand.”

**Regan Lloyd**, 17-year-old living with asthma

“My teachers didn’t really understand what the condition [is] and the severity of it.”

**Shiv Sewlal**, 20-year-old living with asthma

## Looking Toward the Future: Important Factors for New Treatment Options

“My hopes, ideally for a future asthma treatment, would be one that encompasses the word efficiency. I would aspire for a treatment or a medication that hinders wheezing or troubled breathing as a consequence from a mild cold or sinus infection. **I would hope for it to act in a quick manner while imposing long-lasting care.**

Having an asthma treatment that specifically targets the effectiveness of an asthma-inflicted patient’s immune system, would be the most ideal treatment I would like to see developed in the future.”

**Shreaya Madireddy**

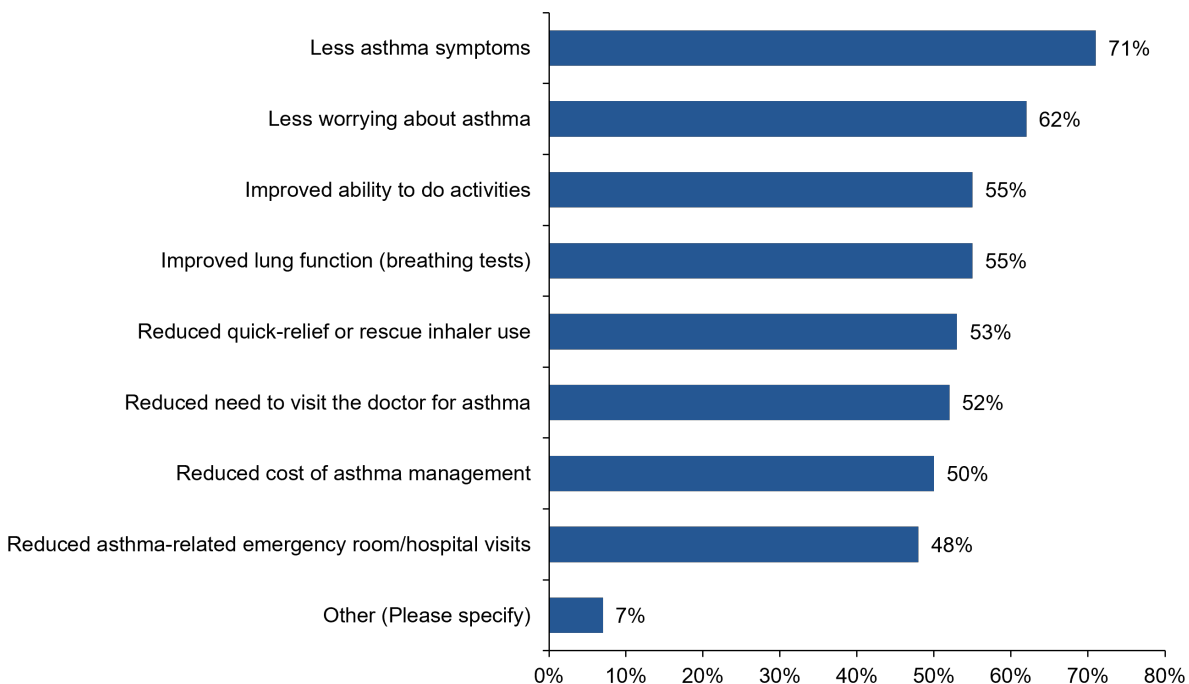
18-year-old living with asthma



At the end of the second session of the Little Airways, Big Voices meeting, the discussion turned to the future. Perspectives on future treatments were also gathered through the survey. Short of a cure, contributors shared important factors for new treatment options. Ultimately, they **want to be able to worry less about their own or their child’s asthma.**

More than half of all survey respondents indicated they would like new treatments that have a mix of clinical and socioemotional outcomes.

Aside from a complete cure, what meaningful improvement would an ideal treatment for asthma in childhood provide?

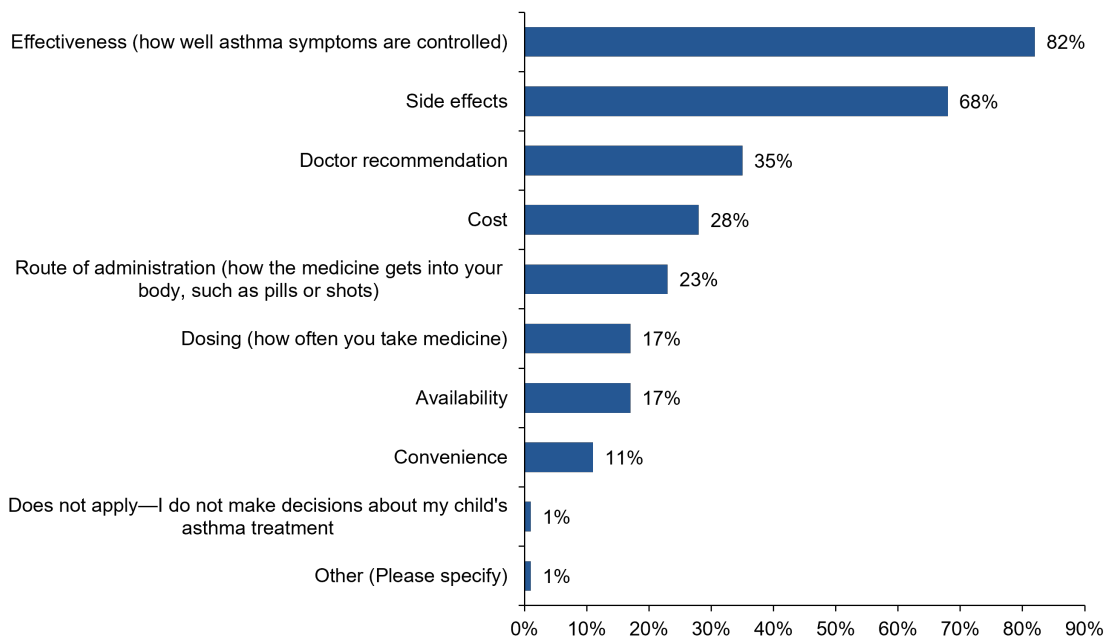


Sample Size = 248

Chart represents responses to Little Airways, Big Voices survey

Parents who completed the survey indicated that overall effectiveness and side effects were important when selecting a treatment. However, about one-third of respondents also closely consider doctors' recommendations, as well as cost and insurance coverage. Factors such as availability, dosing, and convenience, though still important, were reportedly less of a priority.

What factors or information are most important for you to consider when deciding on a course of treatment for your child?



Sample Size = 248

Chart represents responses to Little Airways, Big Voices survey

## Drug Development History and Challenges

There are many considerations to take into account when undergoing drug development. During their opening remarks at the Little Airways, Big Voices meeting, Dr. Rizzo and Dr. Chin shared information on the history of drug development for asthma in children, including several challenges.

There is no one size fits all treatment. Asthma in childhood has a variable natural history, and there are multiple phenotypes. In addition, there are still questions to answer about the underlying mechanisms and genetics.

“Even though asthma is very common, with many approved therapies, there are **a lot of unanswered questions** about underlying mechanisms and genetics that interplay with the environment.”

**Dr. Stacy Chin**  
U.S. Food and Drug Administration



There are also ethical considerations for performing clinical trials in children. Before a treatment can be studied in children, efficacy first needs to be proven in adults. At that point, the goal is to identify the lowest effective dose with minimal side effects.

“Many of these medications will be taken for years. So we need some assurance that these medications are safe for long-term use and will not adversely impact the development or growth of children,” commented Dr. Chin.

There was a desire for treatments that are more efficient, prevent or lessen the frequency of asthma episodes, and have fewer side effects. There was also an interest in holistic alternatives.

“I think it would be great if there were some [treatments with] less side effects, for example, increased heart rate from certain medications that [my daughter] needs,” suggested Amanda Eisen.

Tonya Winders wished “for future treatments that are easier to use, inhalers with fewer side effects, like mood or sleep disturbances, and better routes of administration than inhalers or injections due to fear of needles.”

Ryan Piansky also expressed his hopes for the future. “I hope everyone can get on treatment that is as effective for their asthma as mine has been. One that prevents asthma attacks, reduces the need for a rescue inhaler, eliminates needs for steroids, and has no major side effects.”



*Meeting participants discussing hopes for future treatments*

The desire for treatments with fewer side effects was clear. There were also suggestions for treatments that lasted longer and therefore could be taken less frequently. “One thing that would be interesting to see is a medication for asthma [that lasts] 24 hours, that you could just take the inhaler once,” suggested Andrea Jensen. “Most of the COPD inhalers are 24 hours, but asthma is 12 hours.”

There were also pleas for better or alternative routes of administration. You may recall previous comments about a desire for alternatives to shots (see page 22). This came up once again. “I think biologics have, as I mentioned, really literally saved my son’s life. I think those are very important,” shared Andrea Jensen. “I know someone mentioned, is it possible to turn a biologic into a patch? That would be interesting. I’m not sure how that would work. I know needle phobia is alive and well with a lot of people. So that’d be interesting to see what comes out of that.”

Hopes for treatments that prevent the development of asthma in children were also shared. For example, if a child is at risk for asthma, could a treatment help prevent the onset of the symptoms and resulting health effects. “I personally would like to see more in the area of prevention as opposed to having to worry about how to treat in the future,” commented Kylie from Seattle, Washington. “If my child is going to develop asthma, let’s get them doing something now that might prevent it from being as bad.”

Beyond future treatment ideas themselves, participants shared desires for resources to help encourage treatment adherence, educate more people about asthma in children (e.g., coaches, teachers), and avoid asthma triggers.

Colleen Plunkett proposed the development of an alarm or reminder system. It could both remind children and their caregivers when it is time to take the medication and alert them that the medication is running low. “A positive innovation is that there’s a dose counter on the inhaler that tells you how many doses are left,” she shared. “It would be great if somehow it had an alarm so that kids with special needs would remember to take it.”

Okino Thompson proposed “a form of home inspection. I think [it] will be good if patients keep coming in about the same issue. Like what’s going on at the root of the problem that we can work on, so the medications can work to their full potential.”

Melanie from Washington also had an idea about avoiding asthma triggers. “We need proven technologies or devices that can effectively block or filter out the air pollution from entering our homes and lungs,” she suggested.

She also posed the idea of tailoring treatments to specific asthma triggers. She posed the following questions: “Are some [treatments] better to treat asthma induced by smoke than others? Does the dosing need to be adjusted during wildfire events? Also, exposure to air pollution has been shown to cause asthma development in children. Could a future treatment reverse the harmful effects of air pollution before asthma develops in a child?” These are all very interesting questions to explore.

LaJoy Johnson Law also raised questions about future holistic treatments. “Is there anything holistic that can help prevent hospital visits? That maybe isn’t as strong as a steroid, but ... stronger than the things that are currently out there?” she asked. “Something that improves breathing, something that helps with the wheezing and coughing ... I would love for [my daughter] to be able to be more active,” she continued.

While alternative treatments are not under the FDA’s purview, multiple participants shared an interest in holistic approaches to treating asthma in childhood. Nicole commented, “I definitely agree with LaJoy regarding something more alternative, and holistic versus the steroids.”

As the discussion about future treatments came to an end, the moderator, James, commented there is “such a strong interplay between environment and activities and treatments. They really go hand in hand. So having treatments that help counteract or focus on those environmental triggers do represent important potential treatment approaches.”



# Risk-benefit Assessment

## Framework for Asthma in Childhood

The input provided by people living with asthma in childhood and their caregivers, through the Little Airways, Big Voice initiative, helped to inform our understanding of the condition and current treatment options. Below is a sample framework of how the data from this report may be used to inform a risk-benefit assessment for drugs under review for treating asthma in childhood.

Decision Factor	Evidence and Uncertainties	Conclusions and Reasons
<p><b>Analysis of Condition</b></p>	<p>Asthma is a chronic lung condition. It causes episodes of coughing, wheezing, chest tightness, and shortness of breath. Increased mucus and inflammation of the airways can cause spasms of the bronchial tubes, making it difficult to breathe.</p> <p>Respiratory infections, allergens, exercise, cold weather, air pollution, strong emotions, and tobacco smoke can trigger asthma in children.</p> <p>Asthma is the most common chronic respiratory condition in children. It affects approximately 6 million children (ages 0-17) in the United States.</p>	<p>Asthma can be intermittent, mild, moderate or severe, persistent, and sometimes life-threatening.</p> <p>Shortness of breath or difficulty breathing is commonly reported among children with asthma.</p> <p>Asthma symptoms and side effects of currently available treatments can severely impact children’s quality of life.</p> <p>Nearly all children with asthma (and their families) are affected in some way by the symptoms of the disease or the side effects of their treatments.</p> <p>Children and their parents expressed that asthma impacts their ability to participate in physical activities, go on vacation or travel, take part in social engagements or events, and attend school or daycare.</p> <p>The top fear of children with asthma and their caregivers is the progression of asthma and dying. There are also significant concerns about the side effects of treatments.</p>
<p><b>Current Treatment Options</b></p>	<p>There is no cure for asthma.</p> <p>A combination of control/maintenance and quick-relief medications is commonly used to treat asthma in children. Avoidance of triggers is also important in treating asthma.</p> <p>The same treatments do not work for everyone and combinations of treatments may be necessary.</p> <p>Steroids are commonly used to treat asthma in children. This includes inhaled corticosteroids (ICS) and oral corticosteroids (OCS).</p> <p>OCS have a greater risk of serious long-term side effects than ICS. This can include mood swings, weight gain, high blood pressure, cataracts, adrenal insufficiency, osteoporosis, infections, and stunted growth.</p>	<p>Asthma is a chronic and lifelong condition. Control or maintenance medications are only effective when taken correctly and on schedule.</p> <p>Quick-relief medications are also necessary when asthma symptoms arise.</p> <p>Patients and their loved ones expressed a need for treatments that improve breathing, slow or stop the progression of asthma, and come with fewer side effects. They are also interested in better routes of administration.</p> <p>There are currently no treatments available to prevent the development of asthma.</p>



“We began by hearing the **staggering impact of childhood asthma for over 6 million kids** who are living with this chronic disease and the millions more fearful, yet hopeful, parents and caregivers who are simply praying that their child outgrows the symptoms and condition. But the truth is, **they won’t outgrow it**. The truth is, asthma is a chronic condition with a lifelong sentence. The truth is, approximately 10 people will die today from asthma alone. And the truth is, that the **burden heard here today is mindblowing and absolutely highlights the unmet needs in childhood asthma.**”



## Tonya Winders

Allergy & Asthma Network and a parent of a child living with asthma

At the end of the Little Airways, Big Voices meeting, initiative collaborators Tonya Winders, President & CEO of AAN, and Mary Jo Strobel, Executive Director of APFED, provided an impactful summary and empowering closing remarks.

Tonya reiterated the unmet needs in prevention, diagnosis, treatment, and progression shared during the meeting. This included the need to learn more about the genetic and environmental factors driving asthma, address disparities in those affected by asthma, and do more research on the atopic or allergic march, which refers to the progression of allergic conditions beginning early in life with eczema, then food allergies, and then asthma.

“We implore the FDA to continue to research the atopic march to help us prevent asthma in the early years of life, especially for those living in our most underserved communities,” said Tonya.

She highlighted the challenges of children not only getting diagnosed with asthma, but with specific subsets of asthma. This is important because it can lead to better asthma treatments and improved management.

She reiterated the challenging side effects of currently available treatments for asthma in children such as mood disturbance, sleep disturbance, weight gain, bone loss, and steroid withdrawal.

“All of these conditions are so impactful to children’s long-term health. It’s not just about until they’re 18. What happens beyond that time and are the current treatments enough? Are they actually, in some cases, harming our children rather than helping them?” remarked Tonya.

Looking to the future, she called on the FDA “to explore new routes of administration beyond inhalers, beyond injections, and to consider the massive comorbidity impact on children which make our treatment regimens so much more challenging.”

She also recommended further research into the unmet needs, long-term management, and progression of the disease.

She closed with an impassioned plea: “The truth is no child should be forced to avoid playing outside or going to the beach. No child should be sidelined or made to quit playing a sport that they so dearly love. No child should live with constant anxiety or isolation due to childhood asthma. No parent or caregiver should have to leave their career or live in fear of the 2:00 a.m. phone call from college saying, ‘Mom, I can’t breathe,’ like I experienced with Kaleb in 2018. Nor should they be left guessing if the next time that their child crashes will be the last. No family should experience the loss of a child or a loved one like what we heard of the Del Principe family on her sister’s wedding day. Yes, our community would love a cure, but until that time we implore the FDA to prioritize childhood asthma by advancing research and expediting reviews of new treatment solutions that help us simply breathe better together.”

Mary Jo Strobel then thanked participants for their efforts to “shine a spotlight on the burdens of asthma and childhood, and to illustrate the multifaceted impacts that the condition has on you and your loved ones.” And commented how she “was impressed by the resilience of this community and the determination to move forward, to be candid, and to make a difference.”

The perspectives shared through the Little Airways, Big Voices meeting, written comments, and survey are invaluable and critical for the FDA to “take into consideration if a treatment would be meaningful to the patient,” commented Mary Jo.

She also reiterated the goals and importance of the Little Airways, Big Voices initiative. “Insights shared in this report will help inform the development and regulatory review of potential new asthma treatments that will have a meaningful impact on the lives of children with asthma,” she stated. “Today was about the voice of the patient. And those voices resonated. It’s a crucial step for drug development to treat asthma in children and we look forward to continuing our work to improve the quality of life for all of those living with this chronic condition.”



*Tonya Winders (above) and Mary Jo Strobel (left) shared closing remarks at the Little Airways, Big Voices meeting*

# From the Collaborators: Reflections and Next Steps

“The Little Airways, Big Voices initiative **reaffirmed our commitment to elevating the patient and caregiver voice in drug development.** We are grateful to everyone who candidly shared deeply personal accounts of the challenges they endure while managing childhood asthma.”

**Elisa Zizza**

Asthma and Allergy Foundation of America



Thank you to the patients and caregivers who took part in the Little Airways, Big Voices initiative. Your stories help us raise awareness about the daily disease burden of asthma in childhood and the need for new treatment options.

“The impact of childhood asthma is significant and it extends beyond just the patients — their loved ones are significantly impacted as well,” reflected Mary Jo Strobel, APFED. “Hearing panelists describe the impacts and burdens of living with asthma, and their fears, anxieties, and recollections of fatal and near-fatal asthma attacks painted an unforgettable picture and underscores the urgency to address unmet needs.” We also appreciate the researchers, health care professionals, and industry members who attended the meeting.

“My hope is that through the sharing of the patient perspective in disease burden and desires for future treatment, [the] FDA and others in the pharmaceutical industry are able to better understand desired outcomes and what is most important to the consumer,” reflected Kelly Barta, AAN.

Throughout this initiative, we heard that people managing asthma in childhood want treatments that reduce asthma symptoms, have fewer side effects, and allow them to participate in more activities.

Now we ask that all stakeholders work together to improve the quality of life for people managing asthma in childhood. Together we can take steps to improve asthma **education, advocacy, research, and drug development.**

## Education

- Encourage patients and families to participate in Asthma Self-Management Education (ASME). This is an important component of medication adherence and technique. It can have a positive impact on the clinical management of asthma.
- Provide more education about the severity of asthma for sports coaches, educators, and others who care for children with asthma.
- Invest in educating patients and families about the drug development process.
- Raise awareness about the importance of participating in clinical trials.



## Advocacy

- Help inform policy changes that benefit children with asthma.
- Champion policies that provide funding for education and research about asthma in childhood.
- Support legislation that advocates for quality care and medication coverage.\*



## Research

- Continue to explore the natural history and genetics of asthma.
- Look into ways to prevent the development of asthma in children.
- Research the different subtypes of asthma so health care providers can better diagnose and prescribe appropriately tailored treatment plans.
- Investigate the impact that common triggers (such as respiratory illness or allergies) have on asthma episodes and the efficacy of current treatments.
- Examine the progression of asthma in childhood.
- Study the short- and long-term impacts of adverse side effects to current therapies.
- Include patients and families in the development and implementation of clinical trials.
- Explore the role of holistic and alternative therapies in asthma management.
- Consider new technology to avoid asthma triggers.



## Drug Development

- Invest in targeted therapies and precision medicine.
- Develop drugs with fewer short- and long-term side effects.
- Explore alternative and more efficient modes of treatment delivery.



While reflecting on her hopes for the Little Airways, Big Voices initiative, Deborah P. Brown, Chief Mission Officer for the American Lung Association, shared “Our hope is to utilize the findings outlined in the report to elevate patient-driven priorities and concepts in a way that aids the development of new treatments for pediatric asthma patients and caregivers.”

“The need for new treatment options is clear,” commented Elisa Zizza, AAFA, while reflecting on her biggest takeaway from the initiative. “Including patients and families in the drug development process is the best way to ensure that new therapies address patient needs. We hope that this initiative is the first step.”

Patient advocacy groups, like the ones that collaborated on the Little Airways, Big Voices initiative, support better health outcomes by bringing patients, caregivers, FDA staff, drug and medical device developers, and other stakeholders together to create therapies, educational programs, and resources in response to patient needs.

We implore researchers and drug developers to engage with patient advocacy groups (such as the Little Airways, Big Voices collaborators) early and often. And we encourage patients and caregivers to connect with us for support.



\*While access to quality care and medication coverage are important, they were not part of this event.

## Project Team

### Allergy & Asthma Network

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### American Partnership for Eosinophilic Disorders

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## Acknowledgments

Thank you to the following individuals for supporting the **Little Airways, Big Voices** initiative:

**Larry Bauer**, of Hyman, Phelps, & McNamara, PC, for strategic counsel about PFDD meetings, presenting at the August 11, 2021, community webinar introducing EL-PFDD meetings, and supporting patient and caregiver panelists as they prepared their testimony.

**Taylor Desens**, of Taylor Does Marketing, for designing the Little Airways, Big Voices logo, website, and social media graphics in preparation for the meeting.

**John Dudley, Eric Quigley, & Kyle Rhoderick**, of Dudley Digital Works, for creative and technical services to broadcast the meeting to a live remote audience and preserve it for on-demand viewing.

**Jennifer Roeder**, of Roeder Creative, for strategic communications and outreach support for the initiative, including writing and designing this report in partnership with the project team.

**U.S. Food and Drug Administration** for their commitment to incorporating the patient voice in drug development and evaluation. We would especially like to thank William Lewallen of the Center for Drug Evaluation and Research for his guidance and support as we planned the meeting and prepared this report.

**James Valentine**, of Hyman, Phelps & McNamara, PC, for strategic counsel about PFDD meetings, preparing panelists to convey their experiences, and moderating the meeting.

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## Additional support provided by:

The Allergy & Asthma Network, American Lung Association, American Partnership for Eosinophilic Disorders, and Asthma and Allergy Foundation of America's community and marketing/communications teams.



## Sponsors

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# Meeting Agenda



## Externally-Led Patient-Focused Drug Development (PFDD) Meeting on Childhood Asthma

September 20, 2021, 10:00 a.m. - 3:00 p.m. EST

- 
- 10:00 – 10:05 a.m.      **Welcome and Opening Remarks**  
Sanaz Eftekhari, Vice President of Research, Asthma and Allergy Foundation of America  
Kenneth Mendez, MBA, President and CEO, Asthma and Allergy Foundation of America
- 10:05 – 10:20 a.m.      **FDA Introduction of PFDD Initiative**  
Stacy Chin, MD, Clinical Team Leader, Division of Pulmonary, Allergy, and Critical Care, Center for Drug Evaluation and Research, U.S. Food and Drug Administration
- 10:20 – 10:35 a.m.      **Clinical and Treatment Overview**  
Albert Rizzo, MD, FACP, Chief Medical Officer, American Lung Association
- 10:35 – 10:40 a.m.      **Discussion Format Overview**  
James Valentine, JD, MHS, Meeting Moderator
- 10:40 – 10:45 a.m.      **Getting to Know You Polling**

### Session 1 Living With Asthma: Symptoms and Daily Impact

- 10:45 – 11:10 a.m.      **Session 1 Panelist Statements**  
Patient vignettes will show the daily impacts of managing childhood asthma.
- 11:10 a.m. – 12:30 p.m.      **Audience Discussion and Polling**  
Moderated discussion among meeting participants via Zoom, telephone, or written comments will provide additional perspectives on how asthma impacts daily life.
- 12:30 – 1:00 p.m.      **Lunch Break**
- 1:00 – 1:05 p.m.      **Discussion Format Overview**  
James Valentine, JD, MHS, Meeting Moderator

### Session 2 Perspectives on Current and Future Approaches to Asthma Treatment

- 1:05 – 1:25 p.m.      **Session 2 Panelist Statements**  
Patient vignettes will discuss current treatment options and hopes for future treatments for childhood asthma.
- 1:25 – 2:40 p.m.      **Audience Discussion and Polling**  
Moderated discussion among meeting participants via Zoom, telephone, or written comments will provide additional perspectives on current and future treatment options for childhood asthma.
- 2:40 – 2:50 p.m.      **Meeting Summary**  
Tonya Winders, MBA, President and CEO, Allergy & Asthma Network
- 2:50 – 3:00 p.m.      **Next Steps and Closing Remarks**  
Mary Jo Strobel, Executive Director, American Partnership for Eosinophilic Disorders

#littleairwaysbigvoices #asthma #PFDD



# Meeting Moderators & Speakers

## MODERATORS

### **Sanaz Eftekhari**

Vice President of Research, Asthma and Allergy Foundation of America

Sanaz Eftekhari is the Vice President for Corporate Affairs and Research at the Asthma and Allergy Foundation of America (AAFA). Sanaz leads tactical and strategic conversations with business partners and stakeholders across multiple industries, including patient advocacy organizations, pharmaceutical companies, medical societies, research firms, and government agencies. She works closely with various stakeholders to collect patient insights, develop programs, and increase awareness of asthma, food allergies, and atopic diseases through a variety of social and communications channels. She currently oversees multiple projects to encourage successful patient-centered research and elevate the patient voice. In 2019, Sanaz partnered with five organizations to cohost More Than Skin Deep, an externally-led patient-focused drug development (EL-PFDD) initiative for atopic dermatitis. Sanaz has also co-authored several of AAFA's key research reports, such as Asthma Disparities in America, My Life With Food Allergy, My Life With Asthma, and Atopic Dermatitis in America Summary Report.



### **James Valentine, JD, MHS**

Associate, Hyman, Phelps, and McNamara, PC

James Valentine assists medical product industry and patient advocacy organization clients in a wide range of regulatory matters, including new drug and biologic development and approval issues. He also works with clients on clinical trials operations and compliance matters. Prior to 2014, he worked in the FDA's Office of Health and Constituent Affairs (previously Office of Special Health Issues) where he facilitated patient input in benefit-risk decision-making and served as a liaison to stakeholders on a wide range of regulatory policy issues. He administered the FDA Patient Representative Program, facilitated stakeholder consultations during the reauthorization of PDUFA and MDUFA, helped launch the Patient-Focused Drug Development program, and developed the FDA Patient Network. He also worked at the Center for Drug Evaluation and Research's (CDER) Office of Regulatory Policy where he coordinated the implementation of the medical gases certification scheme that was established in FDASIA, and handled a variety of postmarket safety issues including REMS and safety labeling changes.



## SPEAKERS

### Stacy Chin, MD

Clinical Team Leader, Division of Pulmonary, Allergy, and Critical Care, Center for Drug Evaluation and Research, U.S. Food and Drug Administration

Dr. Stacy Chin is a lead medical officer and associate director for biomedical informatics in the Division of Pulmonology, Allergy, and Critical Care within the Office of Inflammation and Immunology, Office of New Drugs, Center for Drug Evaluation and Research at the FDA. She joined the FDA 9 years ago after completing a fellowship in Allergy and Immunology at Duke University Medical Center in 2012. She completed her residency training in pediatrics at Children's National Medical Center in 2009 and received her medical degree from Georgetown University Medical Center in 2006. Although originally from Arkansas, she now calls Washington, D.C. home.



### Kenneth Mendez, MBA

President and CEO, Asthma and Allergy Foundation of America

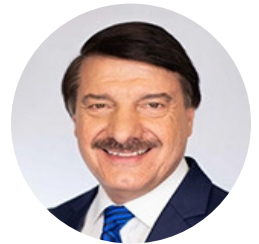
Kenneth Mendez, MBA, became President and Chief Executive Officer of the Asthma and Allergy Foundation of America (AAFA) in early 2018. He came to AAFA from AdvaMed, the world's largest medical technology association, where he served as Senior Executive Vice President and Chief Revenue Officer for 12 years. Since joining AAFA, he has led the organization in establishing a new multi-year strategic plan that emphasizes dramatically reducing the impact of asthma and allergies on the underserved. He has an MBA in marketing from Columbia Business School and a BA in American History and American Art from Harvard College. He also has a personal stake in AAFA's mission as he and two of his children manage asthma and allergies.



### Albert Rizzo, MD, FACP

Chief Medical Officer, American Lung Association

Dr. Albert Rizzo, as Chief Medical Officer (CMO) for the American Lung Association, is the organization's senior medical authority. Dr. Rizzo has long been a key medical advisor to the American Lung Association, a member of the Lung Cancer Expert Medical Advisory Panel and a leading media spokesperson for the Association. In his role as CMO, Dr. Rizzo plays a key role in multiple areas of their mission, including the American Lung Association's Lung HelpLine, research, including the Airways Clinical Research Centers and the Awards and Grants program, as well as advocacy, communications, development, and health promotions. Dr. Rizzo is also the former chief of the Section of Pulmonary and Critical Care Medicine at Christiana Care Health System in Newark, Delaware and continues to practice as a member of Christinia Care Pulmonary Associates. He is board certified in internal medicine, pulmonary, critical care, and sleep medicine and is a clinical assistant professor of medicine at Thomas Jefferson University Medical School in Philadelphia where he obtained his medical degree and completed his residency in internal medicine. Dr. Rizzo received his specialty training at Georgetown University Hospital in Washington, D.C. He is a member of the American Thoracic Society, a Fellow of the American College of Chest Physicians, a Fellow of the American College of Physicians, a Diplomat of the American Board of Sleep Medicine, and a Fellow of the American Association of Sleep Medicine.



## **Mary Jo Strobel**

Executive Director, American Partnership for Eosinophilic Disorders

Mary Jo Strobel has nearly 25 years of professional experience in the nonprofit sector with a specific focus on patient advocacy for allergic conditions. She lives near Washington, D.C. and serves as the Executive Director of the American Partnership for Eosinophilic Disorders (APFED), having been in this role since 2012. She has a broad background and direct experience in a multitude of initiatives related to patient education, disease awareness, advocacy, and research. She collaborates with research investigators, facilitates patient experience data, advises on recruitment strategies, and contributes to research design and protocol. She has co-authored numerous research abstracts and manuscripts that have been published in journals. In addition to invitational speaking engagements around the U.S. and abroad to share insights and information to patients, providers, industry, government agencies, and other nonprofits, she also represents APFED as a member of the Consortium of Eosinophilic Gastrointestinal Disease Researchers; the Rare Disease Clinical Research Network Coalition of Patient Advocacy Groups; the Lay Organization Strategic Partnership of the American Academy of Allergy, Asthma & Immunology; and in several national and global collaboratives to identify and address unmet needs of patients with eosinophil-associated disease.



## **Tonya Winders, MBA**

President and CEO, Allergy & Asthma Network

Tonya Winders, MBA, is currently the President and Chief Executive Officer of the Allergy & Asthma Network, the leading patient advocacy organization dedicated to ending the needless death and suffering due to asthma, allergies, and related conditions. Tonya has over 20 years experience in leadership roles within the allergy and asthma industry. From sales and marketing leadership to managed markets access, she has worked tirelessly to ensure patients have access to effective diagnostic and treatment tools. Tonya serves on several expert panels including the American Thoracic Society Public Advisory Roundtable and Global Initiative for Asthma international guidelines. Furthermore, she serves on the board of directors for the Alliance to Prevent Legionnaires Disease and the American Respiratory Care Foundation and is the current president of the Global Allergy & Airways Patient Platform, representing more than 50 patient organizations throughout the world. Personally, Tonya is the mother of five children, four of whom have asthma and/or allergies, ranging in age from 15-22 years old. She enjoys spending time with her husband of more than 20 years Brian Winders and cheering on her children in various sports.



# Meeting Panelists

Panelists were selected to reflect a range of experiences with childhood asthma.

## Session 1 Living With Asthma: Symptoms and Daily Impact

### Monique Cooper and Javan Allison

Miami, FL

Javan Allison is 13 years old. He was diagnosed with asthma at age 2. After spending a week in the ICU due to asthma, Javan and his mother Monique Cooper now advocate and raise awareness by sharing their experiences.



### Regan Lloyd

Fairfax, VA

Regan Lloyd is a 17-year-old high school senior. She was diagnosed with asthma as a toddler after worsening allergic symptoms. She recounts her journey, how asthma has impacted daily life, severe reactions she's suffered, and how she tried several medications and treatments over the years to control her asthma.



### Nicole Sutton

Tampa, FL

Nicole Sutton is the parent of Nicholas, a 5-year-old boy who was diagnosed with asthma around age 2. She shares her family's journey with asthma, triggers, and the impact of COVID-19 on asthma-related decisions, such as Nicholas attending school.



### Del Principe Family

Bridgewater, NJ

Anne Marie, Larry, and Adrianna Del Principe join us to share the story of their beloved daughter and sister, Alessandra, who was diagnosed with asthma as a teenager. Together, the family recounts the tragic circumstances of the fatal asthma attack Alessandra succumbed to in the spring of 2021 and lament on the need for asthma severity awareness and adherence to treatment plans.



### Esther, Chidiogo, and Chidubem Igboerika

Fresno, CA

Esther Igboerika is a school nurse who has two children with asthma. Her son Chidubem was diagnosed at age 4 and her daughter Chidiogo at age 5. Together they share their thoughts on asthma symptoms and the impact the condition has on their daily lives.



## Session 2 Perspectives on Current and Future Approaches to Treatment

### Jolene MacDonald

South Portland, ME

Jolene MacDonald has an 11-year-old son who has asthma. She talks about the challenges with asthma treatment that her family has experienced, the different doctors involved in her son's care, and strategies that have helped.



### Shreaya Madireddy

Dayton, OH

Shreaya Madireddy is a high school senior who was diagnosed with asthma at age 8. She describes the treatments she has been prescribed to help stabilize her asthma, the restrictions that asthma has placed on daily activities, and how the condition has impacted her quality of life.



### Ryan Piansky

Atlanta, GA

Ryan Piansky is a 21-year-old college student who has lived with asthma since age 2. When he was 18, he was diagnosed with a phenotype of asthma called eosinophilic asthma. He joins us to share the impact asthma has on his life, the side effects from the various treatment options he has used, and how he ultimately arrived at a treatment plan to manage his asthma.



### Colleen and KE Plunkett

New York, NY

KE Plunkett is an 18-year-old college freshman who has suffered from asthma since birth. He has been hospitalized many times for asthma. His mom, Colleen, recounts KE's worst asthma attack and discusses the pros and cons to treatments he has had over the years.



# Meeting Discussion Starters

We are deeply grateful to the following community members for sharing their insights and kicking off live discussions:

## Session 1

Charmayne Anderson  
Caregiver

Mrs. K.A. Hoskinson and her son Charles  
Family managing asthma

Ty-Eisha Rivera  
Caregiver

Jennifer Roeder  
Caregiver

Shiv Sewlal  
Living with asthma

## Session 2

Amanda Eisen  
Caregiver

Nicole Gyimah  
Caregiver

Andrea Jensen  
Caregiver

LaJoy Johnson-Law  
Caregiver

SPC Okino Thompson  
Living with asthma



# Meeting Discussion Questions

## Session 1 Living With Asthma: Symptoms and Daily Impact

1. Of all the symptoms of asthma, which 1-3 symptoms have the most significant impact on your/your child's life?
  - Which symptoms most affect you or your loved one now?
  - Were there other symptoms that were more significant at other times?
  - Were there other symptoms that you noticed (where you suspected something was off, or when looking back after diagnosis you now believe to be related to asthma)?
  - How does asthma affect you or your loved one on best and on worst days? Describe your or your loved one's best days and worst days.
2. How have your or your loved one's symptoms changed over time? How has the ability to cope with the symptoms changed over time?
3. Are there specific activities that are important to you or your loved one that you or they cannot do at all or as fully as you or they would like because of asthma?
  - How does asthma affect your or your loved one's daily life? What are the challenges?
  - How does asthma affect life activities (school/work, learning abilities, self-sufficiency, living situation, activities, etc.)?
  - If you or your loved one could do one activity that you or your loved one currently is unable to, what would it be?
4. What do you fear the most as you or your loved one gets older? What worries you most about your or your loved one's condition?
  - What capabilities are you most concerned about you or your loved one potentially losing while growing older?
  - What frustrates you most about your or your loved one's condition?

## Session 2 Perspectives on Current and Future Approaches to Treatment

1. What are you currently doing to manage your or your loved one's asthma symptoms?
  - Which specific asthma symptoms do the treatments address?
  - How has this treatment regimen changed over time and why?
  - How satisfied are you with available treatments when it comes to the route of administration (for example, shots, pills, oral treatments, inhaled treatments)? For treatments that are mostly done at the doctor's office, would you prefer to have them available for administration at home?
  - What challenges do you or your loved one face when it comes to taking medicines as prescribed?
  - Are there any challenges differentiating between medicines (such as controller inhalers vs quick relief inhalers)?
2. How well do these treatments treat the most significant symptoms of asthma?
  - 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 your or your loved one's current treatments and how do they affect daily life? (Examples of downsides may include bothersome side effects, going to the hospital for treatment, etc.)
4. Short of a complete cure, what specific things would you look for in an ideal treatment for asthma? When considering a new treatment, what factors are important to you?

# Meeting Polling Questions

## Demographic questions

1. Are you?
  - a. An individual age 13-17 living with asthma
  - b. An individual age 18 or older who had asthma in childhood
  - c. The parent/caregiver of a child with asthma
  - d. Both an individual with asthma and a parent/caregiver
  
2. Where do you currently reside?
  - a. US Pacific time
  - b. US Mountain time
  - c. US Central time
  - d. US Eastern time
  - e. US Alaska time
  - f. US Hawaii time
  - g. Canada
  - h. Mexico/Central America
  - i. South America
  - j. Europe
  - k. Asia
  - l. Africa
  - m. Australia
  
3. The person with asthma (you/your child) identify as:
  - a. Female
  - b. Male
  - c. Non-binary
  - d. Prefer not to identify
  - e. Other
  
4. How old is the person with asthma currently?
  - a. 0-5 years of age
  - b. 6-12 years of age
  - c. 13-17 years of age
  - d. 18+ years of age
  
5. At what age did the person with asthma first have symptoms of asthma?
  - a. 0-5 years of age
  - b. 6-12 years of age
  - c. 13-17 years of age
  - d. 18+ years of age



6. To the best of your knowledge, what triggers your/your child's asthma? Select ALL that apply
- a. Physical activity/exercise
  - b. Pollen
  - c. Molds
  - d. Dust mites
  - e. Furry or feathery animals
  - f. Stress or strong emotions
  - g. Irritants in the air (e.g. smoke, pollution, fumes, etc.)
  - h. Increased eosinophils
  - i. Illnesses (e.g. colds, flu)
  - j. Weather (e.g. dry, cold air, thunderstorms)
  - k. Strong emotions
  - l. Medicines
  - m. Not sure

## Topic 1 – Living With Asthma: Symptoms and Daily Impact

1. Which of the following asthma-related health concerns do you have (for you/your child)? Select ALL that apply.
- a. Frequent coughing
  - b. Whistling or wheezing sound when breathing out
  - c. Chest tightness
  - d. Shortness of breath, trouble breathing
  - e. Waking up at night or trouble sleeping
  - f. Late recovery of bronchitis
  - g. Fatigue (tiredness)
  - h. Repeated episodes of bronchitis or pneumonia
  - i. Fatigue
  - j. Need to go to the emergency room
  - k. Mood changes, depression, or anxiety
  - l. Other
2. Select the TOP 3 biggest asthma-related health concerns that you have (for you/your child). Select UP to 3.
- a. Frequent coughing
  - b. Whistling or wheezing sound when breathing out
  - c. Chest tightness
  - d. Shortness of breath, trouble breathing
  - e. Waking up at night or trouble sleeping
  - f. Late recovery of bronchitis
  - g. Fatigue (tiredness)
  - h. Repeated episodes of bronchitis or pneumonia
  - i. Fatigue
  - j. Need to go to the emergency room
  - k. Mood changes, depression, or anxiety
  - l. Other

3. Which of the following activities are most impacted by asthma? Select TOP 3.
  - a. Public speaking
  - b. Sleeping over friend's house
  - c. Participating in social engagements or events
  - d. Participation in sports or recreational activities
  - e. Attending school
  - f. Interacting with family members
  - g. Going on vacation or traveling
  - h. Other
  
4. What worries you most about your/your child's asthma in the future? Select TOP 3.
  - a. The stress of not knowing how asthma will progress (change or get worse)
  - b. Fear of a severe asthma episode
  - c. Hospitalization
  - d. Dying from asthma
  - e. Chronic breathing problems
  - f. Severe coughing and difficulty breathing
  - g. Not having the energy to work and live as you want to
  - h. Not being able to participate in sports or recreational activities
  - i. Having to depend on medicines for the long term
  - j. Other

## Topic 2 – Perspective on Current and Future Approaches to Treatment

1. What medicines or medical treatments have you/your child used to treat or manage asthma? Select ALL that apply.
  - a. Daily control medicines—inhaled steroids (e.g. Flovent, Pulmicort, Asmanex, Alvesco)
  - b. Daily control medicines—leukotriene modifiers (e.g. Singulair, Accolate, Zflo)
  - c. Combination medicines (e.g. Symbicort, Breo Ellipta, Advair)
  - d. Theophylline (Theo-24)
  - e. Biologic agents (e.g. Cinqair, Nucala, Dupixent, Fasentra, Xolair)
  - f. Quick-relief inhalers (e.g. ProAir, Ventolin, Xopenex)
  - g. Oral and intravenous steroids (e.g. Prednisone, Methylprednisone)
  - h. Yearly flu shot
  - i. Allergy shots
  - j. Antihistamines and decongestants
  - k. Antidepressant or antianxiety medication
  - l. Other medications
  - m. I have not/my child has not used medications or medical treatments recently
  
2. How well does the current treatment regimen help control asthma overall?
  - a. Not at all
  - b. Very little
  - c. Somewhat
  - d. To a great extent
  - e. Not applicable/not using treatments

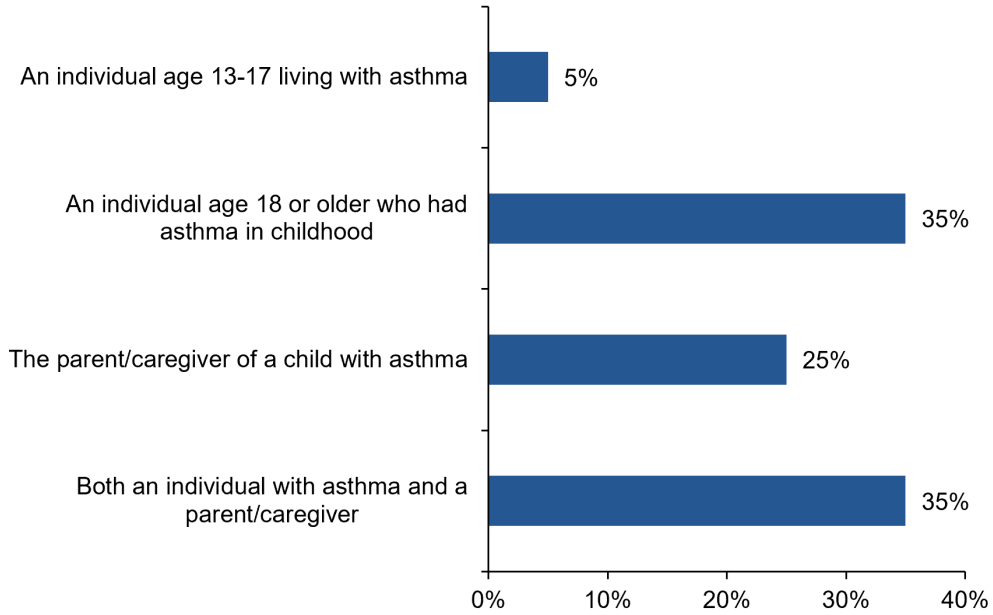
3. What are the biggest drawbacks of your current approach to managing asthma? Select UP to 3.
  - a. Not very effective
  - b. High cost or co-pay, not covered by insurance
  - c. Limited availability or accessibility
  - d. Side effects
  - e. Requires too much effort and/or time commitment
  - f. Not convenient
  - g. Not applicable as I am not/my child is not using any treatments
  
4. Which of the following aspects of your/your child's asthma would you rank as most important for a possible new drug or device treatment? Select UP to 3.
  - a. Improve breathing
  - b. Help with wheezing and coughing
  - c. Allow for increased level of activity
  - d. Help with symptoms of allergies
  - e. Reduce fatigue (tiredness)
  - f. Help with mood changes, depression, or anxiety
  - g. Slow or stop progression (worsening) of asthma
  - h. Other

# Meeting Polling Answers

## Demographic questions

1

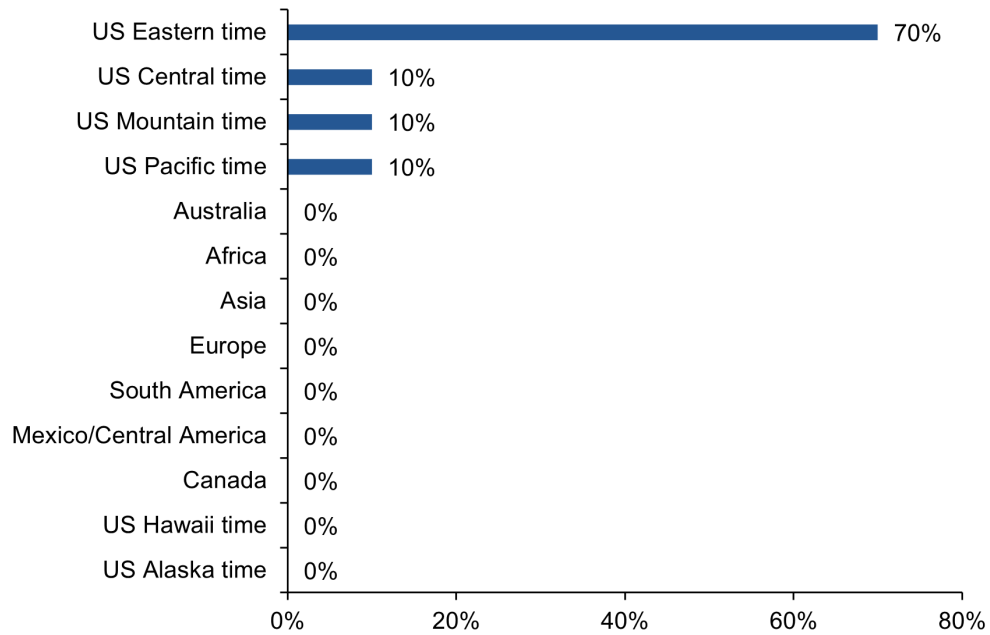
### Are you?



Sample size = 20

2

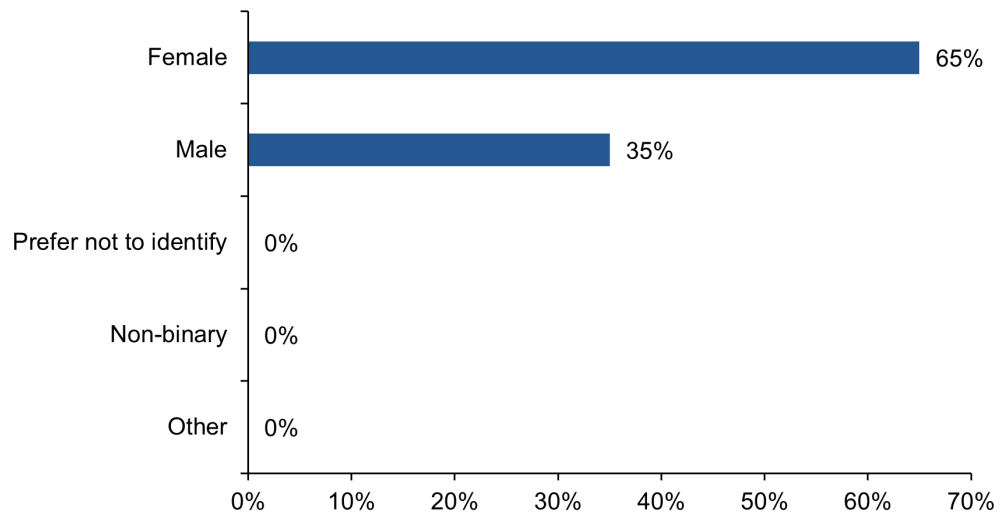
### Where do you currently reside?



Sample size = 21

3

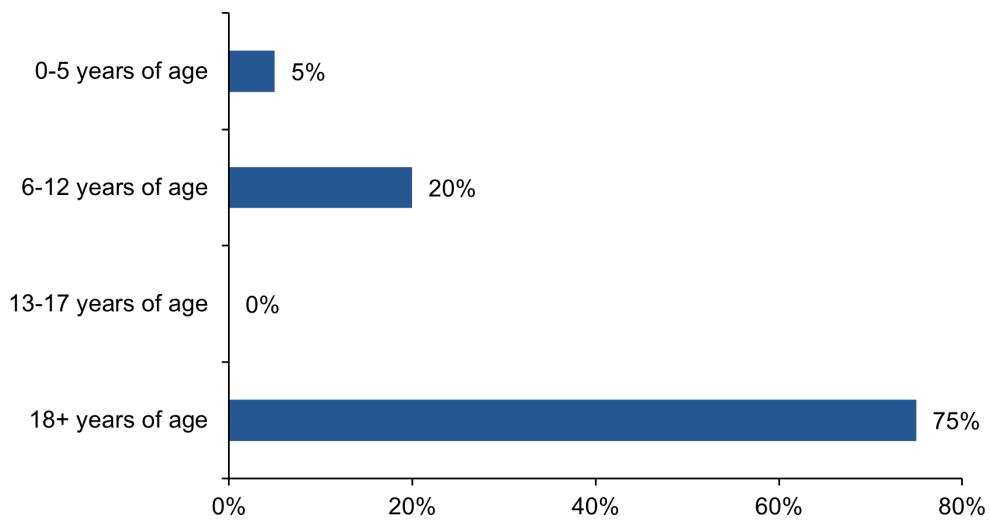
### The person with asthma (you/your child) identify as:



Sample size = 17

4

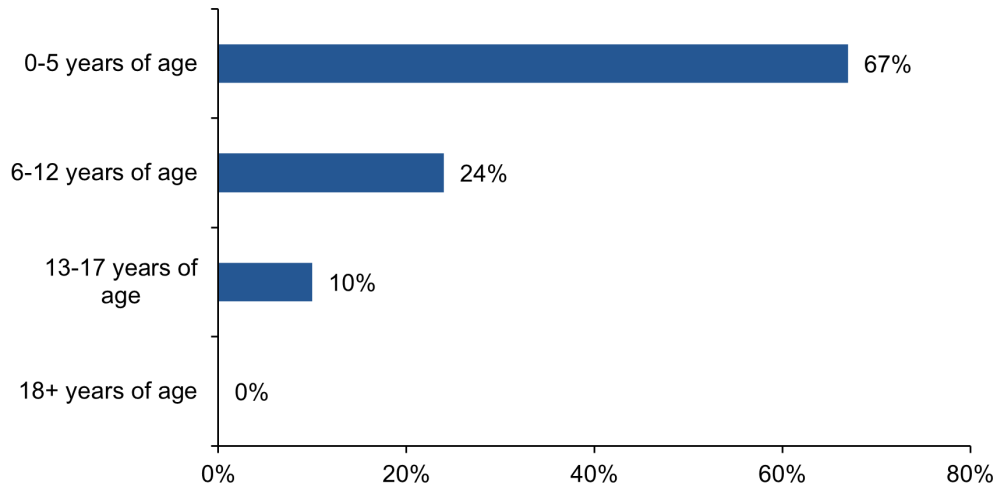
### How old is the person with asthma currently?



Sample size = 20

5

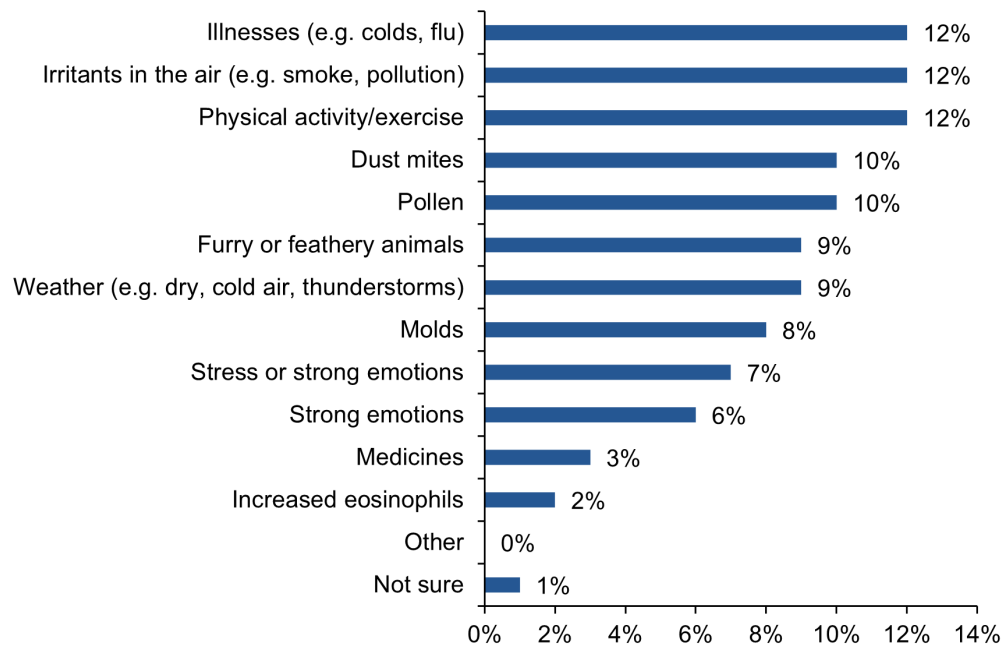
### At what age did the person with asthma first have symptoms of asthma?



Sample size = 21

6

### To the best of your knowledge, what triggers your/your child's asthma? Select ALL that apply

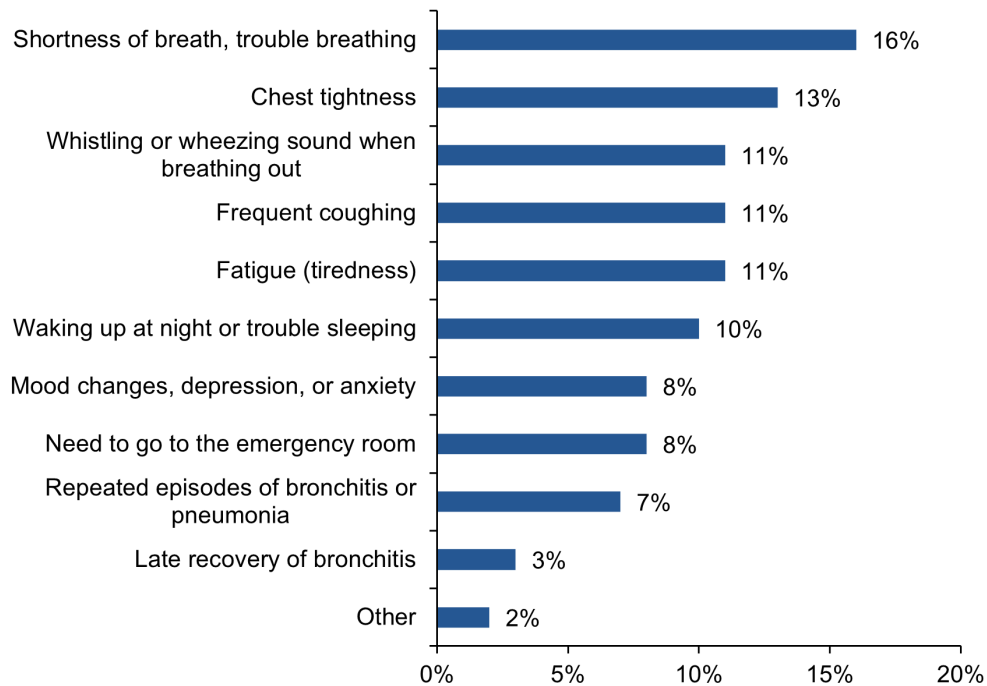


Sample size = 25

## Topic 1 - Living With Asthma: Symptoms and Daily Impact

1

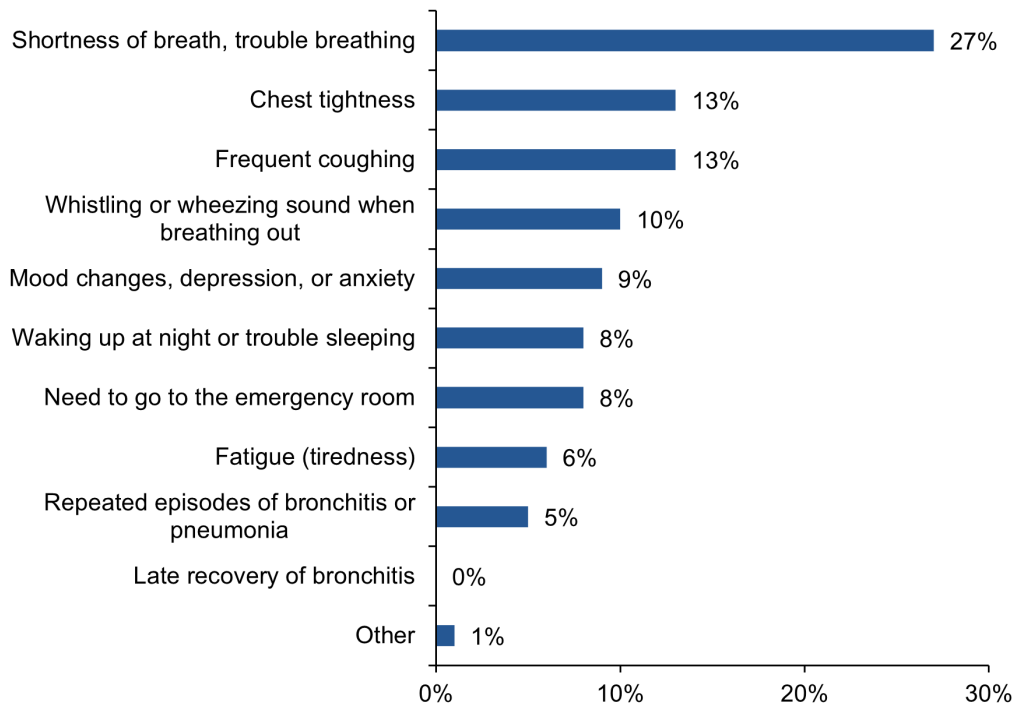
Which of the following asthma-related health concerns do you have (for you/your child)?  
Select ALL that apply



Sample size = 20

2

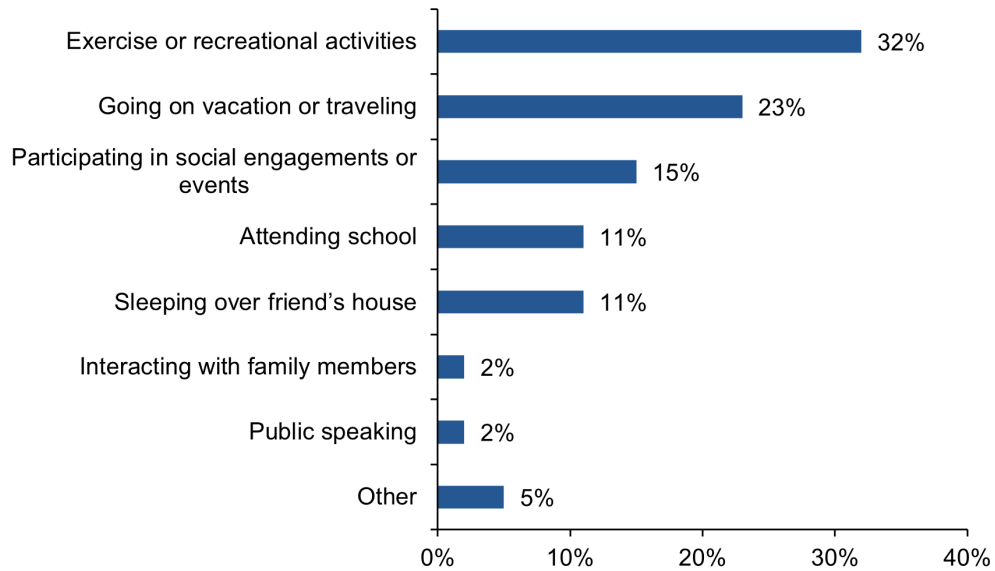
Select the TOP 3 biggest asthma-related health concerns that you have (for you/your child).



Sample size = 26

3

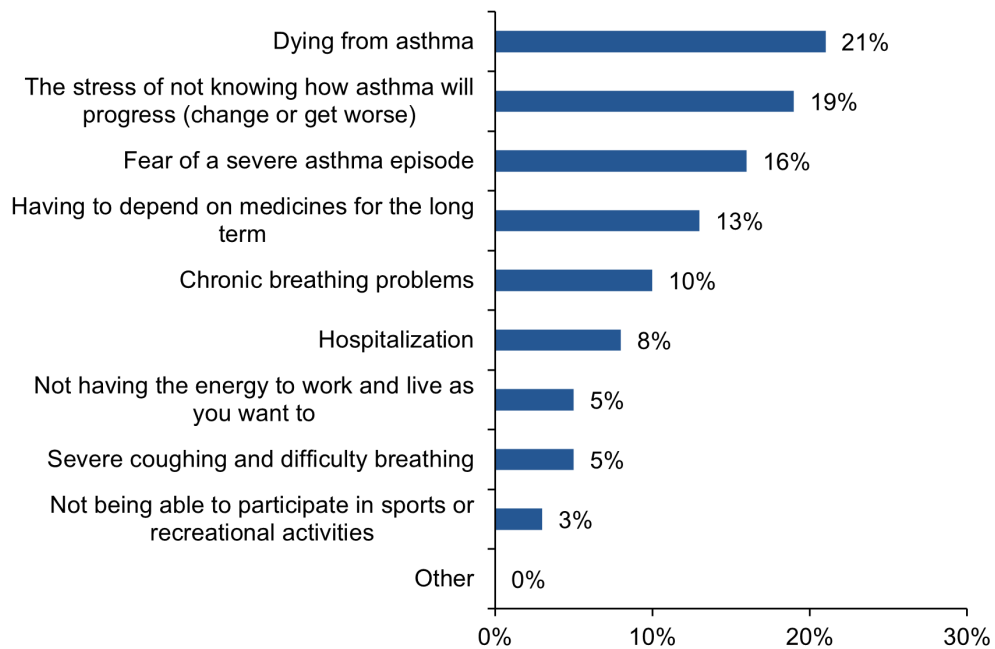
### Which of the following activities are most impacted by asthma? Select TOP 3



Sample size = 23

4

### What worries you most about your/your child's asthma in the future? Select TOP 3

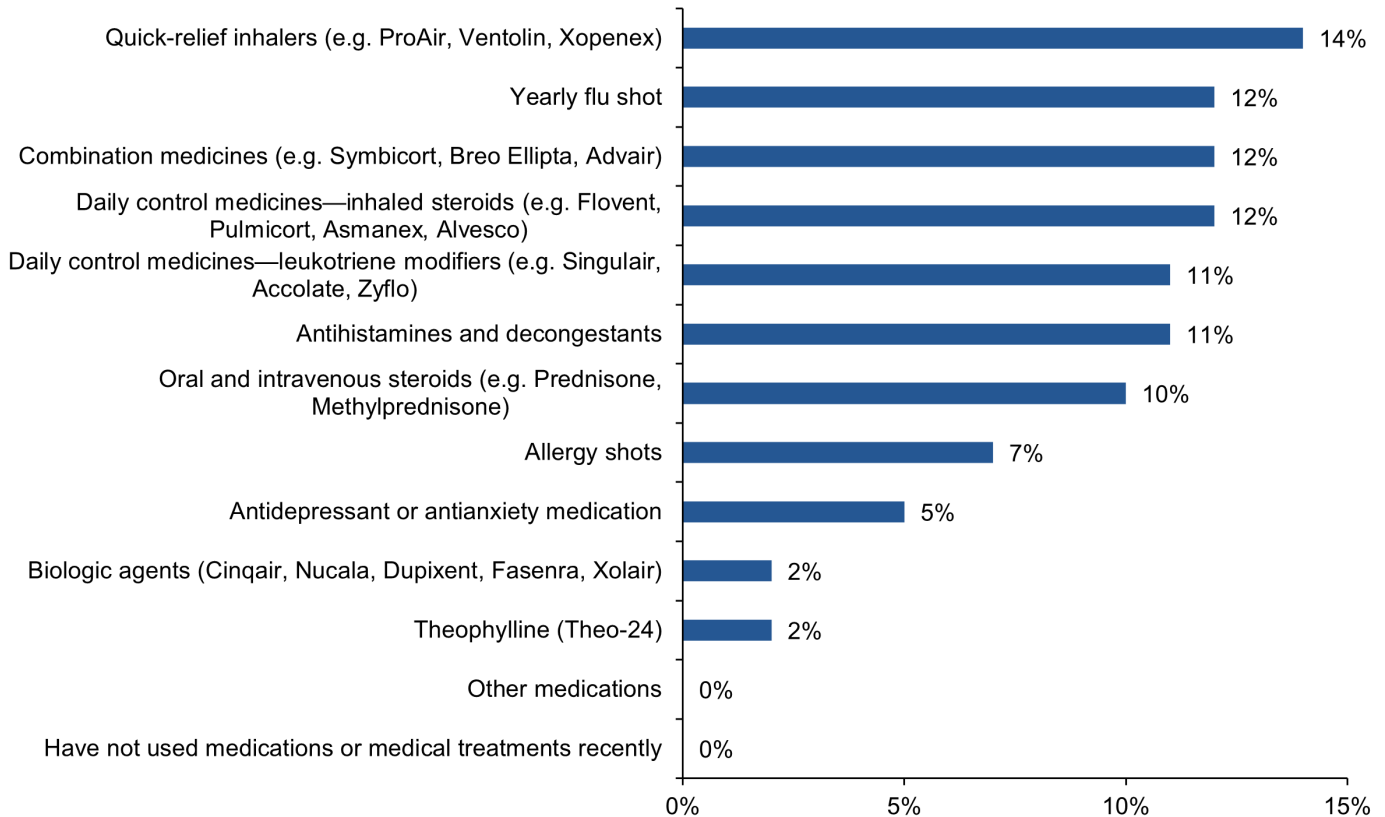


Sample size = 21



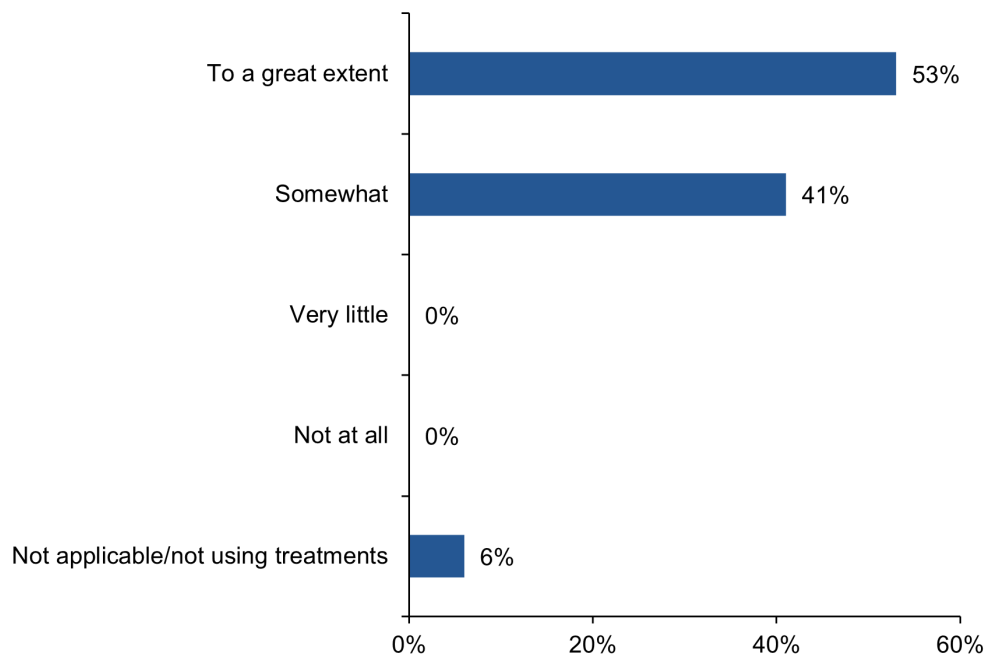
## Topic 2 – Perspective on Current and Future Approaches to Treatment

### 1 What medicines or medical treatments have you/your child used to treat or manage asthma? Select ALL that apply



Sample size = 16

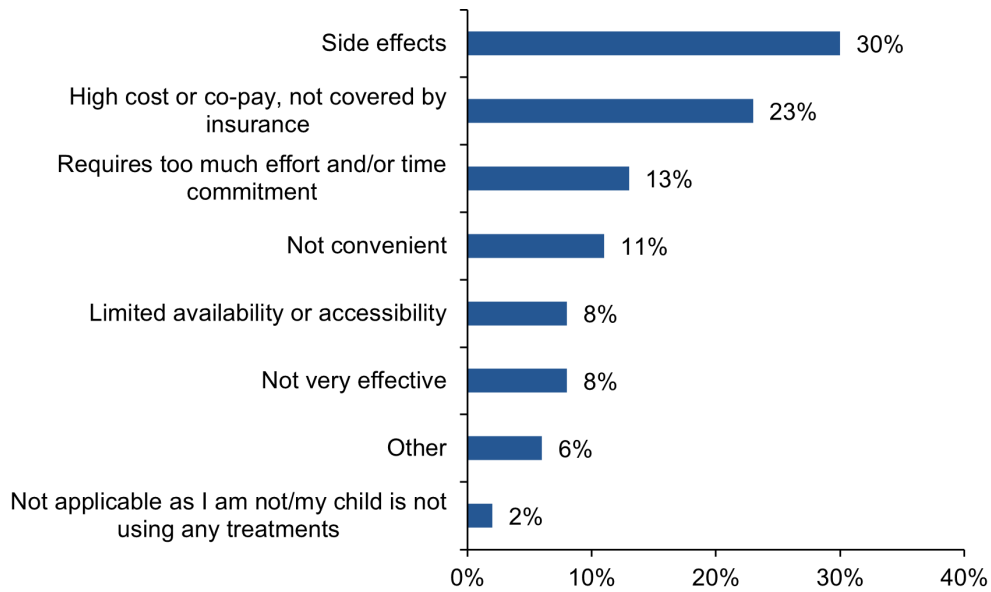
### 2 How well does the current treatment regimen help control asthma overall?



Sample size = 17

3

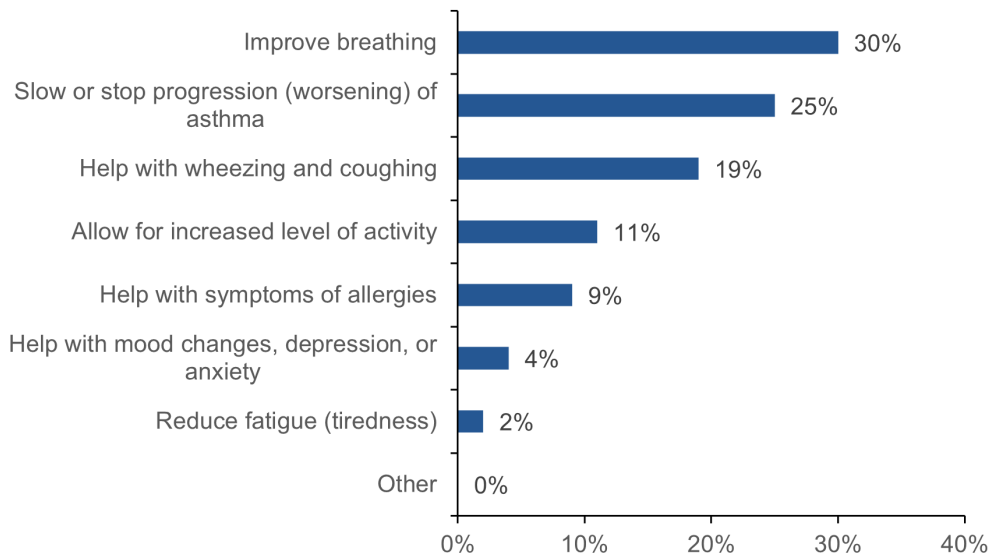
### What are the biggest drawbacks of your current approach to managing asthma? Select UP to 3



Sample size = 22

4

### Which of the following aspects of your/your child's asthma would you rank as most important for a possible new drug or device treatment? Select UP to 3



Sample size = 19

# Results of the Little Airways, Big Voices Survey

## Introduction

In preparation for the Little Airways, Big Voices meeting, the host organizations developed and fielded an online survey to capture additional experiences from patients and caregivers. Similar to the structure of the meeting, the survey asked respondents about the most significant impacts of asthma, satisfaction with current treatment(s), and ideal treatment outcomes. Results from the survey helped guide the development of the meeting and supplement testimonies captured through the meeting and written comments.

## Objectives and Methodology

The survey was designed with the overall objectives of the Little Airways, Big Voices meeting in mind. The primary objectives of the patient and caregiver survey were to:

1. **Inform the meeting.** Organizers used early survey responses to develop the meeting discussion guide and polling questions, and to recruit potential meeting panelists and discussion starters.
2. **Capture the experiences of a broader population of pediatric asthma patients and caregivers.** The survey offered an additional way for individuals to participate in the Little Airways, Big Voices initiative, other than participating in the meeting or submitting written comments. The survey offered the option for respondents to remain anonymous, and did not require a significant time commitment, taking an average of 11 minutes to complete.
3. **Provide quantitative insights that further speak to patient and caregiver experiences.** In addition to the powerful testimonies shared at the virtual meeting and through written comments, the survey allowed the project team to quantitatively validate some of the biggest impacts, concerns, and needs of patients and caregivers.

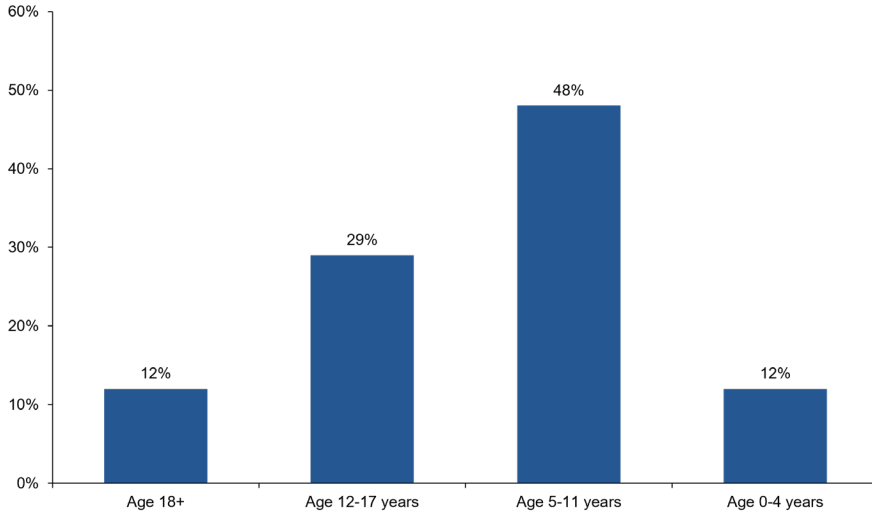
The survey ran from August 2, 2021 to January 17, 2022, and received 248 complete responses. Host organizations used dedicated emails, newsletters, community posts, and social media to recruit participants.

At the beginning of the survey, participants were given the option to provide their preferred name for attribution if open-ended responses were to be included in the Voice of the Patient report. Participants also had the option to attribute their responses anonymously. Asthma patients 13-17 years old and caregivers 18 years or older were permitted to respond to the survey. Caregivers were allowed to take the survey even if their child was over the age of 18. In these instances, caregivers were asked to respond based on their experiences prior to the child turning 18. There were no geographic restrictions to take the survey. The survey was housed by Dynata through an existing contract with the Asthma and Allergy Foundation of America. Respondents who completed the full survey were offered the option to enter a drawing to win one of ten \$50 Amazon gift cards. The survey instrument is provided in its entirety, beginning on page 78.

## Respondent Demographics

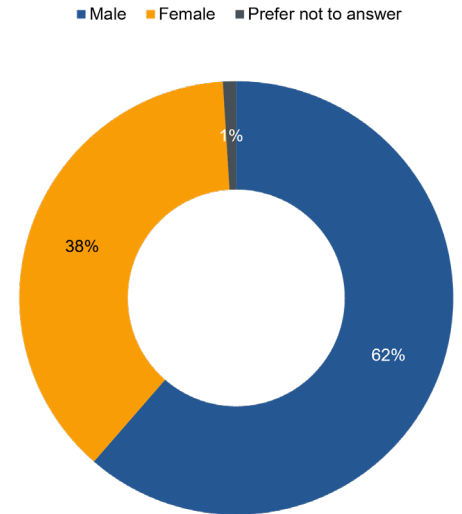
Nearly all (98%) survey responses came from parents or guardians of at least one child with asthma. Among caregivers, one in five (21%) also report having asthma themselves. The distribution of current age and biological sex of the child with asthma is shown below. The distribution for biological sex is similar to that of national prevalence estimates for pediatric asthma. The majority of participants reported their child's current age as under 18, with nearly half (48%) being 5-11 years old.

How old is the child who was diagnosed with asthma?



Sample Size = 243

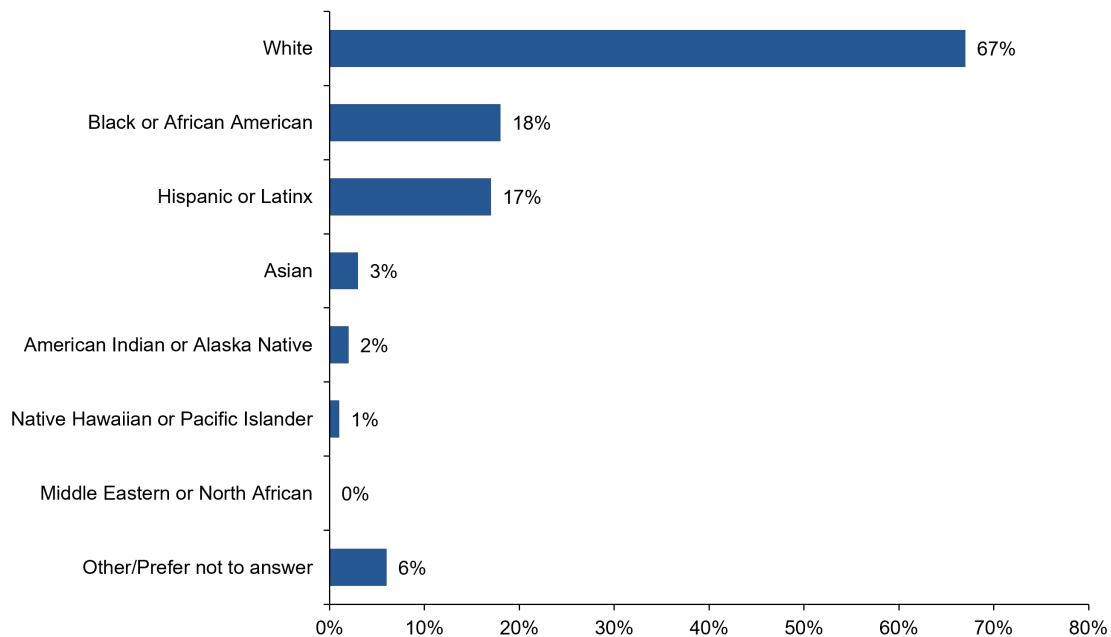
What is your child's biological sex?



Sample size = 248

Respondents were well distributed across the U.S., with the largest group of respondents living in the south (34%). Five percent of respondents came from outside the U.S. Over two-thirds (67%) of respondents indicated their child's race/ethnicity as white; nearly one in five indicated their child's race/ethnicity as Black (18%) or Hispanic (17%).

What is your child's race/ethnicity?

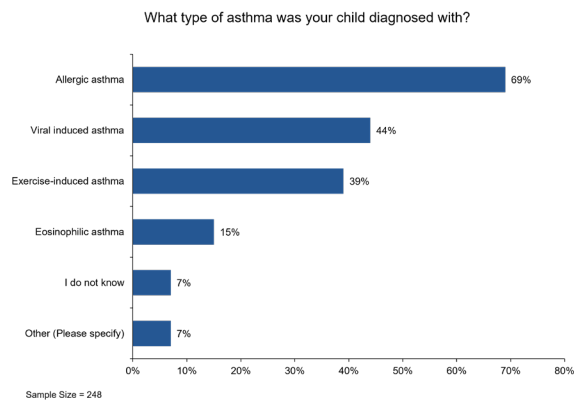
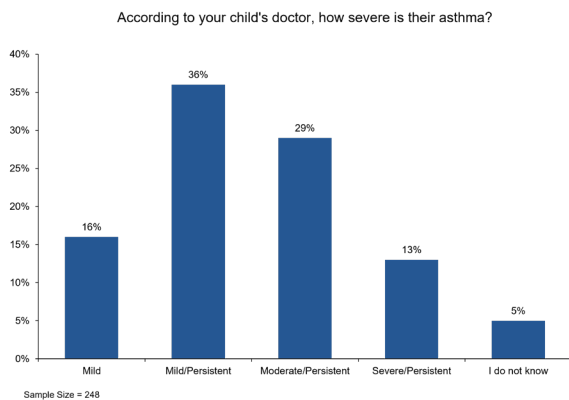


Sample Size = 248

## Symptom Burden and Impacts

### Diagnosis

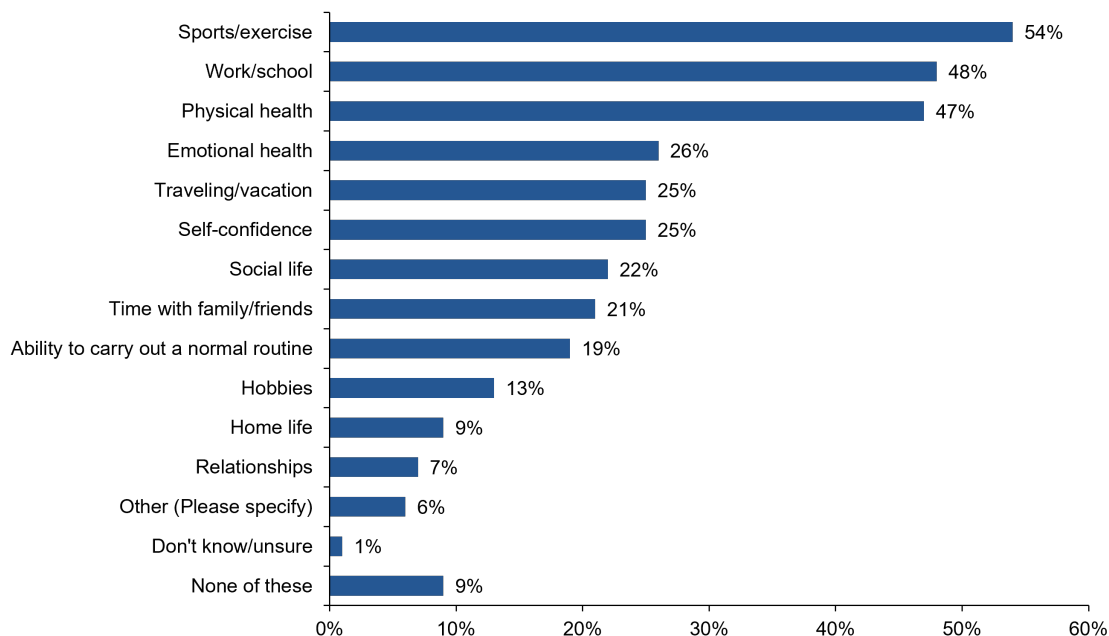
Over half (54%) of respondents indicated their child was diagnosed with asthma more than five years ago, with only 4% indicating their child was diagnosed less than a year ago. Children were most commonly diagnosed with allergic asthma (69%), followed by viral-induced asthma (44%) and exercise-induced asthma (39%). In its present state, a majority of respondents indicated their child has some form of persistent asthma, with the most common being mild/persistent.



### Daily Impacts of Asthma

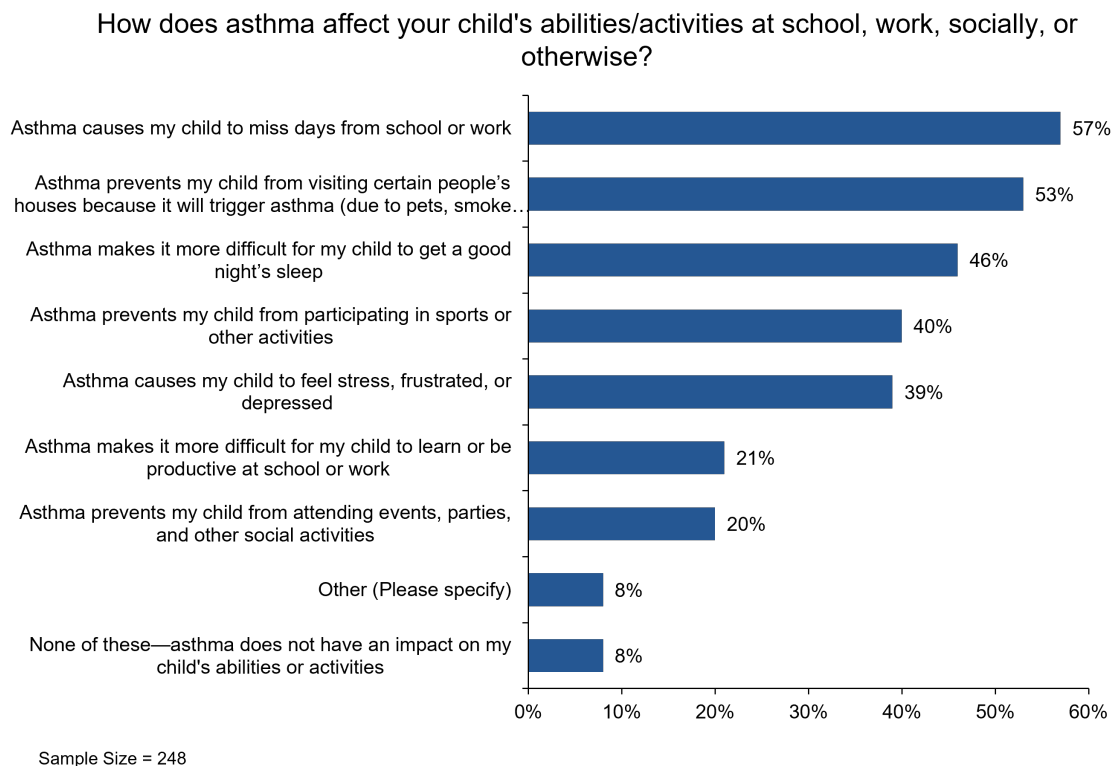
When asked to select the five aspects of the child's life that are most negatively affected by asthma, the most common response was sports and exercise (54%), followed closely by work and school (48%) and physical health (47%). Though the most common responses tended to focus on physical health, respondents also acknowledged the socioemotional consequences of asthma. One in four respondents mentioned emotional health (26%), self-confidence (25%), and traveling or vacations (25%) as negatively impacted by asthma, and one in five said the same about social life (22%) and time with family and friends (21%).

Which of the following aspects of your child's life are most negatively affected by asthma?



Sample Size = 248

Respondents were also asked to describe the impact of asthma on specific activities. Over half of respondents said asthma causes their child to miss days from school or work (57%) or that it prevents their child from visiting certain people’s houses due to the presence of asthma triggers (53%). Respondents also commonly indicated asthma makes it more difficult for their child to get a good night’s sleep (46%), prevents their child from participating in sports or other activities (40%), and causes their child to feel stressed, frustrated, or depressed (39%).



When asked about their child’s current asthma control, three-quarters (75%) of respondents indicated their child’s asthma was well controlled; 17% indicated it was not well controlled, 3% indicated very poorly controlled, and 6% did not know. When asked what it means to caregivers for their child’s asthma to be in control, the most common responses were that their child does not miss days of work or school due to asthma (74%) and that their child does not end up in the hospital for an asthma attack (72%). About three in five respondents also defined control as their child being as active as they want to be (59%) and their child sleeping through the night (58%).

Following are a selection of open text comments about the daily impacts of asthma:

“Every time my child gets a cold or virus, his asthma gets exponentially worse and he eventually develops bronchitis or pneumonia.”

**Julie**, caregiver to a 0-4 year old child with asthma

“Asthma makes my child be dependent on others (school nurse, teacher, etc.) at a point in his life where his peers are becoming more independent.”

**Anonymous**, caregiver to a 12-17 year old child with asthma

“My son loves sports and playing outside but is often unable to do these things because it is hard to get through without using his inhaler. He gets depressed when his asthma flares up and he is unable to attend school, field trips, school activities, sports, etc.”

**Amanda**, caregiver to a 5-11 year old child with asthma

“His asthma is triggered by environmental and dog allergies. The most impact right now is he gets uncomfortable when we visit family [with] pets because he knows it will trigger his asthma and cause him to have to use his albuterol.”

**Anonymous**, caregiver to a 0-4 year old child with asthma

“She now does online schooling, which limits social outings since each time she goes out she seems to get sick and have an asthma exacerbation.”

**Heather**, caregiver to a 12-17 year old child with asthma

“Attending summer camps and clinics have been a significant challenge. It is not because his asthma and allergies are not well managed, but we have found many programs are not capable/willing to provide simple extra supports he may need (proper medical oversight, supervision of inhaler, etc.).”

**Anonymous**, caregiver to a 12-17 year old child with asthma

## Treating and Managing Pediatric Asthma

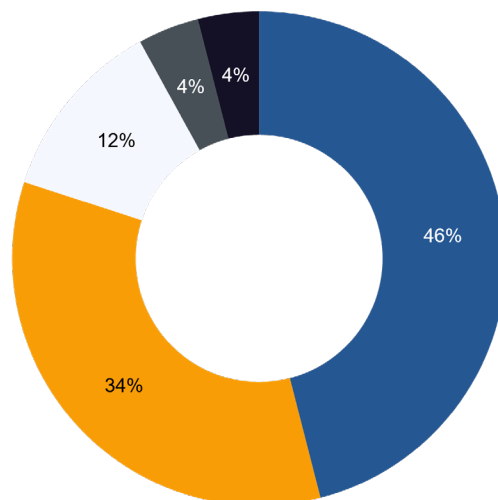
### Satisfaction with Current Treatments

Survey respondents answered several questions about satisfaction with their child’s current treatments and unmet needs that future treatments can provide. Four in five respondents indicated they were somewhat (34%) or very (46%) satisfied that their child’s current asthma medicines are helping to manage their asthma.

When asked about the positive and negative aspects of their child’s current asthma treatments, seven in ten (70%) respondents indicated their child’s asthma medicines effectively reduce asthma symptoms. A majority of respondents also indicated positive aspects such as the ability for the child to take it at home (63%), ease of use (61%), and the ability to have it on hand for whenever it is needed (60%). Nevertheless, one in four (25%) respondents indicated their child’s current asthma treatments cause negative side effects. The most common negative side effects reported were shakiness or jitters, mood or behavioral changes, heart palpitations, stunted growth, and weight gain. Additionally, one in ten respondents indicated their child’s current asthma medications do not reduce asthma symptoms (10%).

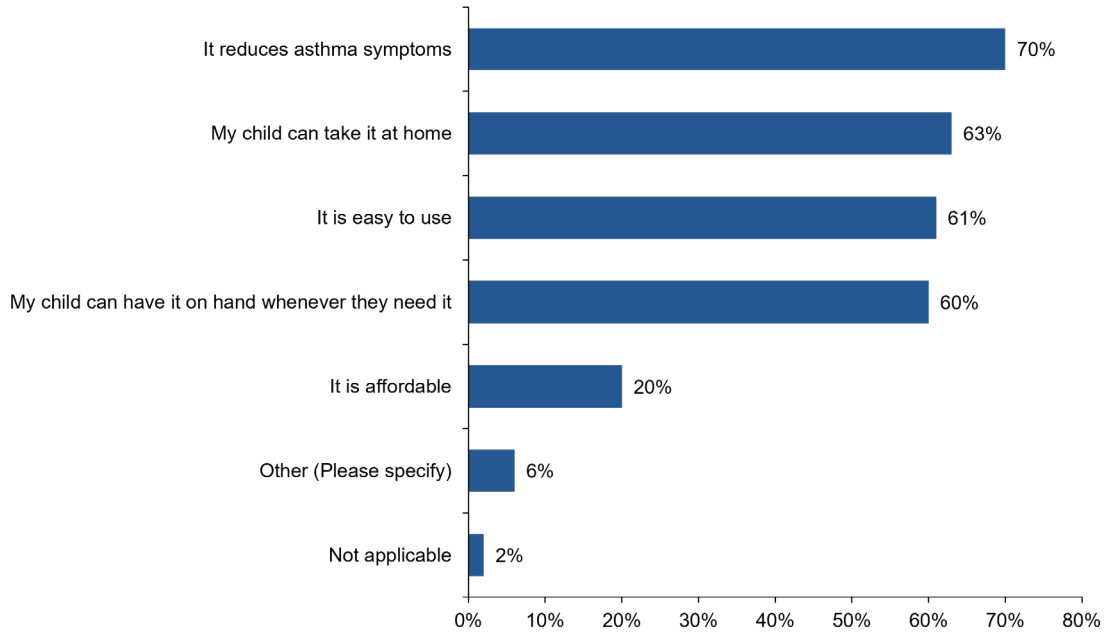
How satisfied are you that your child's current asthma medicines are helping to manage their asthma?

■ Very satisfied ■ Somewhat satisfied ■ Neutral ■ Somewhat unsatisfied ■ Very unsatisfied



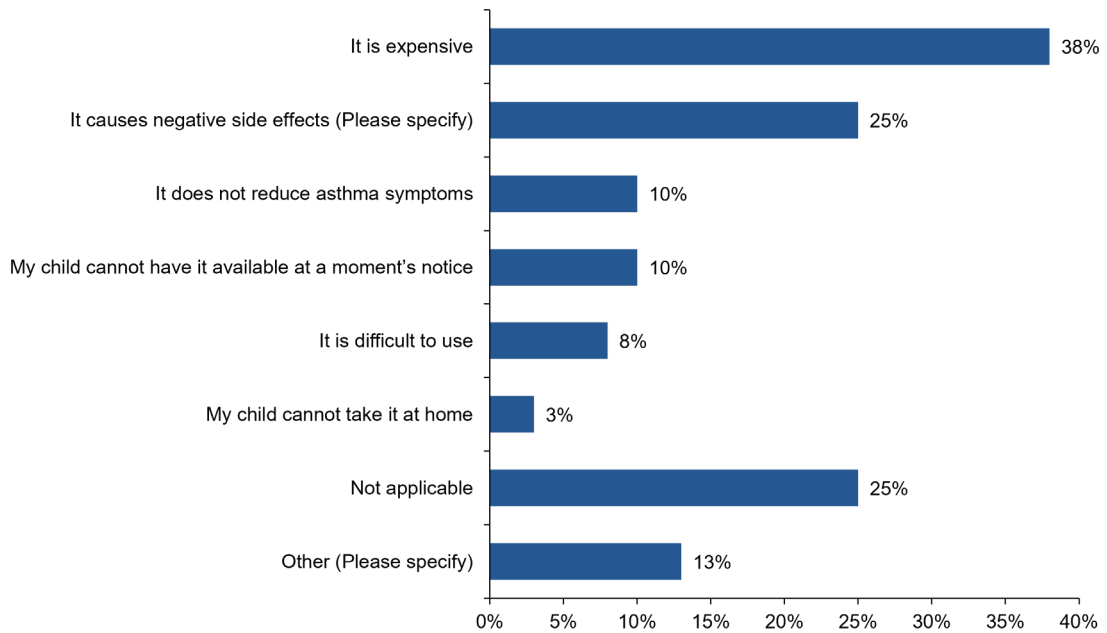
Sample Size = 248

Regarding your child's current asthma medication(s), what do you like about it?



Sample Size = 248

Regarding your child's current asthma medication(s), what don't you like about it?



Sample Size = 248



## Impact of Medication on Daily Life

Even when medication successfully reduces asthma symptoms, the medication, or the process of taking the medication, can still impact daily life in ways that are less than ideal. Some survey respondents mentioned that their child's asthma treatment has brought a change in routine or takes up a significant portion of the day. Others commented about the burden of having to carry medicine at all times, and that side effects impact physical or emotional wellbeing.

Following are a selection of open text comments about the daily impacts of current asthma medication:

"When she has an attack she has to make sure she has her nebulizer with her. She has to take it every few hours. The nebulizer is big and difficult to use on the go. We have gotten a hook up for the car to make it easier, but it does force us to be by an outlet"

**Anonymous**, caregiver to a 0-4 year old child with asthma

"She does not feel well after taking it. Breathing improves but then she must contend with a headache and/or stomach issues"

**Kathie**, caregiver to a 12-17 year old child with asthma

"He ends his night sooner than his siblings to have his nebulizer. For most this wouldn't be an issue, but for a 6 year old it's frustrating."

**Juli**, caregiver to a 5-11 year old child with asthma

"One difficult aspect of having asthma is that while my son can easily participate in activities like sports and camps, it is an added stressor to make sure staff is knowledgeable and prepared to care for him if necessary."

**Anonymous**, caregiver to a 5-11 year old child with asthma

"It takes time to learn to use the inhaler properly and needs to be monitored by an adult. It is just time consuming and we are thrilled if we don't have to take daily meds."

**Vanessa**, caregiver to a 5-11 year old child with asthma

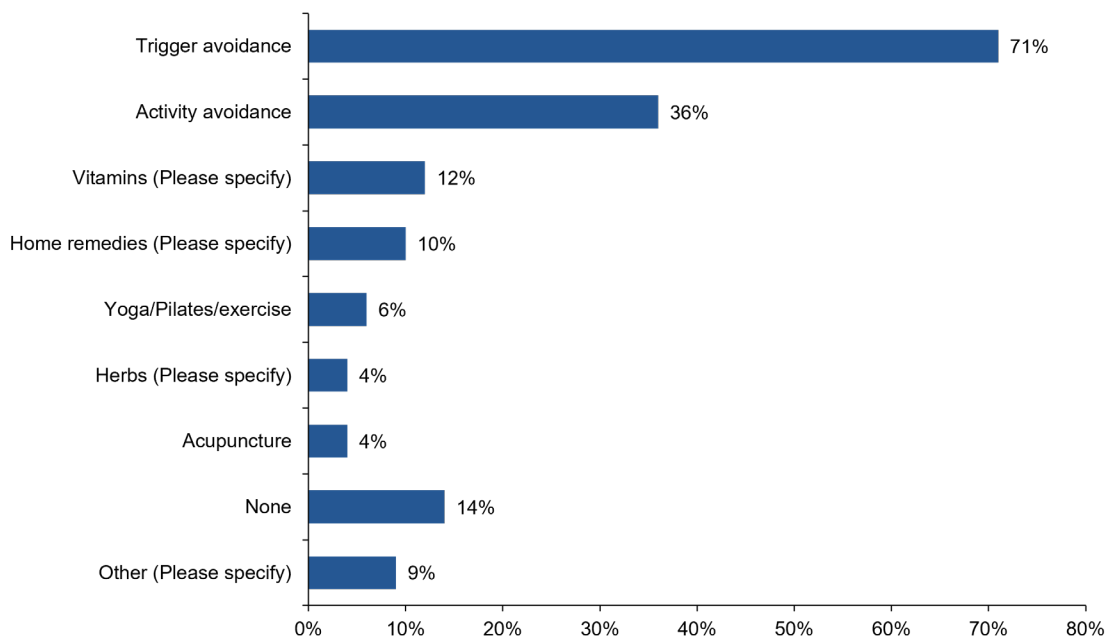
"He has ADD and the simple routine of taking the maintenance inhaler each night/morning before brushing his teeth (even with it being left out on the counter as a visual reminder) so it's really hard to keep it administered as it should be."

**Keri**, caregiver to a 5-11 year old child with asthma

## Alternative Treatments

Some families may seek out additional treatments to complement their medication routine. A majority (71%) of respondents indicated they avoid triggers as a form of treatment. Over one-third (36%) of respondents also indicated they avoid certain activities. Though less common, about one in eight (12%) respondents indicated their child takes vitamins, primarily Vitamin D, Vitamin C, and multivitamins, to help manage asthma. One in ten (10%) also indicated home remedies were used. Home remedies mentioned include essential oils, saline solutions, steam or humidity, and air purifiers. Only 14% of respondents indicated they did not use an alternative form of treatment in conjunction with their prescribed asthma medications.

Besides medication, what other treatments/therapies do you use to treat your child's asthma?



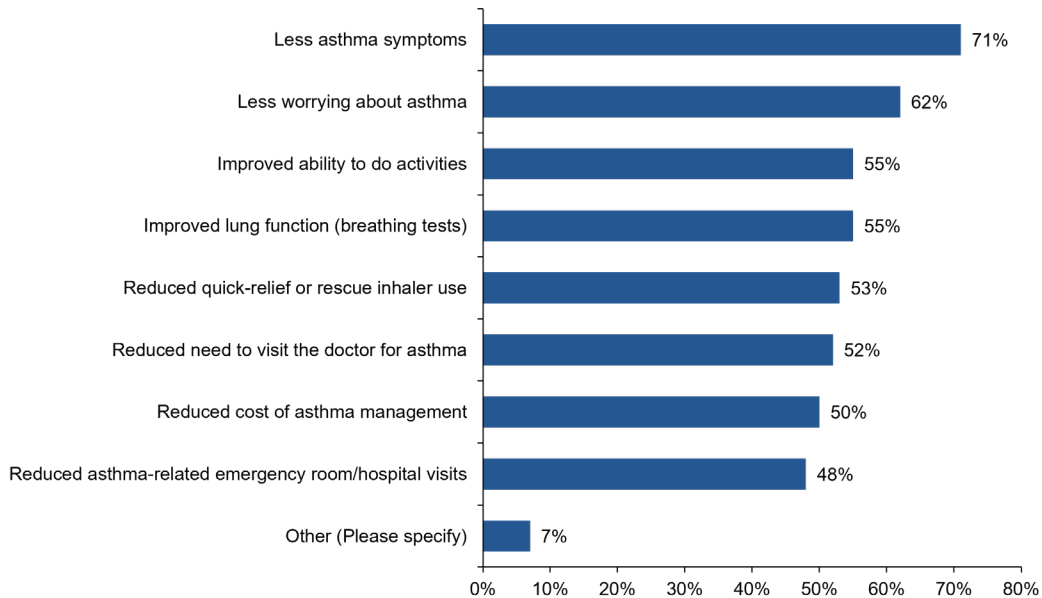
Sample Size = 248

## Looking Ahead

### Ideal Treatment Outcomes

Aside from a complete cure, respondents said the most meaningful improvement a treatment could provide is fewer asthma symptoms (71%), followed by less worrying about asthma (62%). Over half of respondents also indicated that an ideal treatment would result in improved lung function (55%), improved ability to do activities (55%), reduced quick-relief or rescue inhaler use (53%), and reduced need to visit the doctor for asthma (52%).

Aside from a complete cure, what meaningful improvement would an ideal treatment for asthma in childhood provide?

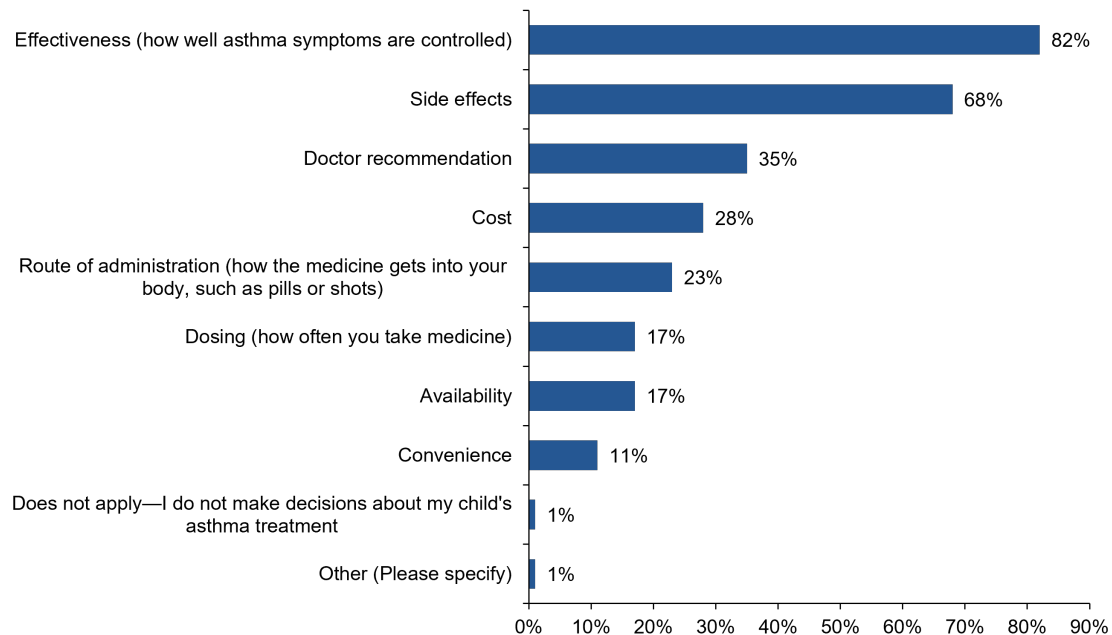


Sample Size = 248

## Considerations for New Treatment

When deciding on a new course of treatment for their child, four in five (82%) respondents indicated that the effectiveness of a treatment was one of the most important factors to consider. Over two-thirds (68%) of respondents also indicated side effects as important to consider. Though still important, factors such as doctor recommendation (35%), cost (28%), route of administration (23%), availability (17%), dosing (17%), and convenience (11%) were less of a priority.

What factors or information are most important for you to consider when deciding on a course of treatment for your child?



Sample Size = 248

Respondents went further into detail when describing how they weigh the pros and cons of treatment. In addition to effectiveness, side effects, and doctor's recommendations, respondents commonly mentioned improving quality of life and the goal of using less medicine overall in open text comments. Following are a selection of open text comments about weighing the pros and cons of treatment:

"We weigh the pros and cons of treatments by looking at the long-term benefits. Keeping our child healthy, going to school, enjoying her social life and growing (possibly outgrowing asthma) is the goal."  
**Anonymous**, caregiver to a 12-17 year old child with asthma

"We prioritize our child's health, but also want her to be on the least amount of medicine possible, with the fewest side effects."  
**Anonymous**, caregiver to a 12-17 year old child with asthma

"We did our best to select a knowledgeable specialist doctor and are regarding him as the expert and are following his recommendations. Have discussed our hopes of moving to a less time-consuming treatment and he is taking that into consideration."  
**Anonymous**, caregiver to a 0-4 year old child with asthma

“Side effects are a huge part of the medication decisions we make. I don’t want my child suffering from side effects that are worse than her actual asthma.”

**Johanna**, caregiver to a 5-11 year old child with asthma

“I read through everything and if it has significant life-altering side effects we think about it and talk to our doctor about the risk vs benefits.”

**Anonymous**, caregiver to a 12-17 year old child with asthma

“I talk to him about his feelings and we go over the full scope of treatments. He is the one who has to live with the decisions of care and treatment. I listen for his feedback if there are side effects or discomfort to gauge if he is to complete treatment and or work for a better choice.”

**Charles**, caregiver to a 5-11 year old child with asthma

### **Continued Analysis of Survey Data**

Little Airways, Big Voices organizers will continue exploring the data from the patient insights survey. Thank you to the 248 individuals who shared their insights and experiences through the Little Airways, Big Voices survey.

## Survey Instrument

### Little Airways Big Voices Survey to Inform Patient-Focused Drug Development for Asthma in Childhood

To bring the voice of families impacted by pediatric asthma to the forefront of drug development and research, we invite patients and families to share their experiences with us!

The Allergy & Asthma Network, the American Lung Association, the American Partnership for Eosinophilic Disorders, and the Asthma and Allergy Foundation of America are hosting a Patient-Focused Drug Development meeting on September 20, 2021 to gather and share patient insights to inform new treatment strategies and to improve health outcomes.

We invite you to share your perspectives for us to include in this important initiative! To thank you for your time, you will have the opportunity to enter for a chance to win one of ten \$50 gift cards if you complete the entire questionnaire.

By completing and submitting this questionnaire, you consent to the inclusion of portions of your answers in our Voice of the Patient Report that will be created after we host the September 20, 2021 meeting. You may choose how to attribute your answers (e.g., full name, first name/last initial, first name only, anonymous).

1. If we include portions of your answers in our Voice of the Patient Report, how do you wish to be identified? (e.g., full name, first name/last initial, first name only, anonymous)
2. What is your relationship to asthma?  
Please select all that apply.
  - a. I am 18+ years old and have asthma
  - b. I am 13-17 years old and have asthma
  - c. I am the parent or guardian of at least one child with asthma
  - d. I have a partner or spouse with asthma
  - e. I have no relationship to asthma
3. If caregiver: How old is the child who was diagnosed with asthma?  
If you have more than one child with asthma under the age of 18, please complete the rest of this survey on behalf of the child with the most severe asthma symptoms.
  - a. Age 18+
  - b. Age 12-17 years
  - c. Age 5-11 years
  - d. Age 0-4 years
4. When was the diagnosis made by a health care provider?
  - a. Less than a year ago
  - b. 1 to 3 years ago
  - c. 4 to 5 years ago
  - d. More than 5 years ago

5. According to [your/their] doctor, how severe is [your/your child's] asthma?
- Mild
  - Mild/Persistent
  - Moderate/Persistent
  - Severe/Persistent
  - I do not know
6. What type of asthma [were you/was your child] diagnosed with?  
Please select all that apply.
- Allergic asthma
  - Eosinophilic asthma (a type of asthma characterized by high levels of white blood cells that cause inflammation and swelling in the airways)
  - Exercise-induced asthma
  - Viral induced asthma
  - Other (Please specify): \_\_\_\_\_
  - I do not know
7. Which of the following aspects of [your/your child's] life are most negatively affected by asthma?  
Please select the top five.
- Physical health
  - Emotional health
  - Self-confidence
  - Ability to carry out a normal routine
  - Home life
  - Social life
  - Relationships
  - Traveling/vacation
  - Time with family/friends
  - Work/school
  - Hobbies
  - Sports/exercise
  - Other (Please specify): \_\_\_\_\_
  - None of these—asthma does not have an impact on [my/their] daily life
  - Don't know/unsure
8. How does asthma affect [your/your child's] abilities/activities at school, work, socially, or otherwise?  
Please select all that apply.
- Asthma prevents [me/my child] from participating in sports or other activities
  - Asthma prevents [me/my child] from attending events, parties, and other social activities
  - Asthma prevents [me/my child] from visiting certain people's houses because it will trigger asthma (due to pets, smoke exposure, etc.)
  - Asthma causes [me/my child] to miss days from school or work
  - Asthma makes it more difficult for [me/my child] to learn or be productive at school or work
  - Asthma makes it more difficult for [me/my child] to get a good night's sleep
  - Asthma causes [me/my child] to feel stress, frustrated, or depressed
  - Other (Please specify): \_\_\_\_\_
  - None of these – asthma does not have an impact on [my/their] abilities or activities

9. Are there specific activities that are important to [you/your child], but [you/they] cannot do them at all, or as fully, because of asthma?
  
10. According to [your/their] doctor, how well is [your/your child's] asthma currently controlled?
  - a. Well controlled
  - b. Not well controlled
  - c. Very poorly controlled
  - d. I do not know
  
11. If caregiver: What does it mean to you for your child's asthma to be "well-controlled"? Please choose all of the options below that define "well-controlled" asthma to you; this does not mean that the item must currently be true.
  - a. My child does not end up in the hospital for an asthma attack
  - b. My child does not miss days of school/work due to asthma
  - c. I do not miss days of school/work to care for my child
  - d. My child does not use a quick-relief or rescue inhaler
  - e. My child does not use a controller medicine unless they have symptoms
  - f. I do not miss out on time with my child
  - g. I do not miss out on activities to care for my child
  - h. My child can be as active as they want to be
  - i. My child has normal lung function (breathing tests)
  - j. My child's social life is not impacted
  - k. My child does not have any symptoms
  - l. Other people do not notice that my child has asthma
  - m. My child can sleep through the night
  - n. I can sleep through the night
  - o. My child only goes to the doctor when they are sick
  - p. My child does not worry about their asthma
  - q. I do not worry about my child's asthma
  - r. My child is not anxious or depressed
  - s. Asthma is not a burden for my child
  - t. My child's asthma is not a burden for me
  - u. Other (Please specify): \_\_\_\_\_



12. If patient: What does it mean to you for your asthma to be “well-controlled”?  
Please choose all of the options below that define “well-controlled” asthma to you; this does not mean that the item must currently be true.
- a. I do not end up in the hospital for an asthma attack
  - b. I do not miss days of school/work due to asthma
  - c. I do not use a quick-relief or rescue inhaler
  - d. I do not use a controller medicine unless I have symptoms
  - e. I do not miss out on time with friends/family
  - f. I do not miss out on activities
  - g. I can be as active as I want to be
  - h. I have normal lung function (breathing tests)
  - i. My social life is not impacted
  - j. I do not have any symptoms
  - k. Other people do not notice that I have asthma
  - l. I can sleep through the night
  - m. I only go to the doctor when I am sick
  - n. I do not worry about my asthma
  - o. I am not anxious or depressed
  - p. Asthma is not a burden for me
  - q. Other (Please specify): \_\_\_\_\_
13. How satisfied are you that [your/your child’s] current asthma medicines are helping to manage [your/their] asthma?
- a. Very satisfied
  - b. Somewhat satisfied
  - c. Neutral
  - d. Somewhat unsatisfied
  - e. Very unsatisfied
14. Regarding [your/your child’s] current asthma medication(s), what do you like about it?  
Please select all that apply.
- a. [I/My child] can have it on hand whenever [I/they] need it
  - b. It is easy to use
  - c. [I/My child] can take it at home
  - d. It reduces asthma symptoms
  - e. It is affordable
  - f. Other (Please specify): \_\_\_\_\_
  - g. Not applicable
15. Regarding [your/your child’s] current asthma medication(s), what don’t you like about it?  
Please select all that apply.
- a. [I/My child] cannot have it available at a moment’s notice
  - b. It is difficult to use
  - c. [I/My child] cannot take it at home
  - d. It does not reduce asthma symptoms
  - e. It is expensive
  - f. It causes negative side effects (Please specify): \_\_\_\_\_
  - g. Other (Please specify): \_\_\_\_\_

16. Does [your/your child's] current medicine(s) impact [your/their] daily life? If so, how?
17. Besides medication, what other treatments/therapies do you use to treat [your/your child's] asthma? Please select all that apply.
- a. Trigger avoidance
  - b. Activity avoidance
  - c. Yoga/Pilates/exercise
  - d. Acupuncture
  - e. Herbs (Please specify): \_\_\_\_\_
  - f. Vitamins (Please specify): \_\_\_\_\_
  - g. Home remedies (Please specify): \_\_\_\_\_
  - h. Other (Please specify): \_\_\_\_\_
  - i. None
18. Aside from a complete cure, what meaningful improvement would an ideal treatment for asthma in childhood provide? Please select all that apply.
- a. Less asthma symptoms
  - b. Reduced quick-relief or rescue inhaler use
  - c. Reduced asthma-related emergency room/hospital visits
  - d. Reduced need to visit the doctor for asthma
  - e. Reduced cost of asthma management
  - f. Improved lung function (breathing tests)
  - g. Improved ability to do activities
  - h. Less worrying about asthma
  - i. Other (Please specify): \_\_\_\_\_
19. What factors or information are most important for you to consider when deciding on a course of treatment for [you/your child]? Please select the top three.
- a. Cost
  - b. Availability
  - c. Convenience
  - d. Dosing (how often you take medicine)
  - e. Effectiveness (how well asthma symptoms are controlled)
  - f. Side effects
  - g. Doctor recommendation
  - h. Route of administration (how the medicine gets into your body, such as pills or shots)
  - i. Other (Please specify): \_\_\_\_\_
  - j. Does not apply—I do not make decisions about [my/my child's] asthma treatment
20. How do you weigh the pros and cons of treatments (e.g. potential benefits of a treatment versus any risks such as side effects)?
21. What is [your/your child's] biological sex?
- a. Male
  - b. Female
  - c. Prefer not to answer

22. What is [your/your child's] race/ethnicity?

Please select all that apply.

- a. American Indian or Alaska Native
- b. Asian
- c. Black or African American
- d. Hispanic or Latinx
- e. Middle Eastern or North African
- f. Native Hawaiian or Pacific Islander
- g. White
- h. Other/Prefer not to answer

23. Which of the following categories includes your household income?

- a. Under \$25,000
- b. \$25,000-\$49,999
- c. \$50,000-\$74,999
- d. \$75,000-\$99,999
- e. \$100,000-\$149,999
- f. \$150,000-\$199,999
- g. \$200,000+
- h. Prefer not to answer

24. In what U.S. state or territory do you reside?

25. Which best describes your location?

- a. Urban
- b. Rural
- c. Suburban
- d. Prefer not to answer

Thank you for completing the survey. The purpose of this survey was to bring the voice of families impacted by pediatric asthma to the forefront of drug development and research.

As mentioned, we may include portions of your answers in our Voice of the Patient Report that will be created after we host the September 20, 2021 meeting. You can find more information about the meeting on our website.

Your response has been recorded. You may now close the survey window.

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# Little Airways Big Voices

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