



Bridging the Gap: Outreach & Engagement with the ME/CFS Community

Allison Kanas

Administrative Director & Director, Community Outreach &
Engagement

Center for Solutions for ME/CFS | Center for Infection & Immunity

Mailman School of Public Health | Columbia University

Outreach

Communication & Dissemination of
Information & Findings

Engagement

Connection & Partnership with
the ME/CFS Community



THE MICROBE DISCOVERY PROJECT

Fundraising for groundbreaking research into ME/CFS.

The Microbe Discovery Project



Who We Are

WHO WE ARE

WHAT WE DO

OUR HISTORY

COMMUNITY

LATEST NEWS

SUPPORT US



W. Ian Lipkin, MD
Columbia University
Director for the Center for Solutions for ME/CFS
Leader of Project 1: Microbiology of ME/CFS



Dana March Palmer, PhD
Columbia University
Deputy Director for the Center for Solutions for ME/CFS



John Greally, PhD, MB, BCh
Albert Einstein College of Medicine
Co-Leader of Project 2: Molecular Signatures for ME/CFS Sub-Types (Gene Expression)



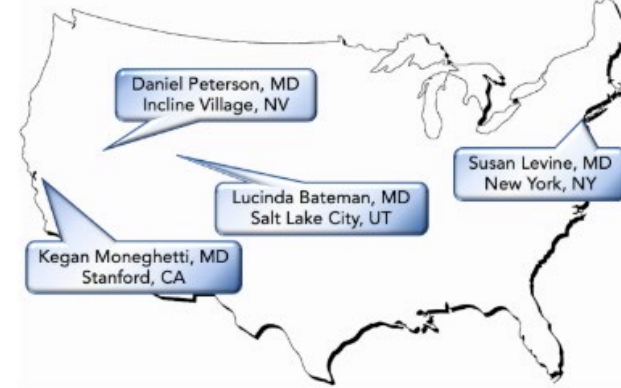
Oliver Fiehn, PhD
University of California, Davis
Co-Leader of Project 2: Molecular Signatures for ME/CFS Sub-Types (Metabolomics)



Anthony Komaroff, MD
Harvard University
Leader of Project 3: Clinical Correlates and Diagnostics in ME/CFS



Paul Newswanger, MPH
Columbia University
Project Coordinator



Lucinda Bateman, MD
Bateman Horne Center



Susan Levine, MD
Founder, Medical Office of Susan M. Levine, MD



Kegan Moneghetti, MD
Stanford University



Daniel Peterson, MD
Sierra Internal Medicine at Incline Village





What We Do

WHO WE ARE

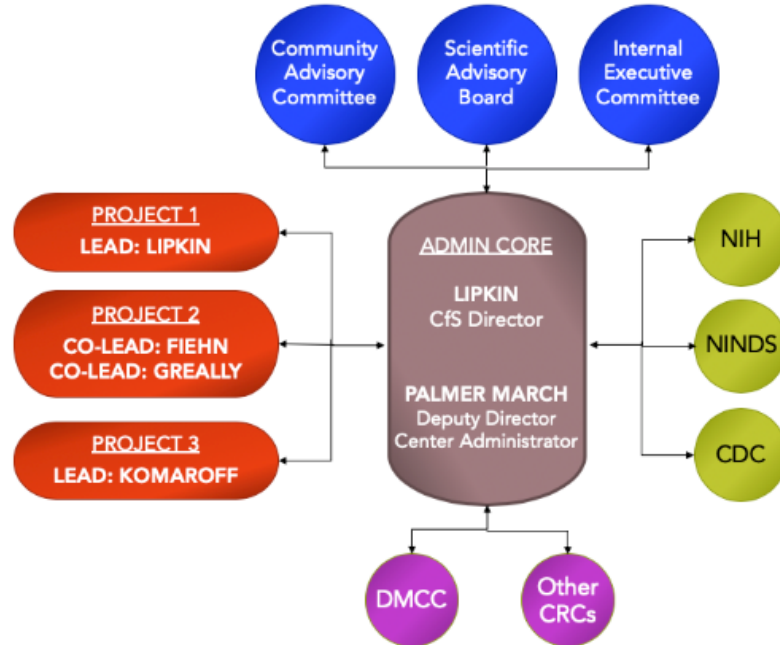
WHAT WE DO

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Our funding during the first two years of the Collaborative Center Program will be used to mine the rich data and sample sets established with the support of the NIH, the Hutchins Family Foundation, and the Microbe Discovery Project. We will use state-of-the-art sequencing methods to search for molecular footprints of potential bacterial, fungal, and viral triggers of disease. This work is inspired by discoveries in our laboratory and others pointing to the importance of the microbiome, the virome, and the fungome as determinants of health. We will look for immune responses that may persist long after an infectious agent has either been cleared from the body or become dormant, and for autoantibodies. We will also profile metabolites in plasma and gene expression in white blood cells.

Clinical research studies will connect with the laboratory studies. We will examine the impact of physical activity on the microbiome, the metabolome, and the transcriptome for clues to understanding the basis of persistent fatigue, cognitive dysfunction, and other symptoms after exercise. We will design a mobile app and mine existing datasets for insights into clinical features, comorbidities, and sub-types that could refine laboratory analyses and enhance care.

We are hoping to find additional resources for epigenetic studies that could explain how genes are turned on or off in response to exercise. Clinical trials are not part of our current mandate. However, we are aware of the urgency and need for progress in clinical care. Each of our projects has been prioritized for its potential to lead to solutions for ME/CFS through the development of animal models of ME/CFS or clinical trials of antibiotics, pre- and probiotics, antifungals, antivirals, or immunomodulatory treatments.

Click the buttons below to read more information about each of the three main projects supported by the NIH award.



The CfS for ME/CFS is designed to rapidly adapt to the insights and opportunities that are continuously emerging in the field of ME/CFS research. Accordingly, we are a center without walls—we recruit new investigators nationally and internationally based on their commitment and expertise rather than their institutional affiliation.

Our current lead clinical researchers include Anthony Komaroff (Harvard), Sue Levine (private practice, New York City), Kegan Moneghetti (Stanford), Lucinda Bateman (Bateman Horne Center), and Dan Peterson (Sierra Internal Medicine). Our current leading laboratory-based researchers include W. Ian Lipkin (pathogen discovery, Columbia), Oliver Fiehn (metabolomics, UC Davis), and John Greally (gene expression, Albert Einstein College of Medicine). We recently initiated work with Benjamin Garcia (proteomics, University of Pennsylvania) with support from Solve ME/CFS. We also have an epidemiology core led by Dana March Palmer (Columbia).





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COMMUNITY GROUPS

The ME/CFS community has such strength in supporting each other as we navigate towards answers for this devastating disease. These are just a few of the patient forums available to find out more information on advocacy and learn about each other's journeys.



#MEAction is a grassroots, international organization that provides a platform to empower people with ME and related conditions and advocates for patients in the pursuit of health equality. Their mission is to continually build community and provide a voice for patients, families, and allies of ME, based on the belief that while it may be difficult to individually advocate, making activism accessible can amass a louder voice for the community as a whole.



Solve ME/CFS Initiative (SMCI) is a non-profit disease organization that works to accelerate the discovery of safe and effective treatments for ME/CFS, strives for an aggressive expansion of research funding that will lead to a cure, and seeks to engage the entire ME/CFS community in research and advocacy. SMCI serves patients and researchers alike, acting as an information and data hub for the ME/CFS community.

PATIENT RESOURCES

Have something to say? Need some more information? Here are some of the online places you can visit to read about what others are experiencing, share what you have encountered on your own path, or review some of the resources that may have some additional information.

Patient Forums



Science for ME is "where science and the ME/CFS community meet" with numerous message boards similar to a Reddit discussion board.



Phoenix Rising provides people with ME/CFS information to support their health and well-being. They publish articles and a newsletter, maintain the largest ME/CFS forum in the world, and have the biggest database of information about ME/CFS on the web.



Founded by Cort Johnson, Health Rising is dedicated to providing timely, accurate information to people with ME/CFS and fibromyalgia.



Written by Simon McGrath, the ME/CFS Research Review blog aims to explain the most promising biomedical findings with in-depth explanations of the science in the latest published studies.



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722 W. 168th St. New York, NY 10032

The Center for Solutions for ME/CFS (CfsforMECFS) is an inter-disciplinary NIH-funded research center at Columbia University comprised of clinicians and scientists committed to understanding the pathogenesis of ME/CFS to prevent and mitigate the disease.

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http://mailman.columbia.edu/cfsformecfs

(212) 342-9031

Typically replies within a day
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Center for Solutions for MECFS

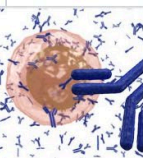
September 24 at 1:46 PM

Health Rising by Cort Johnson

September 22 at 1:50 PM

Ian Lipkin on Long Hauling with the Coronavirus, a Possible B-cell Subset, and Protein Biomarkers for #MECFS

Ian Lipkin talks on his own long hauling experienc... See More



SIMMARONRESEARCH.COM

Ian Lipkin on Long Hauling with the Coronavirus, a Possible B-cell Subse...

Dr. Ian Lipkin, known to much of the world as the "virus hunter", has throughout his career developed new technologies for discoverin...

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Center for Solutions for ME/CFS

@CfsforMECFS

The #CenterforSolutions @ColumbiaMSPH is committed to understanding the pathogenesis of #MECFS. Led by Dr. W. Ian Lipkin of @Columbia_CII

New York, NY cfsformecfs.org Joined April 2017

107 Following 1,245 Followers

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Center for Solutions for ME/CFS @CfsforMECFS · Aug 28

You ask, we answer! Review our #proteomics blog below and submit your questions using the #AskOurResearchers hashtag!



A Proteomics Study from the Center: Searching for the Criminal

On July 21, 2020, the results of a proteomics study by the Center for Solutions for ME/CFS was published by the journal PLoS ONE. ...

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Ask our Researchers Video Q & A Series

I find it very interesting that there are almost no records (at least publicly) since about 1990 and onwards of reported epidemics that were seen in the 1980's that put ME/CFS on the US medical map. Do you have any inclination for why that is? Do these reported outbreaks tell us anything about ME/CFS in general today in your medical opinion?

From CDC talk: "it begins to look sort of like an anemia of chronic disease, with red blood cell damage and so forth, oxidated, stress." What needs to be done to follow-up on this "remarkable" finding? Could this relate to the body's response to pathogens which crave iron?

Can you explain what type of data you are looking at and give examples of what information you are trying to find from the data?

You are enrolling some participants for the Exercise Tolerance Testing (ETT). Understandably many patients are wary of this sort of stressor test. Do you think patients will generally tolerate the testing protocol and do you think testing tend gain mild to moderately affected patients as participants?

I would like to ask why so few studies are done without considering PEM. Wouldn't it make more sense to take and analyze samples before/during and after a 2-day-(i)CPET?

Many are wondering how reliable metabolomic findings seem to be many complexities and variables. What can you tell us about this?

From CDC talk "proteomic studies that reveal differentially, a differential expression of immunoglobulin kappa and light chains and heavy chains, which are present at increased concentrations in individuals with ME/CFS" Can you explain this in simple terms please?

Given some of the deepest experience out of any clinician in the field with studying and treating this illness, I wanted to ask you about the term "subsets" very often in this field. What does your research tell you about how many true "subsets" there are with ME/CFS patients?

YouTube Analytics

Center for Solutions for ME/CFS
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The Center for Solutions for ME/CFS at Columbia University presents the "Ask Our Researchers – Video Q&A Series", in which the center's scientists and clinicians answer questions from the ME/CFS community.

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September 2019 – October 2019

- ▶ 1,200 views
- ▶ 62 subscribers
- ▶ 116 hours watched



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- Support the rigorous search for microbes that contribute...**
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YouTube

October 2019 – October 2020

- ▶ 8,000 views **567% ↑**
- ▶ 260 subscribers **333% ↑**
- ▶ 520 hours watched **348% ↑**




Facebook Analytics

 **Center for Solutions for MECFS**
October 16 at 1:00 PM · 🌐

Dr. Anthony Komaroff covers COVID-19 #longhaulers in a new piece for [Harvard Health Publishing](#).

"If just 5% develop lingering symptoms... we would double the number of Americans suffering from ME/CFS in the next two years."
<https://www.health.harvard.edu/.../the-tragedy-of-the-...>




HEALTH.HARVARD.EDU
The tragedy of the post-COVID "long haulers" - Harvard Health Blog

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 **Center for Solutions for MECFS**
October 20 at 1:01 PM · 🌐

Thank you to our network partners for their contribution to this robust piece in [TIME](#) on #COVID long-haulers and the research potential it poses for understanding the origins of #MECFS.

Jaime Seltzer [The #MEAction Network](#), Dr. Anthony Komaroff [Brigham and Women's / Mass General Health Care Center](#), Avi Nath [National Institutes of Health \(NIH\)](#), [Solve MECFS Initiative](#)
<https://time.com/5897992/long-haul-coronavirus-me-cfs/>



TIME.COM
Studying Long-Haul Coronavirus Could Bring Benefits—and Recognition—to Forgotten Patients

👍👍👍 You, Allison Kanas and 14 others 1 Share

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Write a comment...

Facebook
October 2020 – November 2020

- ▶ 800 followers
- ▶ 450 people reached
- ▶ 47% engagement rate

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Center for Solutions for ME/CFS @CfsforMECFS · Oct 30
We are excited to announce the launch of the @NIH #MECFS Outreach and Engagement @RTI_Intl @ME @PlzSolveCFS

Read more about...

Center for Solutions for ME/CFS @CfsforMECFS · Oct 27
Long time #MECFS clinician, @ngklimas weighs in on the challenges COVID-19 #longhaulers may face in the wake of a novel virus in this commentary for the @usnews.

Check it out here:



Commentary: Help Is Out There for COVID 'Long Haulers'
Clinicians should draw on knowledge surrounding chronic fatigue syndrome in treating patients suffering from the lingering effects o...
usnews.com

November 5, 2020
by Allison
: the Center

TREACH
THE

ME/CFS

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Twitter

October 2020 – November 2020

- ▶ 1,300 followers
- ▶ 24,000 impressions

CFSforME/CFS.org

About the Center for Solutions

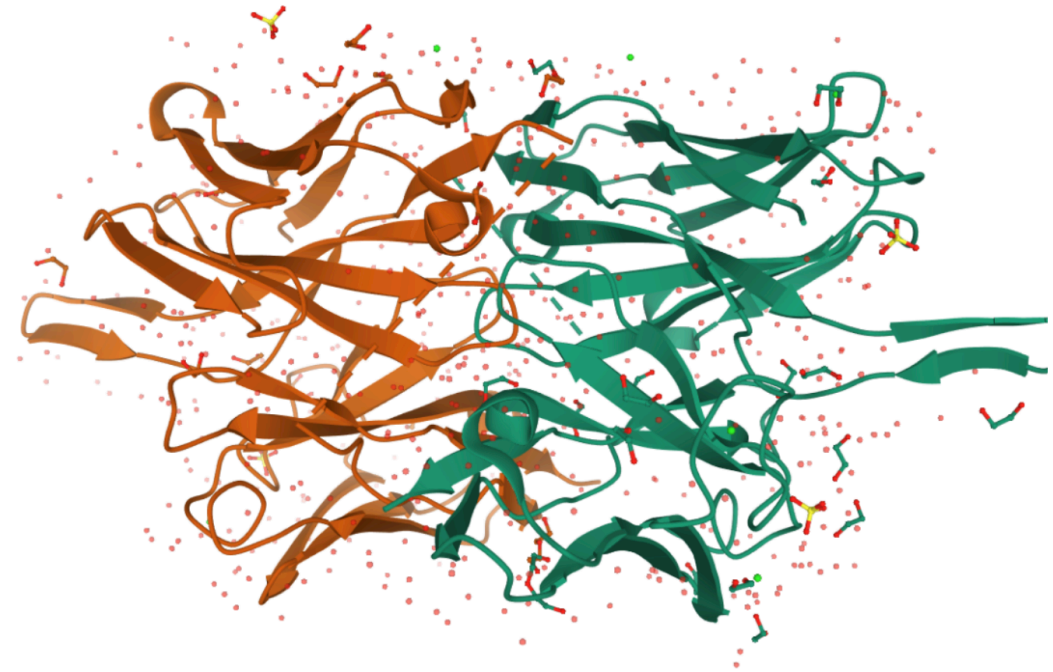
The Center for Solutions for ME/CFS is an inter-disciplinary, inter-institutional center comprised of clinicians, clinical investigators, basic scientists who are committing to working together to understand the pathogenesis of ME/CFS and develop evidence-based strategies for interventions that prevent and mitigate disease.

Topics

- #AskOurResearchers
- -omics studies
- Grant Opportunities
- ME/CFS
- Science behind ME/CFS
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-omics studies

A Proteomics Study from the Center: Searching for the Criminal

On July 21, 2020, the results of a proteomics study by the Center for Solutions for ME/CFS was published by the journal PLoS ONE. Proteomics uses new technologies—that have become available in the last two decades—to precisely identify large numbers of proteins and measure their levels. The measurement is...

July 28, 2020

Will There Be a Post-COVID-19 Form of ME/CFS?

cfsformecfs.org

Launched February 2020

- ▶ 7,500 views
- ▶ 5,000 unique visitors
- ▶ 62 countries reached



By Dr. Anthony Komaroff

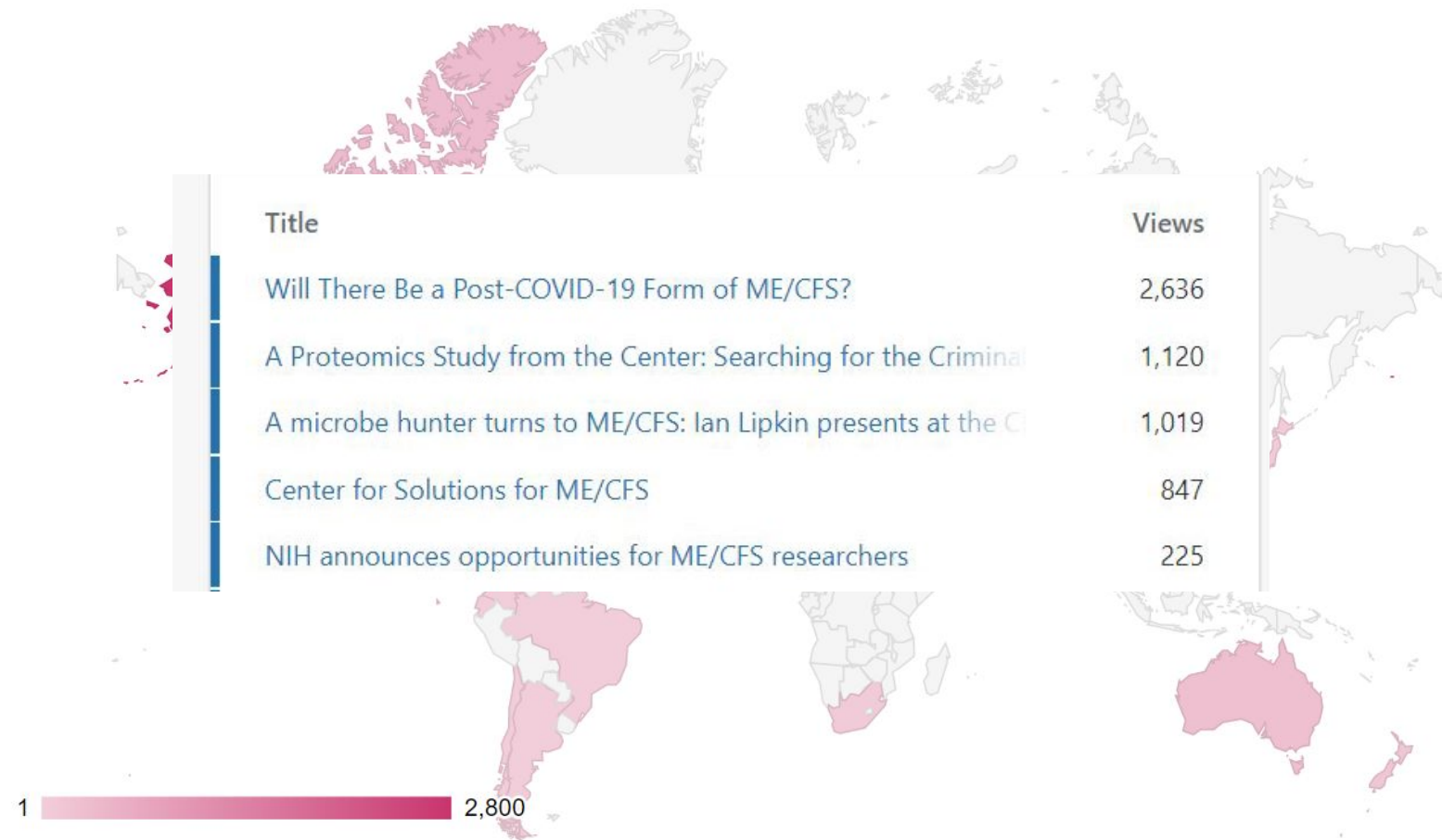
Will some people who get COVID-19 subsequently develop ME/CFS? After all, many people with ME/CFS say that their illness began with some kind of infection: “a virus,” “a flu,” “a bad cold.” When it started, their illness didn’t feel that different from similar illnesses in the past, so no tests were done to determine what kind of infection it was. Their doctors thought there was no need, since these minor infections typically get better. Only this one didn’t get better, and the cause of the initial illness remained a mystery.

Blog Analytics

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Community Advisory Committee (CAC)

QUESTIONS RESPONSES 43

Section 1 of 4

Columbia Center for Solutions for ME/CFS COMMUNITY ADVISORY COMMITTEE APPLICATION | June 2018

The Center for Solutions for ME/CFS is seeking applications for the Community Advisory Committee.

Email address *

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- Developed CAC Application 2018
- Reviewed over 40 applicants in late 2018
- In early 2019 accepted 8 members

COMMUNITY ADVISORY COMMITTEE

THE CENTER FOR SOLUTIONS FOR ME/CFS
The Center for Solutions for ME/CFS (CfS for ME/CFS) is a multi-institutional, inter-disciplinary research center dedicated to understanding the biology of ME/CFS and developing diagnostic tests and methods for preventing and treating disease. It builds on decades of work by a network of expert clinicians and laboratory scientists with expertise in epidemiology, infectious disease, immunology, genetics and biochemistry, as well as a large cohort of well-characterized patients and biological samples. Our efforts will be linked with those of other Collaborative Research Centers and guided by close interactions with the ME/CFS community.

The Community Advisory Committee, the Scientific Advisory Board, and the Internal Executive Committee will advise Center activities.

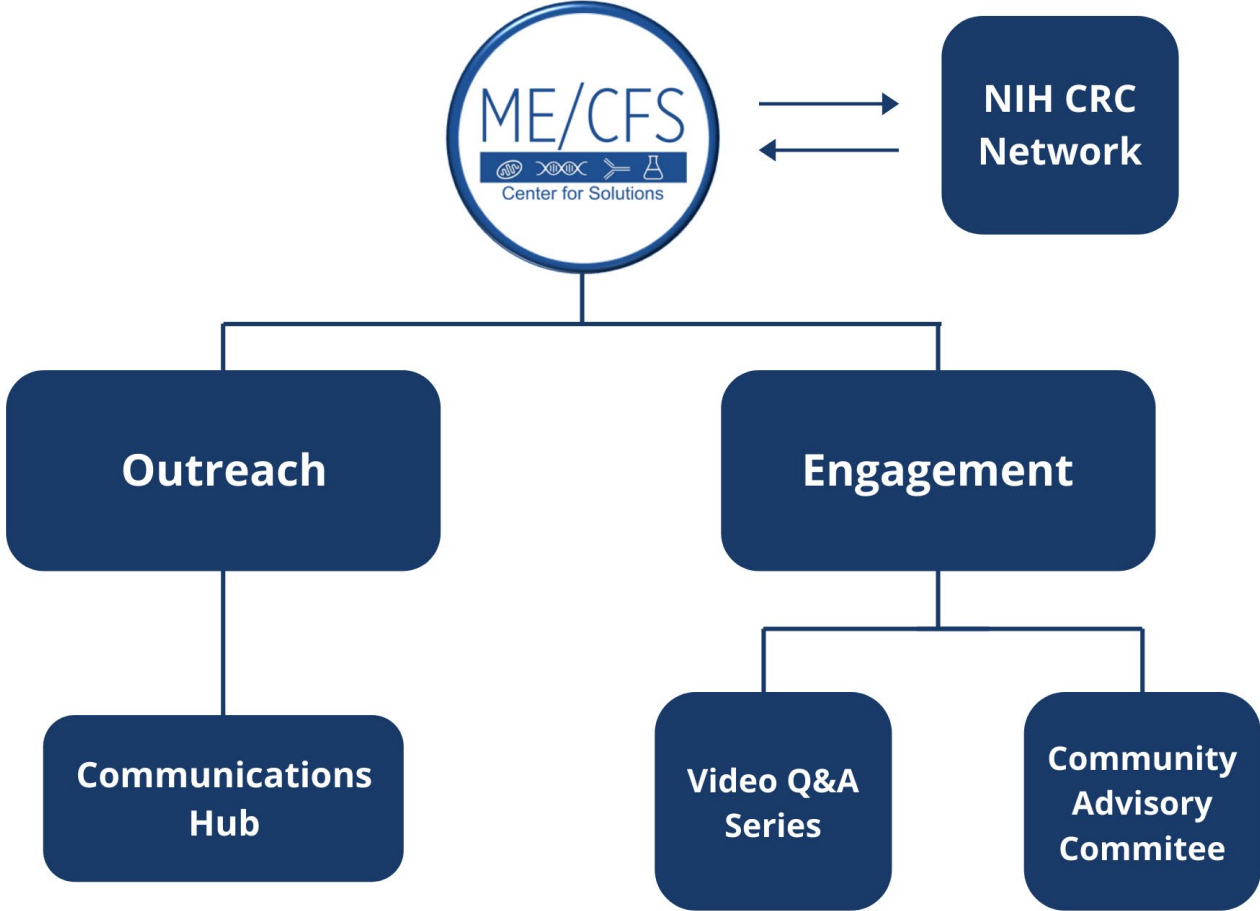
PURPOSE
The specific role of the Community Advisory Committee is to assist with the development and execution of community engagement/outreach and partnership activities. It will help focus the CfS for ME/CFS investigators on patient priorities and challenges, serve as a communications liaison between the ME/CFS community and the Center, and assist with study recruitment. Specifically, the Community Advisory Committee will:

- Obtain and disseminate information to the community about the Center
- Inform the community about the center and participation in research participation and serve as an advocate for the community
- Provide advice and counsel regarding community need and projected priorities for the Center
- Assist the Center in weighing and balancing the strategic priorities among the various constituencies it serves
- Participate in the development of working groups for select Center activities

Plan for CAC Working Group



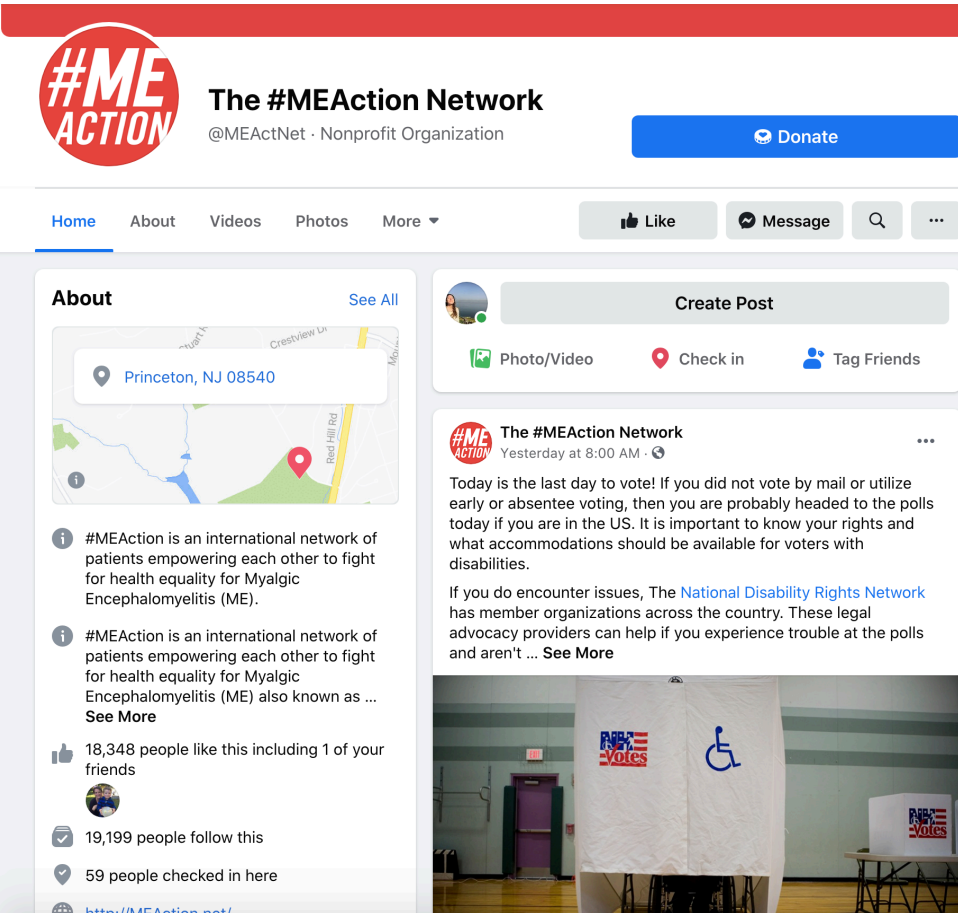
Expanded Outreach & Engagement Approach



Network Online Outlets

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Canada (ICanCME) Alain Moreaux Lab	Web: cihr-irsc.gc.ca/ Twitter: @irsc_cihr Facebook: /HealthResearchInCanada
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#MEAction	Web: meaction.net Twitter: @MEActNetYou Facebook: /MEActNet
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Network Online Outlets



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#MEAction is an international network of patients empowering each other to fight for health equality for Myalgic Encephalomyelitis (ME).

#MEAction is an international network of patients empowering each other to fight for health equality for Myalgic Encephalomyelitis (ME) also known as ... See More

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59 people checked in here

<http://MEAction.net/>


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The #MEAction Network
 Yesterday at 8:00 AM

Today is the last day to vote! If you did not vote by mail or utilize early or absentee voting, then you are probably headed to the polls today if you are in the US. It is important to know your rights and what accommodations should be available for voters with disabilities.

If you do encounter issues, The [National Disability Rights Network](#) has member organizations across the country. These legal advocacy providers can help if you experience trouble at the polls and aren't ... See More




Cornell Center for Enervating NeuroImmune Disease
 @CornellMECFS · Follows you

Collaborative #research center based @Cornell directed by @DrMaureenHanson encompassing a variety of projects on #ME/CFS. Visit our website below for more info.

neuroimmune.cornell.edu Joined March 2018

64 Following 775 Followers

Followed by ICanCME Research Network, MEAction Colorado, and 22 others you follow

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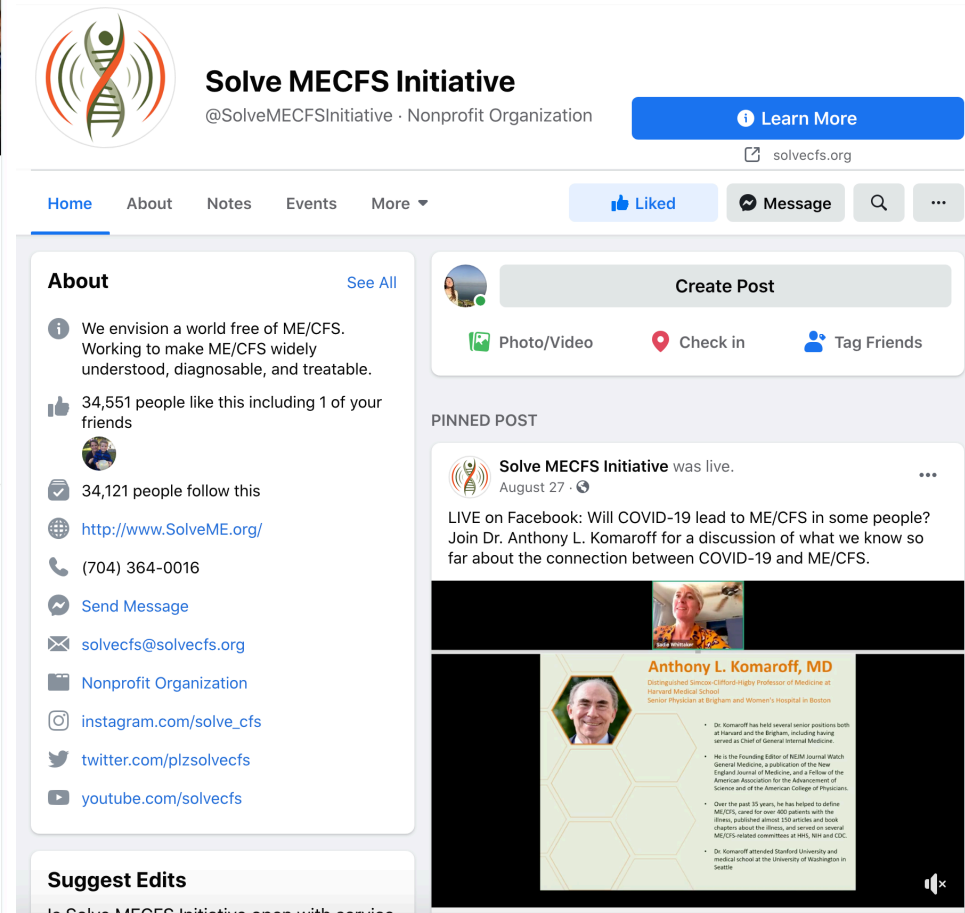
Cornell Center for Enervating NeuroImmune Disease · Nov 2

We look forward to continuing our collaboration with @CfsforMECFS as part of the new @NIH #ME/CFS Outreach and Engagement Initiative. This includes partners @Derya_ @RTL_Intl @MEActNet @BatemanHorne @ICanCMEResearch @PlzSolveCFS. More information at:



Bridging the Gap: Outreach & Engagement with the ME/CFS Comm...
 We are excited to announce the launch of the ME/CFS Collaborative Research Center's outreach and engagement initiative led by the ...
cfsformecfs.org

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Solve MECFS Initiative
 @SolveMECFSInitiative · Nonprofit Organization

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solvecfs.org

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We envision a world free of ME/CFS. Working to make ME/CFS widely understood, diagnosable, and treatable.

34,551 people like this including 1 of your friends

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Solve MECFS Initiative open with service

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Solve MECFS Initiative was live.
 August 27

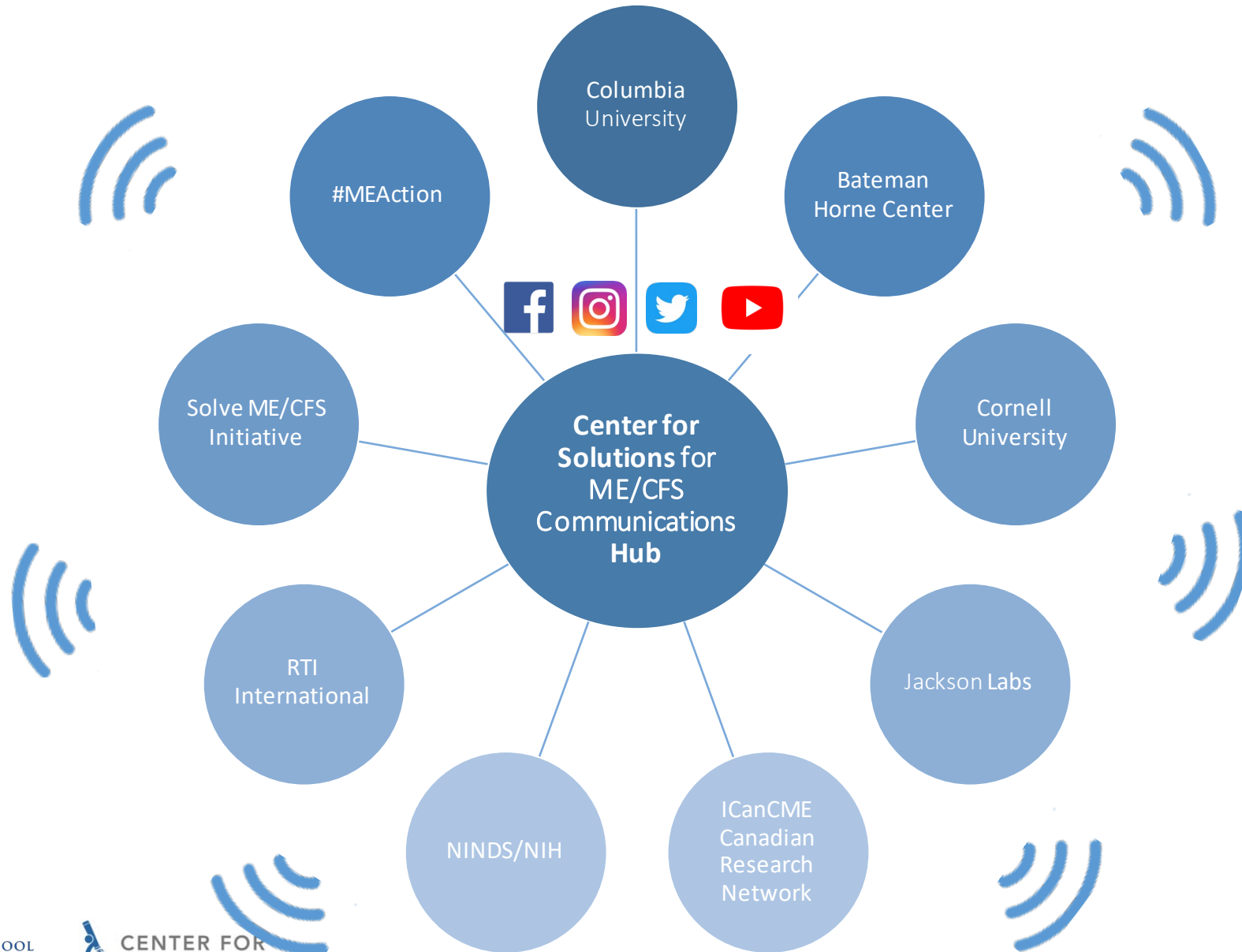
LIVE on Facebook: Will COVID-19 lead to ME/CFS in some people? Join Dr. Anthony L. Komaroff for a discussion of what we know so far about the connection between COVID-19 and ME/CFS.

Anthony L. Komaroff, MD
 Distinguished Simons Clifford-Highy Professor of Medicine at Harvard Medical School
 Senior Physician at Brigham and Women's Hospital in Boston

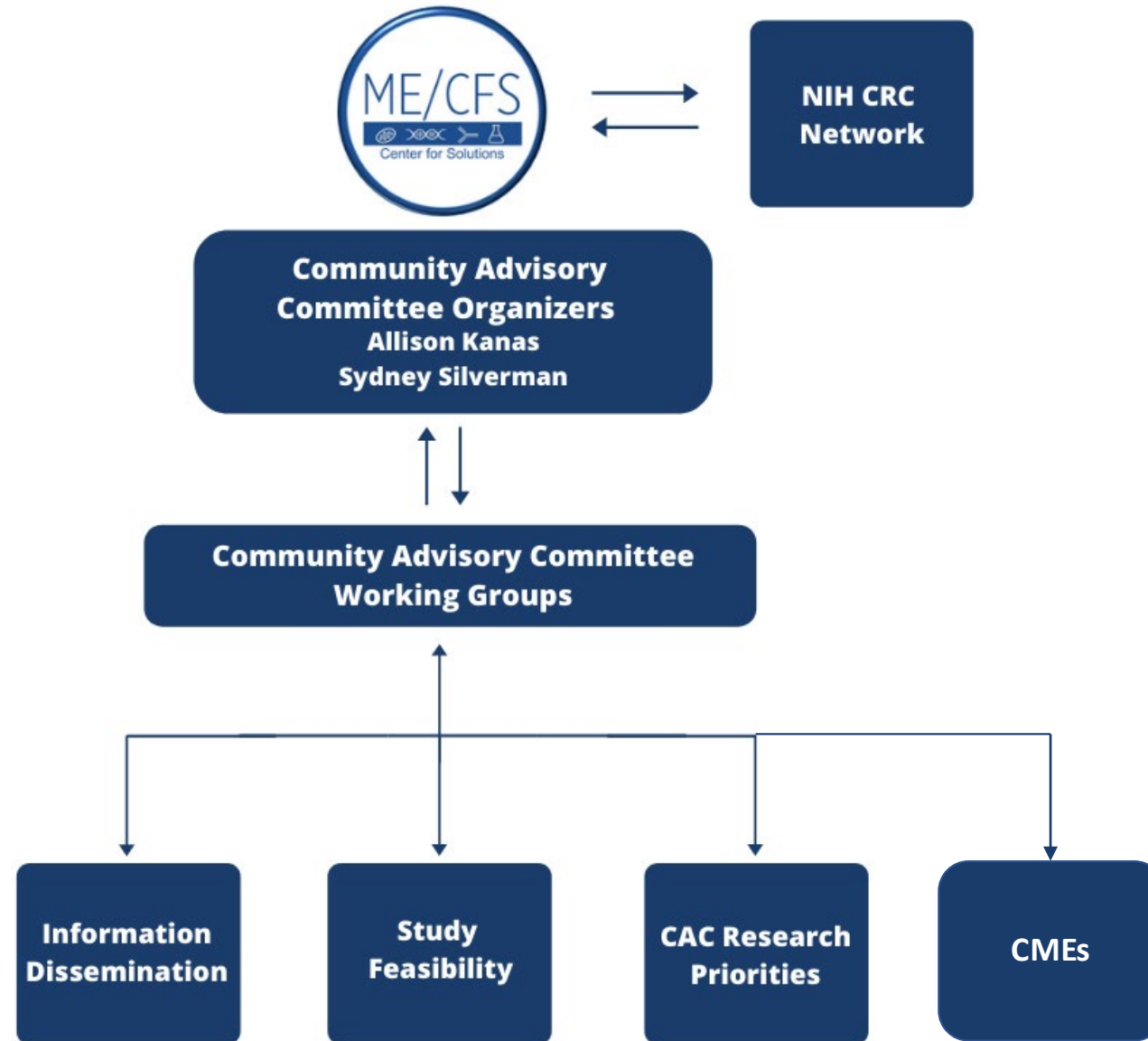
- Dr. Komaroff has held several senior positions both at Harvard and the Brigham, including being named as Chief of General Internal Medicine.
- He is the Founding Editor of *HEALTH* journal which General Medicine, a publication of the *New England Journal of Medicine*, and a Fellow of the American Association for the Advancement of Science and of the American College of Physicians.
- Over the past 20 years, he has helped to define ME/CFS, cared for over 800 patients with the illness, published almost 100 articles and book chapters about the illness, and served on several ME/CFS-related committees at NIH, NIH and CDC.
- Dr. Komaroff attended Stanford University and medical school at the University of Washington in Seattle.



Network-Wide Communications Hub



Network-Wide Community Advisory Committee (CAC)



CAC Working Group Goals

**Information
Dissemination** →



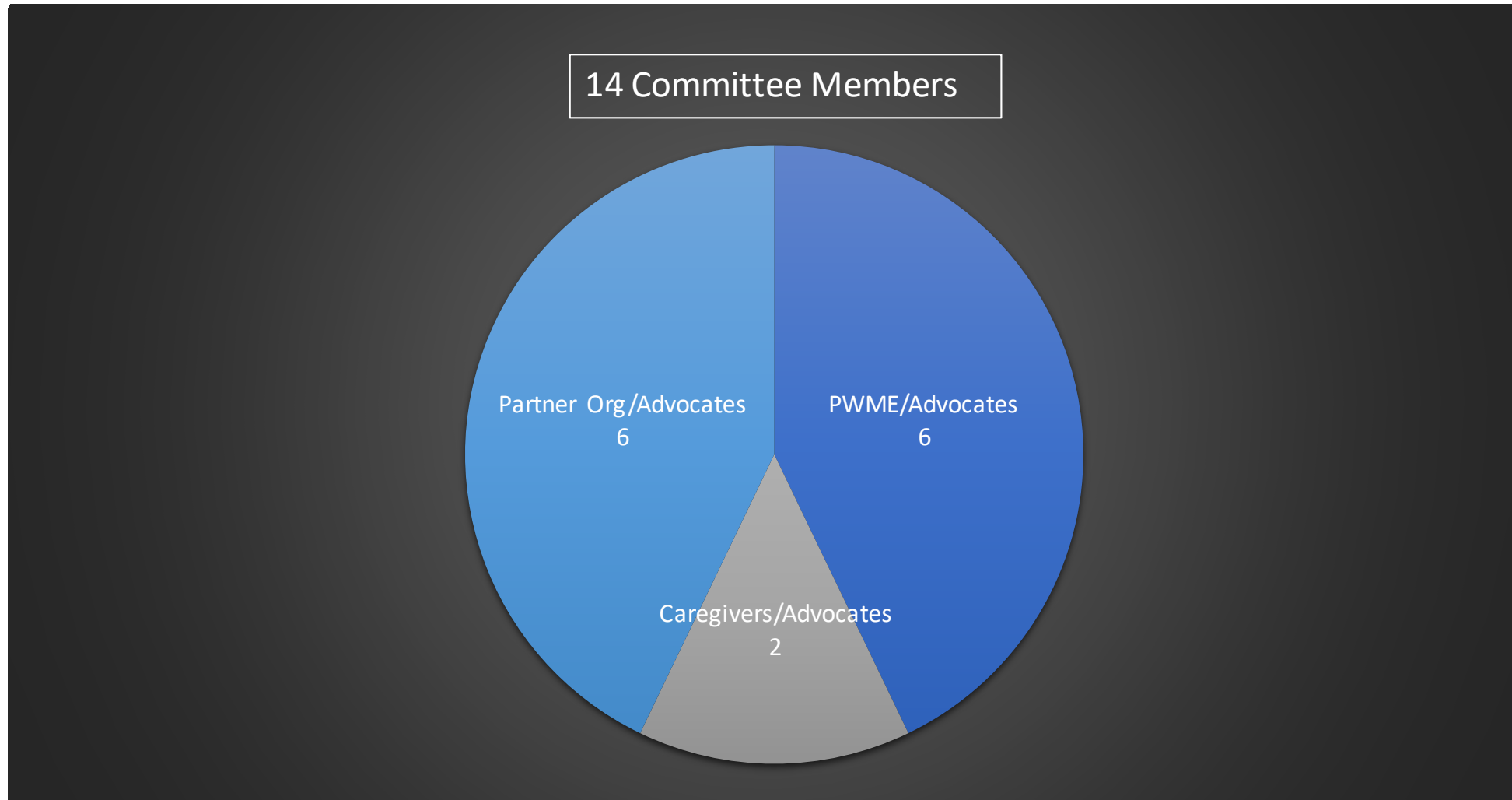
Study Feasibility →



**Research
Priorities** →



Community Advisory Committee Members



Bridging the Gap



**People with
ME/CFS**



Advocates



Caregivers



Researchers



Clinicians



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