

The Program Will Begin Shortly!

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Welcome!

ME/CFS: Changing the Narrative

with Ed Yong

Massachusetts ME/CFS and FM Association

Annual Meeting of the Membership

October 28, 2023

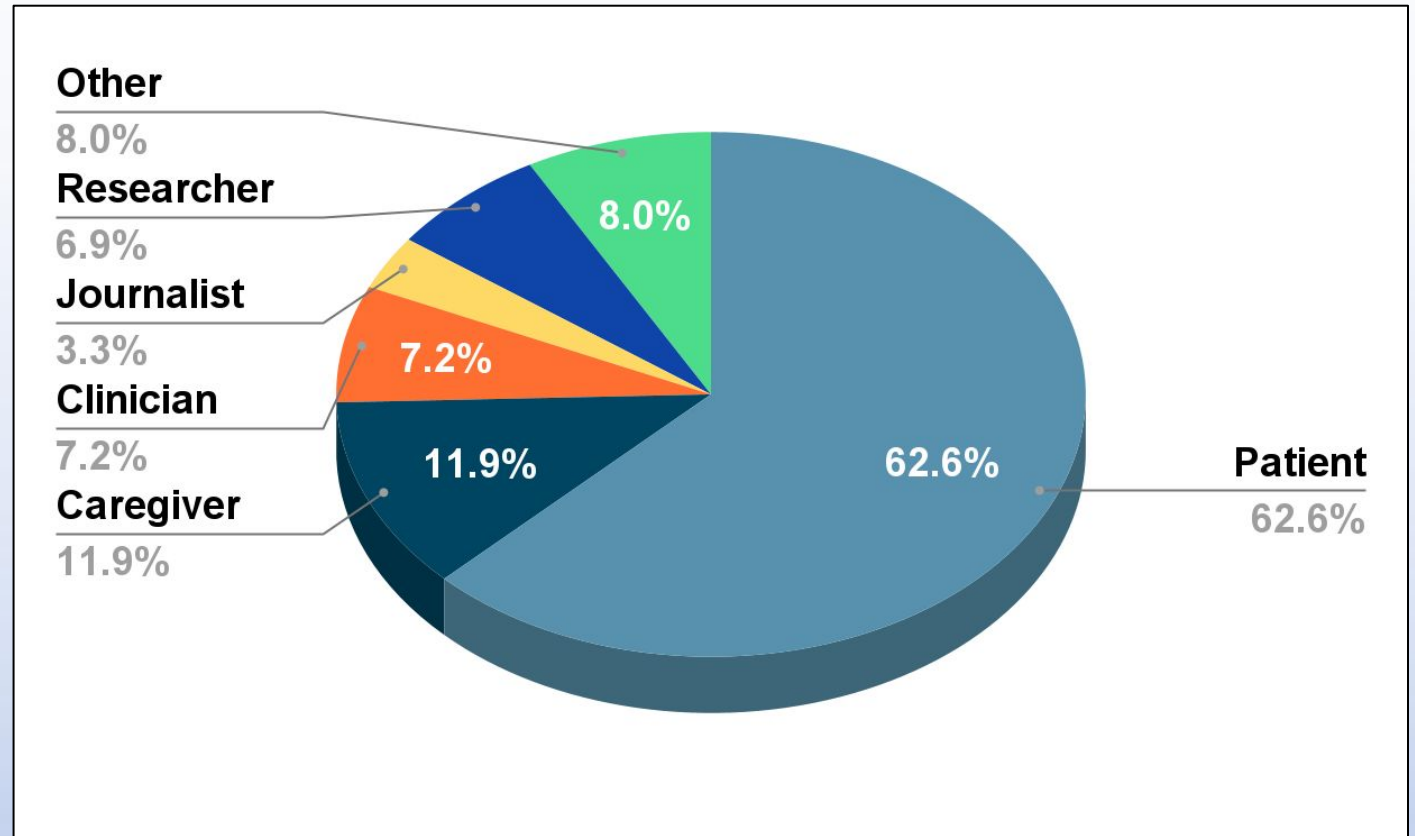
Phil Chernin

Co-President



Thank You for Being Here!

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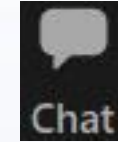
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Agenda

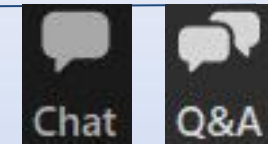
1:00 **Welcome** - Phil Chernin, Co-President
 MassME@40 - Susan Buckley, Co-President
 Massachusetts Movers and Shakers - Phil



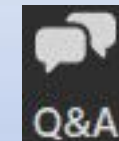
1:25 **Introducing Ed Yong** - Helen McGunnigle
 Changing the Narrative - Ed Yong



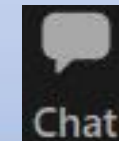
2:15 **BREAK**



2:25 **Q & A**, Facilitated by Helen
 Wrap-Up, Phil

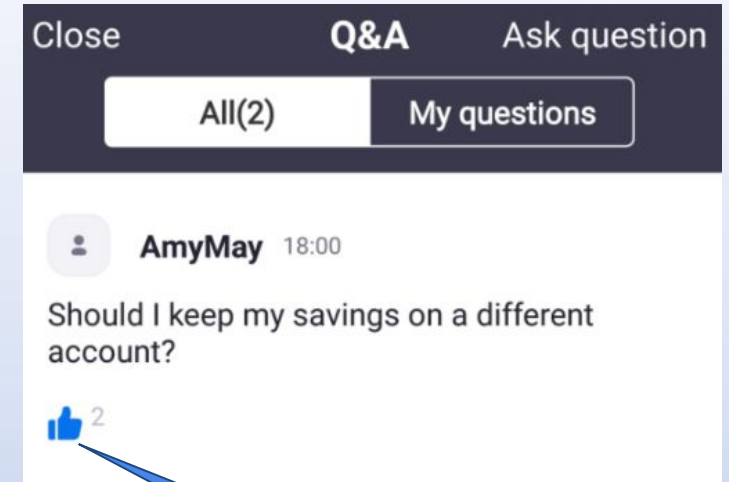
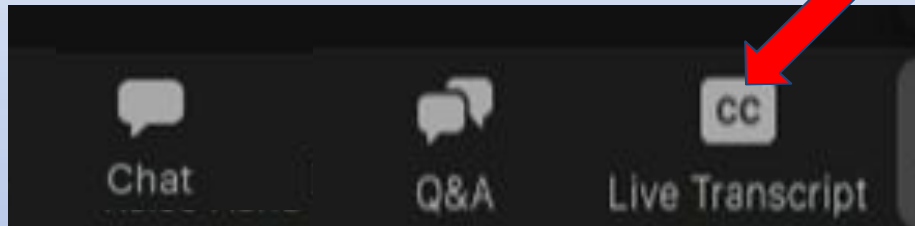


Chat will stay open for 10 minutes following the end of the meeting



Meeting Information

- This meeting is being recorded for later viewing
- Use the **Chat** for informal dialog between registrants and/or feedback to presenters
- Use **Q&A** to pose question(s) to Ed
- **Upvote** questions others have asked
- Zoom has Closed Captioning option



click to upvote
a question



MassME@40

1983 - 2023

Susan Buckley

Co-President



Our Mission

EDUCATE

SUPPORT

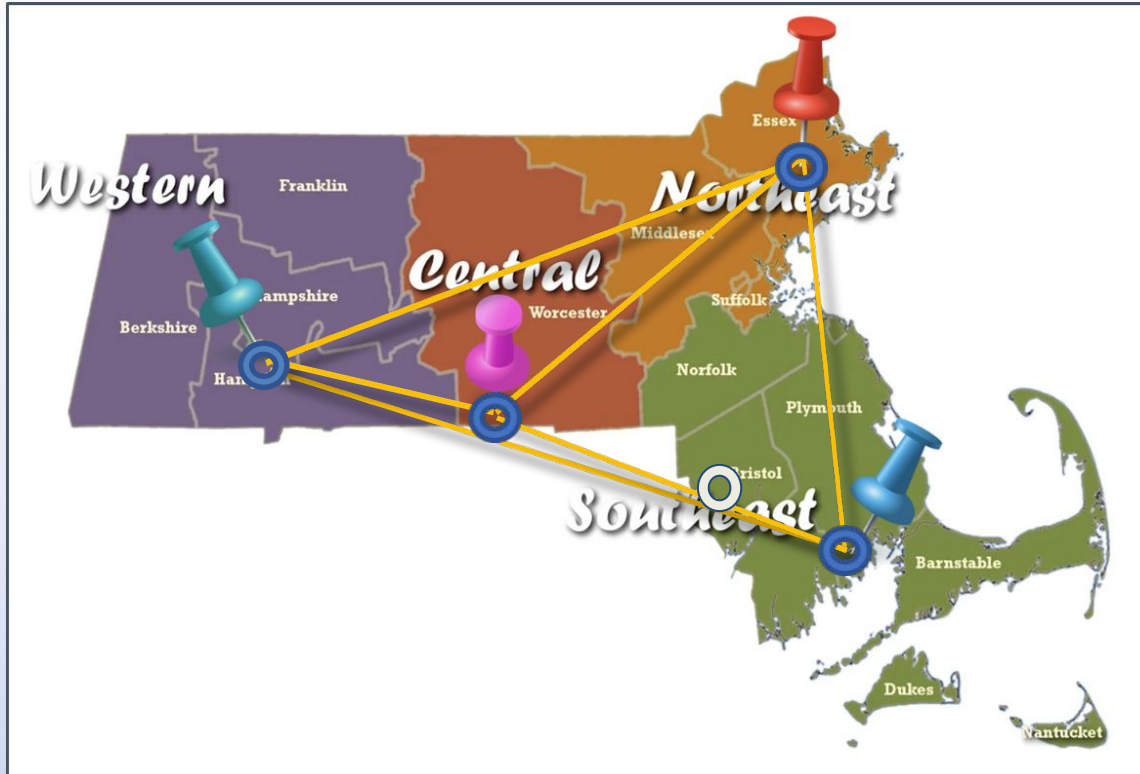
We support people living with ME/CFS and their families by connecting them to supportive resources and each other, and by educating and advocating to expand the ME/CFS healthcare and social service infrastructure in Massachusetts.

ADVOCATE

SUSTAIN



Beginnings



1983

First support group in Quincy expanded to a network of peer support groups across the state

Beginnings

The above-named incorporator(s) do hereby associate (themselves) with the intention of forming a corporation under the provisions of General Laws, Chapter 180 and hereby state(s):

88 131002

1. The name by which the corporation shall be known is:

Massachusetts CEBV Syndrome Association, Inc.

2. The purposes for which the corporation is formed is as follows:

001004271

The Massachusetts CEBV Syndrome Association, Inc. is a charitable, non-profit corporation, incorporated under the applicable laws of the Commonwealth of Massachusetts including but not limited to M.G.L. c. 180, s. 4 et seq. and subject to

1985 Incorporated as Massachusetts Chronic Epstein Barr Virus Syndrome Association



MASSME@40



NEW LIGHT



1983 – 1993: The background

Yuppie 'flu is all in the mind say psychiatrists

A GROUP of psychiatrists has overwhelmingly concluded that myalgic encephalomyelitis (ME) — sometimes called Yuppie flu — is all in the mind.

The conclusions, reached by 150 British psychiatrists attending a pharmaceutical conference in Jersey, are set to reopen the increasingly heated debate over the cause of ME, an illness which leaves its victims with no energy, muscle pains and allergies.

Presenting research findings to the conference, Dr Sean Lynch, a psychiatrist from St James's University Hospital in

Leeds, said: "There is no strong evidence of persistent viral infection in any but a small number of patients."

With 12pc of the population develop a viral infection in any one year, he said, even the small number of patients shown to have an infection were not significant.

However, Dr Lynch, a medical adviser to the conference, said the psychiatrists said they were not to know anything.

Dr Shepherd presented a variety of sources claimed supported

By VICTORIA MACDONALD
in London

triggered by viruses, vaccinations or neurotoxins, such as sheep dips.

He admitted there could be underlying factors, such as stress, but

medical observations recorded in Oxford, America and Australia.

"We are dealing with a broad, heterogeneous spectrum and the definitions do not take this into account," says Dr Shepherd.

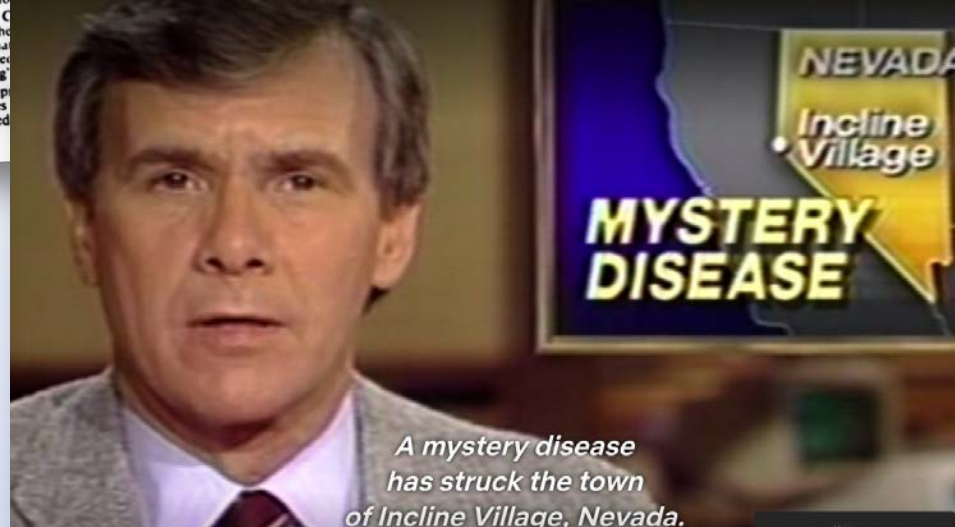
"There is no doubt that some people have psychological disturbances but at the other end of the spectrum there are clear

furrow and see patients who more often than not are psychologically ill.

"Then there are those of us seeing a different group of patients, and the side is communicating with the

Dr Lynch pointed to a number of hospital-based studies which had found that 50 per cent of patients being treated for myalgic encephalomyelitis had a "major" depression.

Dr Lynch said the psychiatrists said they were not to know anything.



The Disease of a Thousand Names

CFIDS

Chronic Fatigue/Immune Dysfunction Syndrome

by David S. Bell MD, FAAP

property of the MA CFIDS Assoc.
Please return to the address
below:

CFIDS LIBRARY
c/o Pat Kearns
Ten Oak Street
Quincy, MA 02169

Also Known As

Chronic Fatigue Syndrome; CFS; Chronic Immune Activation Syndrome; CIAS; Chronic Immune Dysfunction Syndrome; CIDS; Fibromyalgia; Fibrositis; Fibromyalgia; FM; Chronic Epstein-Barr Virus Syndrome; CEBV; Chronic Active Epstein-Barr Virus Infection; CAEBV; Myalgic Encephalomyelitis; ME; Benign Myalgic Encephalomyelitis; Atypical Poliomyelitis; Post-Viral Fatigue Syndrome; PVFS; Postinfectious Fatigue Syndrome; Iceland Disease; Akureyri Disease; Tapanui Flu; Royal Free Disease; Epidemic Vegetative Neuritis; Chronic Mononucleosis; Familial Chronic Mononucleosis; Persistent Myalgia Following Sore Throat; Ecological Disease; Multiple Chemical Sensitivity Syndrome; Allergic-Fatigue Syndrome; Chronic Fatigue State; Antibody Negative Lupus; Antibody Negative Lyme Disease; Lyndonville Chronic Mononucleosis; Atypical Multiple Sclerosis; Epidemic Neuromyasthenia; Neuromyasthenia; Neurasthenia; Neurocirculatory Asthenia; Fabricula; Yuppie Flu; Yuppie Plague; Raggedy Ann Syndrome;

Case Definitions

1986 UK: Ramsey criteria for ME

1988 US: Holmes criteria for CFS



MassME's First Decade

- **1987** Began publishing *The Update*
- **1991** New name — MassCFIDS
- **1992** Published the Disability Primer
- **1992** Published the Primer for Clinicians



CHRONIC FATIGUE SYNDROME:

A Primer For Physicians and Allied Health Professionals

written by

Alan Gurwitt, M.D., Chairman, Sharon Barrett, M.D., Sunnie Brown, R.N.,
Edna C.A. Butaney, M.D., Bonnie Gorman, R.N., M.S., James L. Kilgore, Ph.D.,
Erin O'Grady, LPN, Walter Potaznick, O.D., FAAO, Barbara Saltzstein, LIC.S.W.,
Ann Sanford, R.N., Warnie Webster, M.D., Victoria Zimmer, R.N.

*This project is funded by the
Mass CFIDS Association*

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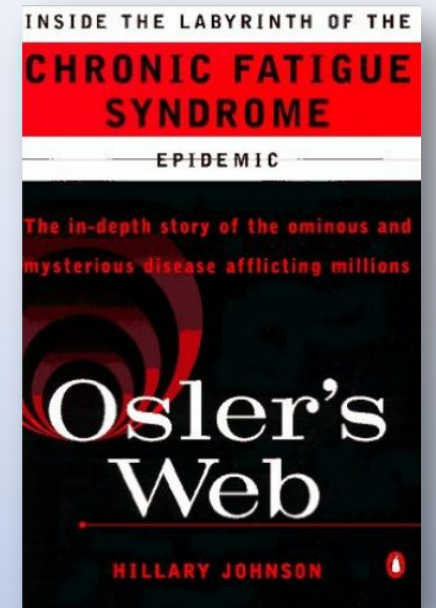
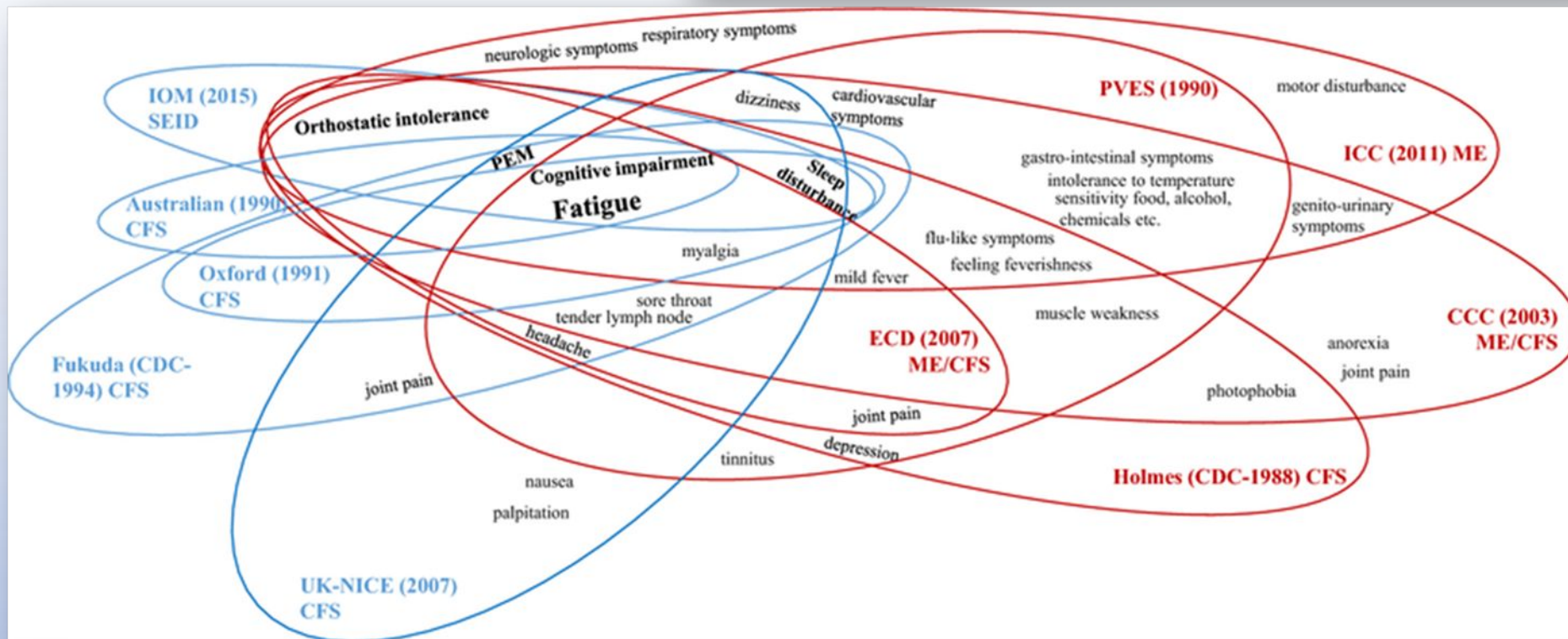
1993 - 2013: The background

Case Definitions

1994 UK: London Criteria
1994 US: Fukuda criteria
2003 Canadian Consensus Criteria
2011 International Consensus Criteria



The Chronic Fatigue Syndrome Advisory Committee (CFSAC) provides advice and recommendations to the Secretary of Health and Human Services (HHS) through the Assistant Secretary for Health on issues related to Myalgic Encephalomyelitis and Chronic Fatigue Syndrome (ME/CFS).



“I watched the ME Conference DVD at the weekend. I have to confess that I cried all through the first DVD. Living with ME, you just so used to putting up with ignorance and misunderstanding, and so to hear a group of people gathered together in one room talking about ME sensibly, was just totally overwhelming.”



MassME's Middle Decades

- **1997** Launched website
- **1998** Co-hosted major conference
- **1999** Added Fibromyalgia to our mission
- **2005 – 2008** The 'lean years'
- **2008 – 2012** Rebuilding



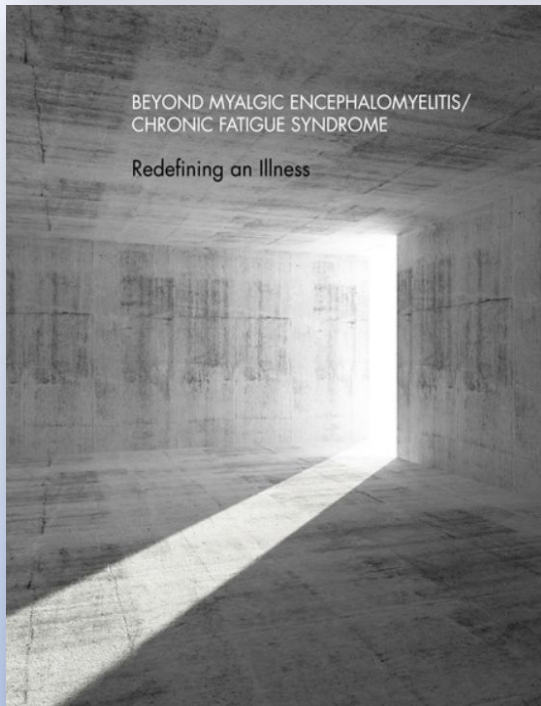
2013 - 2023: The background

FIRST OPINION

Bad science misled millions with chronic fatigue syndrome. Here's how we fought back

By Julie Rehmeier Sept. 21, 2016

Reprints



September 23, 2020

As Their Numbers Grow, COVID-19 "Long Haulers" Stump Experts

JAMA

Characterizing long COVID in an international cohort: 7 months of symptoms and their impact

Hannah E. Davis ¹ • Gina S. Assaf ¹ • Lisa McCorkell ¹ • Hannah Wei ¹ • Ryan J. Low ¹ • Yochai Re'em ¹ • et al.

[Show all authors](#) • [Show footnotes](#)

[Open Access](#) • Published: July 15, 2021 • DOI: <https://doi.org/10.1016/j.eclinm.2021.101611>



LONG-HAULERS ARE REDEFINING COVID-19

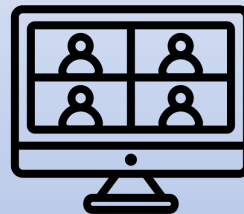
Without understanding the lingering illness that some patients experience, we can't understand the pandemic.

By Ed Yong



MassME's Fourth Decade

- **2018** New (current) name
- **2018** Hosted screenings of *Unrest*
- **2021** Developed resources for Long COVID and joined the Long COVID Alliance
- **2022** First paid staff

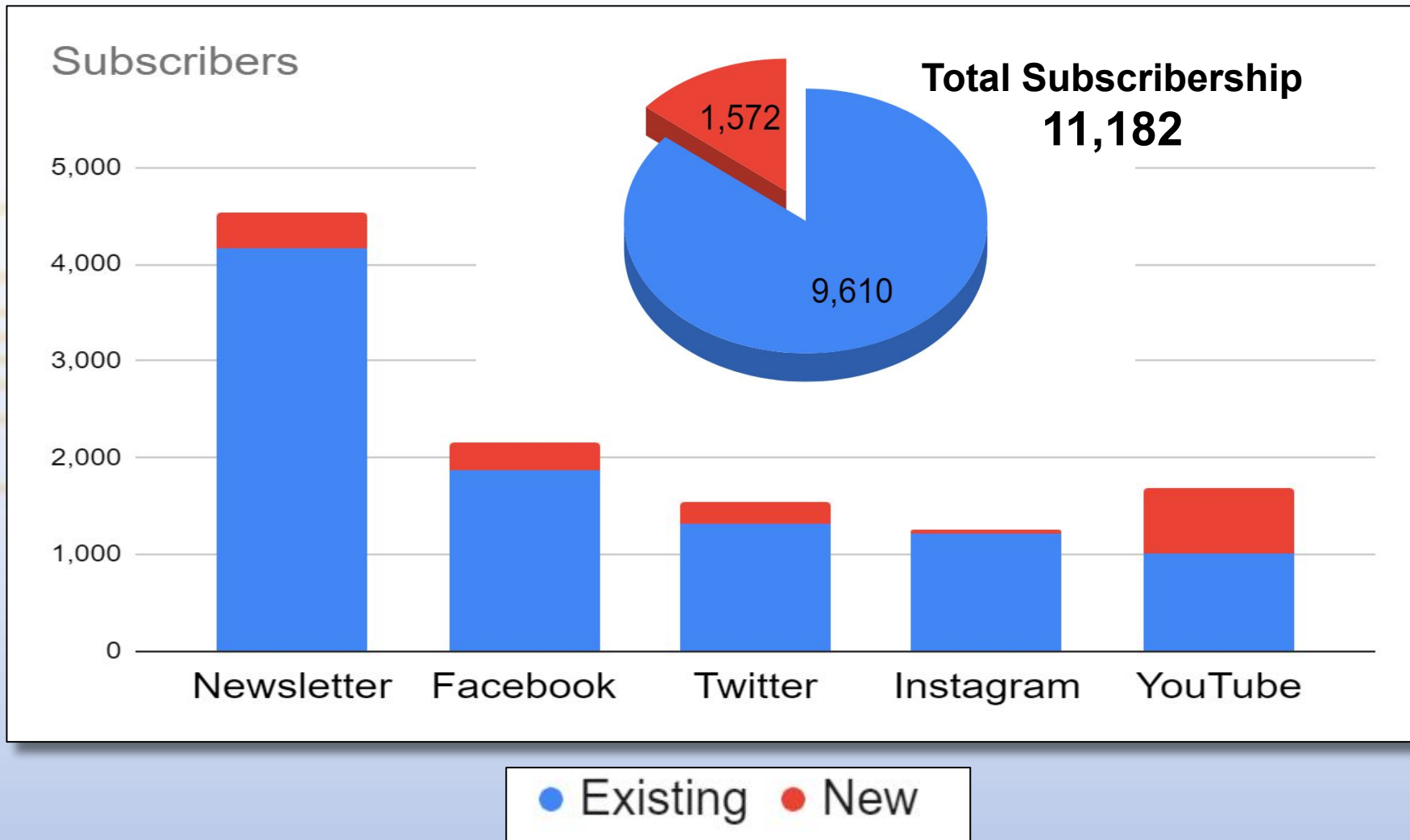


Our Reach in 2023

- 4537 people receive our monthly newsletter
- 746 people participated in Sunday Conversations
- 208 people received individual guidance, referral, and information
- 178 people participated in our support groups



Subscribers in 2023



Into the Future

NATIONAL
ACADEMIES

Sciences
Engineering
Medicine

Toward a Common Research Agenda in Infection-Associated Chronic Illnesses: A Workshop to Examine Common, Overlapping Clinical and Biological Factors

THE POWER OF COMMUNITY:
#IACCPAC INITIATIVE TEAM IDENTIFIES
NEEDS AND PRIORITIES OF THE
INFECTION-ASSOCIATED CHRONIC
CONDITIONS COMMUNITY

**ME/CFS Research
Roadmap**
WEBINAR SERIES

Scientists are meeting in Santa Fe to unravel the mystery of long COVID



National Institute of
Neurological Disorders
and Stroke



MASSME@40



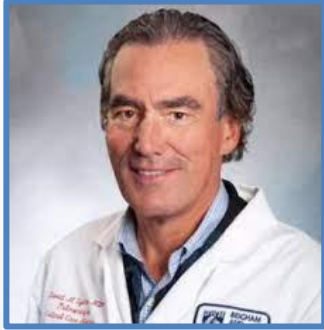
NEW LIGHT



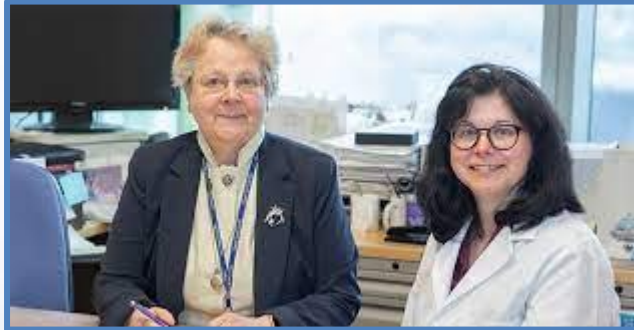
Massachusetts Movers and Shakers



Charmian Proskauer
USAWG



David Systrom
BWH



Liisa Selin and Anna Gil
UMass Chan Medical School



Anthony Komaroff
Harvard Medical
School



Amy Proal
PolyBio



Beth Pollack
Tal Research Group



Erica Verrillo
AAMES



Rep. Mindy Domb
MA Legislature



Ayanna Pressley
MA Representative



Donna Felsenstein
MGH



Michael VanElzakker
MGH



Rivka Solomon
Intrepid Advocate



Hayla Sluss
UMass Chan
Medical School



Massachusetts Movers and Shakers

Mindy Domb, Representative Hampshire 5th District



- Champion for health equity in Massachusetts
- H2147: Long COVID and related illnesses
- Facilitated MassME testimony before legislature



Massachusetts Movers and Shakers

Donna Felsenstein, M.D. MGH Infectious Disease

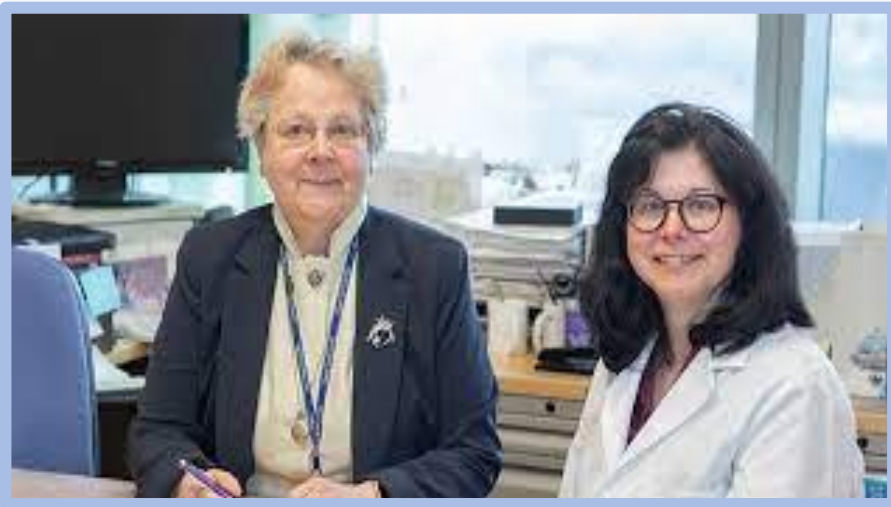


- ME/CFS Clinical Practice for FOUR DECADES!
- Member, US ME/CFS Clinician's Coalition
- Advanced Lyme Disease Testing and Treatments



Massachusetts Movers and Shakers

Liisa K. Selin, MD, PhD, UMass Chan Medical School
Anna Gil, PhD, UMass Chan Medical School



- Ramsey award winners and NIH Researchers UMass Chan Medical School
- T cell exhaustion in ME/CFS, Long Covid and multiple sclerosis

Massachusetts Movers and Shakers

Anthony Komaroff, MD



- Professor of Medicine, Harvard Medical School
- Director Emeritus, Division of General Internal Medicine, Brigham & Women's
- Caregiver and researcher, ME/CFS, for 40 years

"More than any other scientific journalist in recent years, Ed Yong has understood and communicated the importance of ME/CFS and other, similar post-acute infection illnesses. He deserves our gratitude."



Massachusetts Movers and Shakers

Beth Pollack, Research Scientist MIT



- IACC shared pathophysiology/MAESTRO
- NIH ME/CFS Research Roadmap Working Group
- Patient Led Research Collaborative

“Thank you so much, Ed Yong, for writing about ME/CFS with the detailed nuance and expertise it requires, while also writing with deep compassion and care about the patient experience.”



Massachusetts Movers and Shakers

Amy Proal, Founder PolyBio Research



- Interdisciplinary IACC research
- Rapid translational results
- Articulate, passionate communicator:
“LongCovid and ME/CFS are not mysterious or hopeless”



Massachusetts Movers and Shakers

Charmian Proskauer, USAWG



- Founding member and current Chair of the U.S. Action Working Group (USAWG)
- Past President of MassME
- Leader of Sunday Conversations lectures

“Ed Yong’s 2022 piece in the Atlantic really put ME/CFS in front of a national audience. It’s my go-to reference when we want to quickly educate someone who is new to this community.”*



Massachusetts Movers and Shakers

Ayanna Pressley, Representative, 7th Congressional District



- ...Those closest to pain should be closest to power
- Co-author: Treat Long COVID Act
- Facilitates legislation review by MassME

Massachusetts Movers and Shakers

Hayla K Sluss, PhD



- Director RECLAIM commonalities in IACC
- UMass Chan Disability Curriculum Working Group

“Ed Yong captured the complex physical, social, and economic impact of ME/CFS and Long COVID. His empathy and thoughtful consideration is what we all hope for anyone working with patients in complex chronic illness.”



Massachusetts Movers and Shakers

Rivka Solomon, Independent Advocate



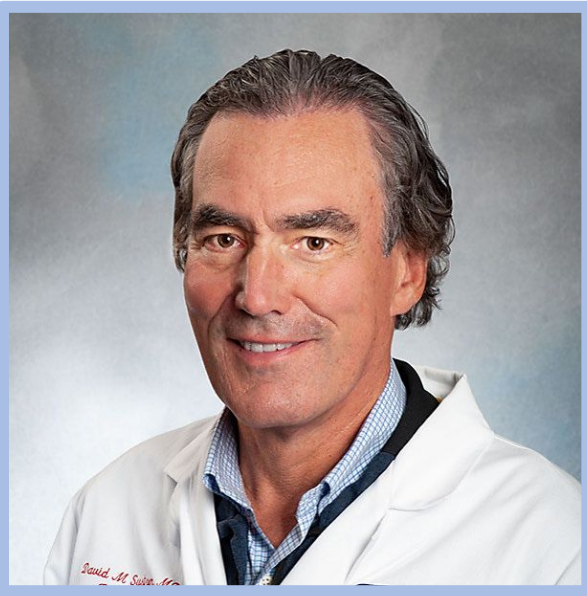
- 30+ years advocating for, and organizing with, people with ME/CFS and Long COVID
- Representing our community on Capitol Hill, with healthcare facilities, researchers, & the media (e.g. PBS NewsHour, WBUR, Wash Post)
- Longtime member of MassME

"Ed, thank you for caring about people with ME/CFS and Long COVID."



Massachusetts Movers and Shakers

David Systrom, BWH Heart and Vascular Center



- Co-Director: Ronald G. Tompkins Harvard ME/CFS Collaborative
- Pioneered the use of Invasive Cardiopulmonary Exercise Test for research and diagnosis in ME/CFS
- Published a clinical trial on the use of Pyridostigmine/Mestinon

"Thank you Ed for your fabulous work in educating the public about all things ME and long Covid; the physician scientists working in the area are most grateful."



Massachusetts Movers and Shakers

Michael VanElzakker, Co-Founder PolyBio



- Pioneering work in ME/CFS neuroinflammation
- Research on Vagus nerve and microglia cell behavior
- Relentless advocate for ME/CFS funding



Massachusetts Movers and Shakers

Erica Verrillo, AMMES



- Founder of the American ME and CFS Society (<https://ammes.org/>)
- Author of *Chronic Fatigue Syndrome: A Treatment Guide, 2nd Edition*
- Former Editor at *ProHealth*

“Ed Yong’s essays are not only deserving of a Pulitzer Prize, they have been life savers for the many people with Long COVID who simply have been ignored. Those of us who have suffered with ME for decades are more than familiar with the experience of being pushed aside, which makes Yong’s essays all the more significant.”



MASSACHUSETTS ME/CFS AND FM ASSOCIATION ANNUAL EVENT

ME/CFS: CHANGING THE NARRATIVE

**Guest Speaker:
Ed Yong**

Media partner: STAT News
STAT

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Introduction by Helen McGunnigle, Volunteer



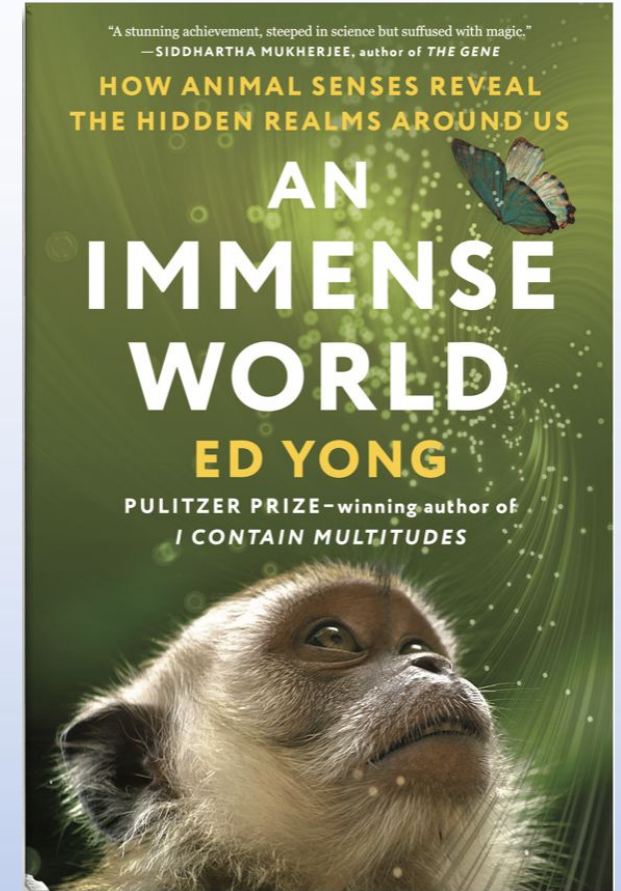
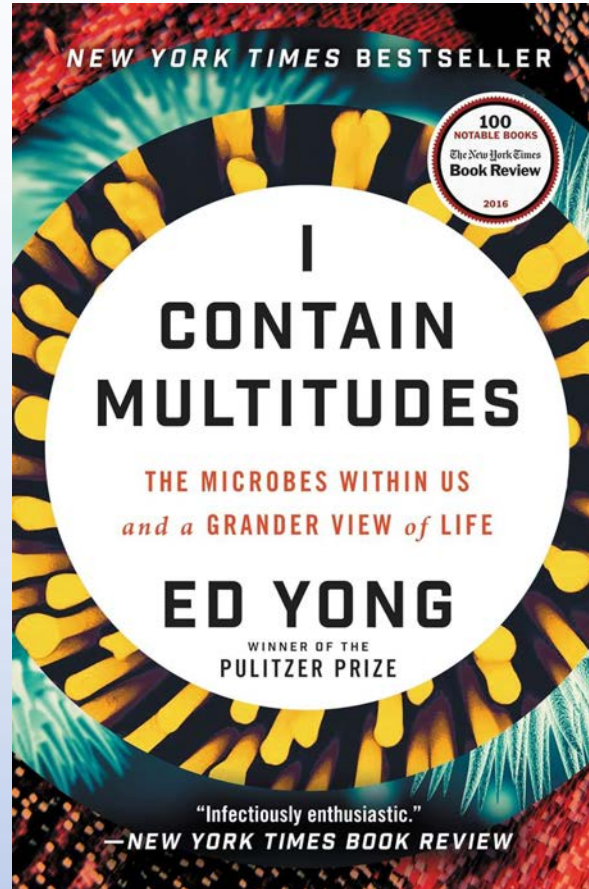
Awards

- Pulitzer Prize in explanatory journalism
- George Polk Award for science reporting
- Benton Award for distinguished public service
- Victor Cohn Prize for medical science reporting
- Neil and Susan Sheehan Award for Investigative Journalism
- John P. McGovern Award from the American Medical Writers' Association
- AAAS Kavli Science Journalism Award for in-depth reporting



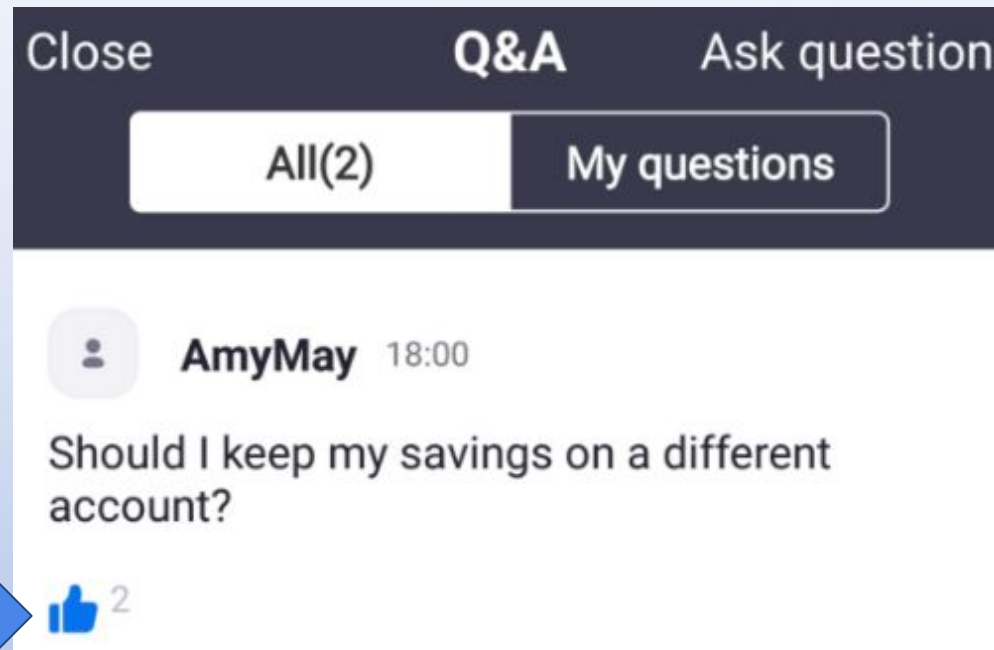
Publications

- The Atlantic
- National Geographic
- The New Yorker
- Wired
- The New York Times
- Nature
- New Scientist
- Scientific American



10 Minute Break

- Use Q&A to pose question(s) to Ed
- Upvote questions others have asked



Click to upvote a question



The soothing music you are about to hear has been generously shared with us by our friend Will Baird.



To enjoy more of Will's music, visit him at www.WillBaird.com



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Solve M.E.



ME/CFS Advocates of Rochester
Promoting community, awareness, advocacy and support.



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Whittemore Peterson Institute



Committed to finding answers for the millions impacted by ME through research, education, and individualized service programs.



www.wpi.ngo

WPI believes that the work of the MassME organization is vital to the wellbeing of our chronic disease patient population.



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Open Medicine Foundation (OMF)



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Envisioning improved health care for patients suffering from multisystem chronic, complex diseases with collaboration between patients, clinicians, and researchers.



THANK YOU

Solve M.E.



solvecfs.org

Serving as a catalyst for critical research into diagnostics, treatments, and cures for ME/CFS, Long COVID, and other infection associated chronic conditions.

This topic is very important and timely for our community.



THANK YOU

#MEAAction



meaction.net

Building a global movement to fight for recognition, education, and research so that, one day, all people with ME will have support and access to compassionate and effective care.

#MEAAction believes that narrative change can improve awareness and understanding of ME.



THANK YOU

ME/CFS Advocates of Rochester



about.me/MECFS.Rochester

Patients with ME/CFS and their supporters engaging in education, research and outreach regarding ME/CFS.

We partner with like-minded organizations promoting community, awareness, advocacy, and support for individuals affected by ME/CFS in Upstate New York.



THANK YOU

NJ ME/CFS Association



We are patients and families with ME/CFS and we are here to support, inform, and help you to deal with this serious illness.



njmecfsa.org

We too are a patient advocacy/health organization and wish to promote such activities.



THANK YOU

Johnson Compounding



naturalcompounder.com

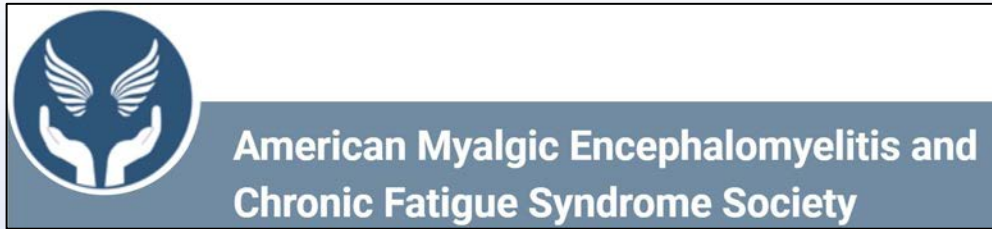
Providing compounding services which includes pediatric & ophthalmic compounding, Men & Women's health, as well as providing Consultative services for any & all of your Naturopathic, Dietary & Nutritional needs.

At Johnson Compounding we are happy to support MassME and the goal to improve patients quality of life that are struggling every day.



THANK YOU

American ME and CFS Society



ammes.org

Dedicated to serving the needs of patients and caregivers through support, advocacy, and education.

MassME, you do a great job!



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health, medicine, and the life
sciences.

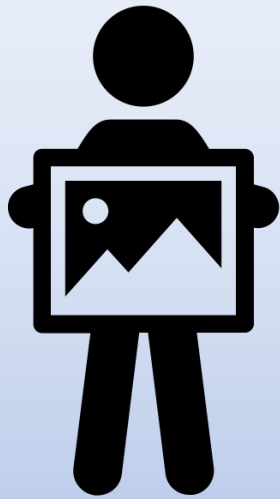


Illuminated Bridges in MA

World ME Day, May 12, 2023



Letters to MassME and our Patient Art Share



*Thank you to the people with ME/CFS
who share their art with us!*





'Heal'
by CJM



Dear MassME...

“I’m sorry for crying...it’s just that **you are the first person I ever talked to that seems to understand.**”



Dear MassME...

"Your organization has been a godsend to my family. Thank you for all you do!"





Turtle Boy
by Dyana/Diana



Dear MassME...

"I desperately need your organization's help with direction and referrals! [My son] tries to do something but crashes after 5 minutes."





Dear MassME...

“ I can’t find a [primary care physician] who will take Medicaid. **Do they think I want to be on Medicaid?**

Before I became sick I was working full-time, I was respected for what I did. I need your help.”





'Self Portrait (Tired)'

by Jehan Keziere

@jetsnacko



Dear MassME...

“MassMECFS very literally walked me through diagnosing myself and working with the Social Security System and [long term disability].

It continues to be a go-to for me
when I need a reality check.”

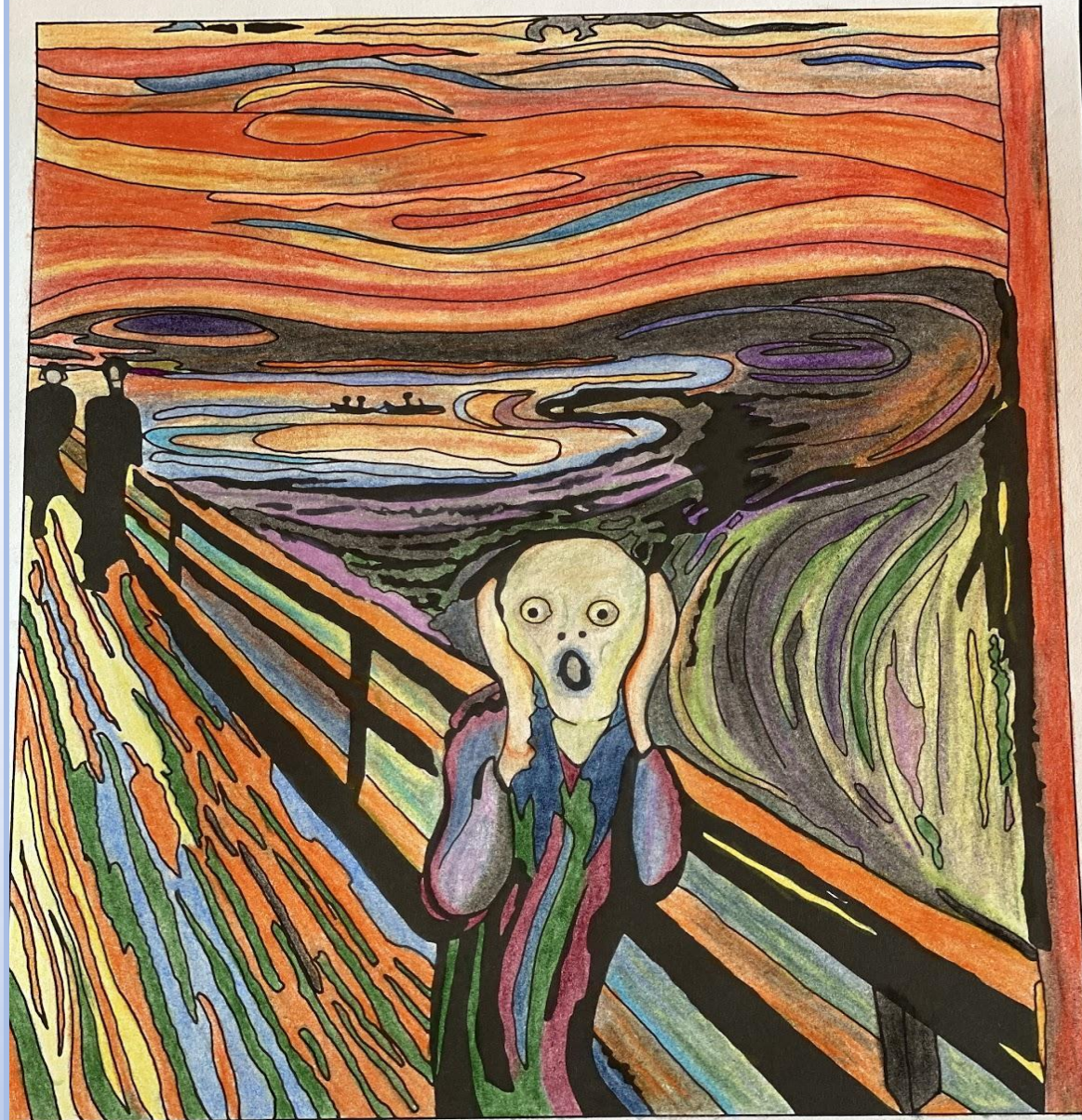




Dear MassME...

“Please, please help me find a specialist to see my 16- year-old daughter who has been suffering for 3 years...**Everyone treats her like this is psychosomatic**, and she cannot get accommodations at school.”





~ P. Thorpe 2020
Pandemic / ME/CFS

The Scream, by Edvard Munch symbolizes the anxiety of the human condition.

Colored in 2020 during the covid pandemic and in my 17th year disabled with ME/CFS.

P. Thorpe



Dear MassME...

"It's a great thing that you and your work teammates are doing. Much appreciated."



Dear MassME...

“Just a note to tell you **thank you for
your help** in locating an attorney.





'Healing Hand'
by DELORE

Dear MassME...

**"Thanks for giving me hope.
I finally zeroed in on what I might need."**





Dear MassME...

“Thank you for giving me hope. I can’t believe that I am smiling about this horrible illness.”





Untitled
by Melissa Kulig



Dear MassME...

“You deserve an award for helping patients despite being a patient yourself. **You are in my heart.**”





Dear MassME...

“Hello! **I am very grateful** and happy to tell you that through your referral...my daughter was diagnosed with ME/CFS! Thank you!





'White Sea Glass n Pearl'
by Dyana/Diana



Dear MassME...

“None of these doctors really recognize CFS as an actual disease, and I need a diagnosis so that I can let others know that I am suffering from a disabling illness. **If there is anything worse than going through this, it is not having anyone believe me...**”



Dear MassME...

"Thank you SO very much for all your hard work compiling this information."





'Green for a Hopeful Spring'
by Melissa Kulig



Dear MassME...

“Thank you so very much for researching and organizing all of this incredible housing information. **I am so grateful to you.** Truly.”





Dear MassME...

"I am just now digesting all of this and am so **grateful for people like you** in the world who volunteer to improve the lives of others."





'Varied Shades on
the Healing Path'
by CJM





Dear MassME...

“Thank you so very much for these helpful resources.

I am grateful for the work of you and your colleagues. I truly hope someday that the efforts to find precise diagnostic tools and therapeutics will benefit patients who suffer from this condition.”





Dear MassME...

"This is wonderful. Thank you very much for doing the research and compiling these names for me. I know every bit of work and interaction takes energy and my daughter and I are very grateful that you have shared some of that precious resource with us."





Dear MassME...

"MassME was an unexpected gift that provided me with medical insights and most importantly access to thousands of other people who are suffering just like me. To be able to share coping skills and learn effective treatment methods from people who wear the same shoes...was, and is, **a priceless find.**"





Dear MassME...

"You should not underestimate the importance of what you are doing. **You guys really make a difference!"**





Dear MassME...

"Oh my gosh. I can't believe you called me back!

I'm sorry. I need to catch my breath."





Dear MassME...

"I must find a doctor capable of understanding my illness...I have been unable to hold a job despite being more functional than some others with the illness. **I wish I could work!**"



Dear MassME...

“Following each MD appointment **there is no follow-up**, so they either do not believe me or they feel I am too sick or terminal and do not want to be involved. And I have to start from scratch.”



Dear MassME...

"I have no help, I can't get help.

Please I need someone to really help."





Dear MassME...

“THANK YOU! All of this is amazing help. **I feel so supported and so much less alone!**

Thank you so much!!”



MASSACHUSETTS ME/CFS AND FM ASSOCIATION ANNUAL EVENT

ME/CFS: CHANGING THE NARRATIVE

Q & A with
Ed Yong

Media partner: STAT News
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November 6, 2023



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Monday, November 6, 2023



12:00 PM ET – 4:00 PM ET

Doors open at 11



Auditoriums E & F
Dartmouth–Hitchcock
Medical Center
One Medical Center Drive
Lebanon, NH 03766

Plan of the Day

- 12:00–12:10 Opening Remarks
- 12:10–1:10 Grand Rounds Lecture
- 1:15–2:15 Educating Each Other: Enhancing Patient/
Provider Collaboration
- 2:30–2:50 The Future of Medicine and Research
- 2:50–4:00 Navigating the Systems: Challenges and
Strategies
- 4:00 Closing Remarks

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The Chat Will Remain Open For Another 10 Minutes



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