Massachusetts ME/CFS & FM
ASSOCIATION
EDUCATION, SUPPORT & ADVOCACY SINCE 1985

Zoom through 40 years of ME/CFS with MassME!

June 18, 2023

Housekeeping

- Please stay muted
- Put comments in the chat
- A recording of the presentation will be posted after the event

While we have done our best to be accurate, we have also been selective in choosing highlights of our Association's and our community's history.

We apologize if we have made any errors and welcome corrections.

Massachusetts ME/CFS & FM
ASSOCIATION
EDUCATION, SUPPORT & ADVOCACY SINCE 1985

Welcome!

Susan Buckley
MassME Co-President

MASSME@40

NEW LIGHT

Massachusetts ME/CFS & FM
ASSOCIATION
EDUCATION, SUPPORT & ADVOCACY SINCE 1985

Zoom through 40 years of ME/CFS with MassME!

First Decade: Charmian Proskauer

Second Decade: Phil Chernin

Third Decade: Hayla Sluss

Fourth Decade: Helen McGunnigle

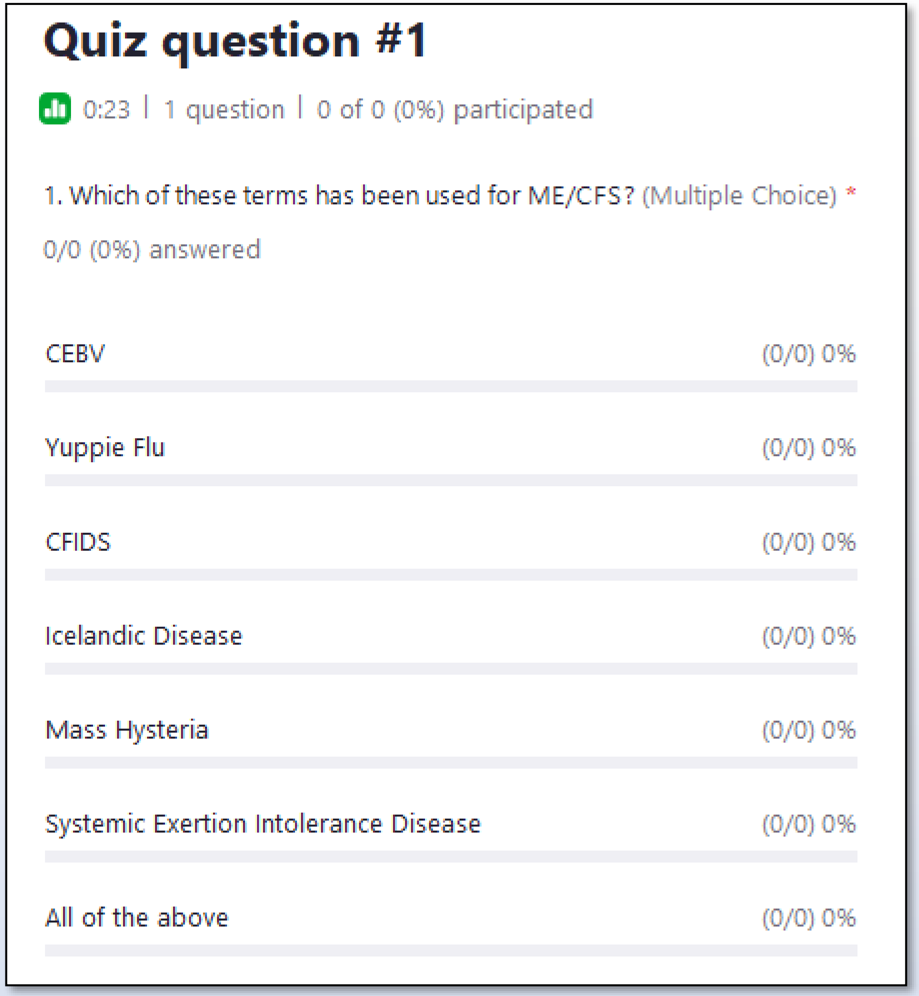
Interview: Jehan Keziere and Ken Casanova

Massachusetts ME/CFS & FM
ASSOCIATION
EDUCATION, SUPPORT & ADVOCACY SINCE 1985

First Decade 1983-1992

Building a solid foundation.

Charmian Proskauer
MassME Past President



Quiz question #1

0:23 | 1 question | 0 of 0 (0%) participated

1. Which of these terms has been used for ME/CFS? (Multiple Choice) *

0/0 (0%) answered

CEBV	(0/0) 0%
Yuppie Flu	(0/0) 0%
CFIDS	(0/0) 0%
Icelandic Disease	(0/0) 0%
Mass Hysteria	(0/0) 0%
Systemic Exertion Intolerance Disease	(0/0) 0%
All of the above	(0/0) 0%

1983 - 1992 World Events

1986
Ramsay criteria

1988
Holmes case definition

1992
First Primer

Dr. Gurwitt/MassME collaborates on First Primer for Adults

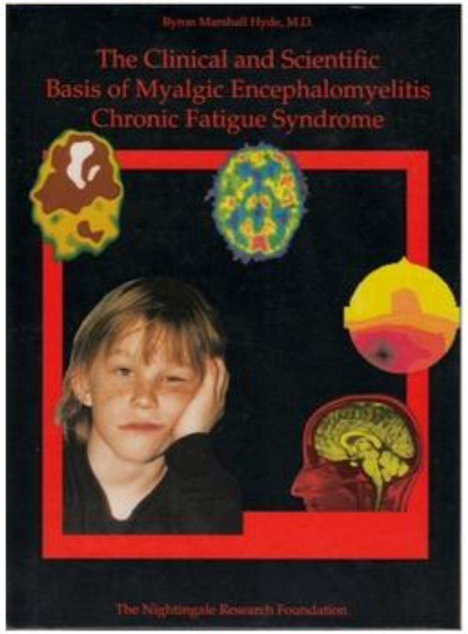
chronic CEBV

1985 JAMA Paper
Dr. Strauss
recognizing chronic EBV

Incline Village Outbreak

1984

786 research publications



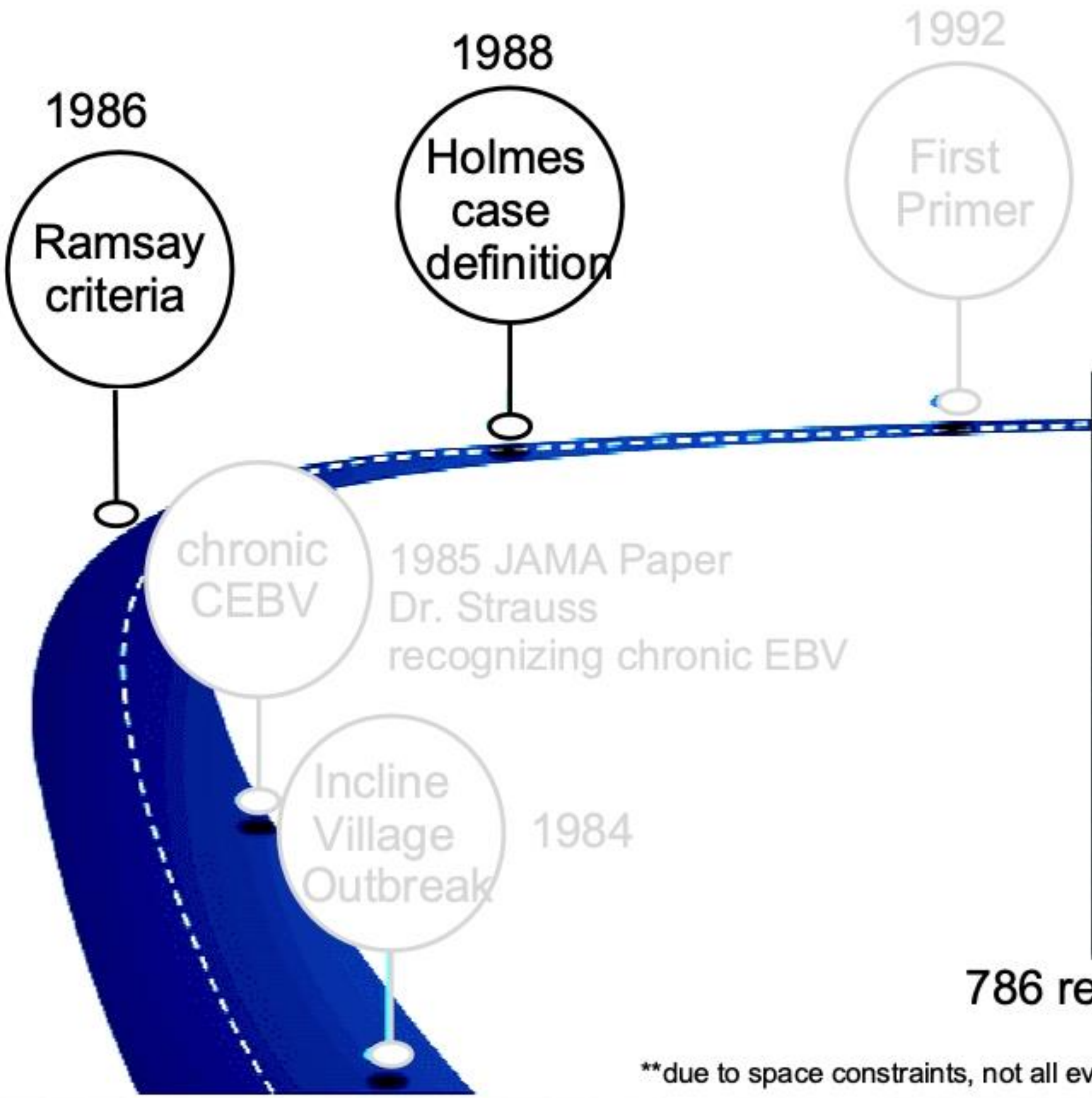
Byron Marshall Hyde, M.D.

The Clinical and Scientific
Basis of Myalgic Encephalomyelitis
Chronic Fatigue Syndrome

The Nightingale Research Foundation

**due to space constraints, not all events are listed

1983 - 1992 World Events



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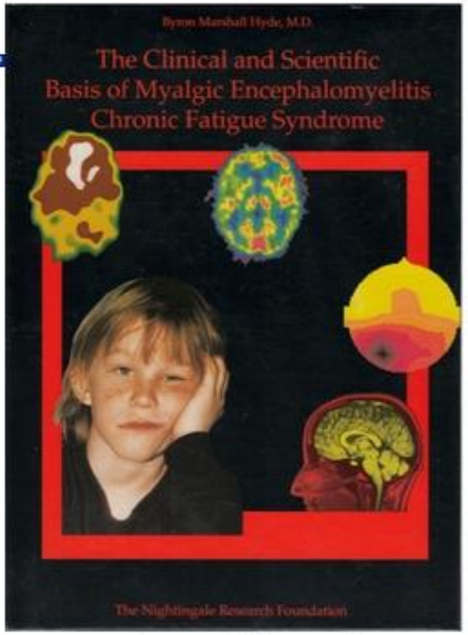

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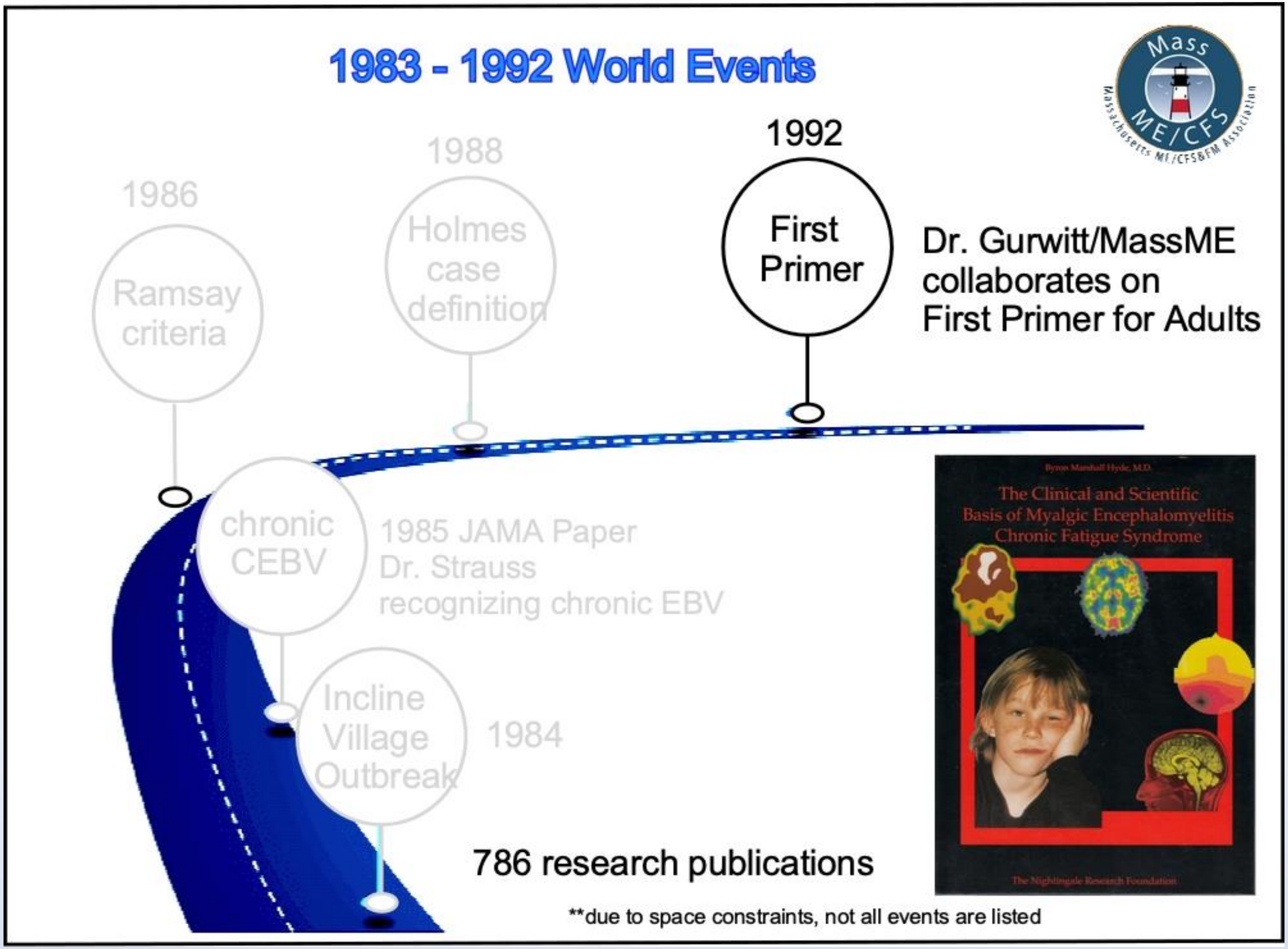

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Chronic Fatigue Syndrome
The Nightingale Research Foundation

786 research publications

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The Disease of a Thousand Names

CFIDS

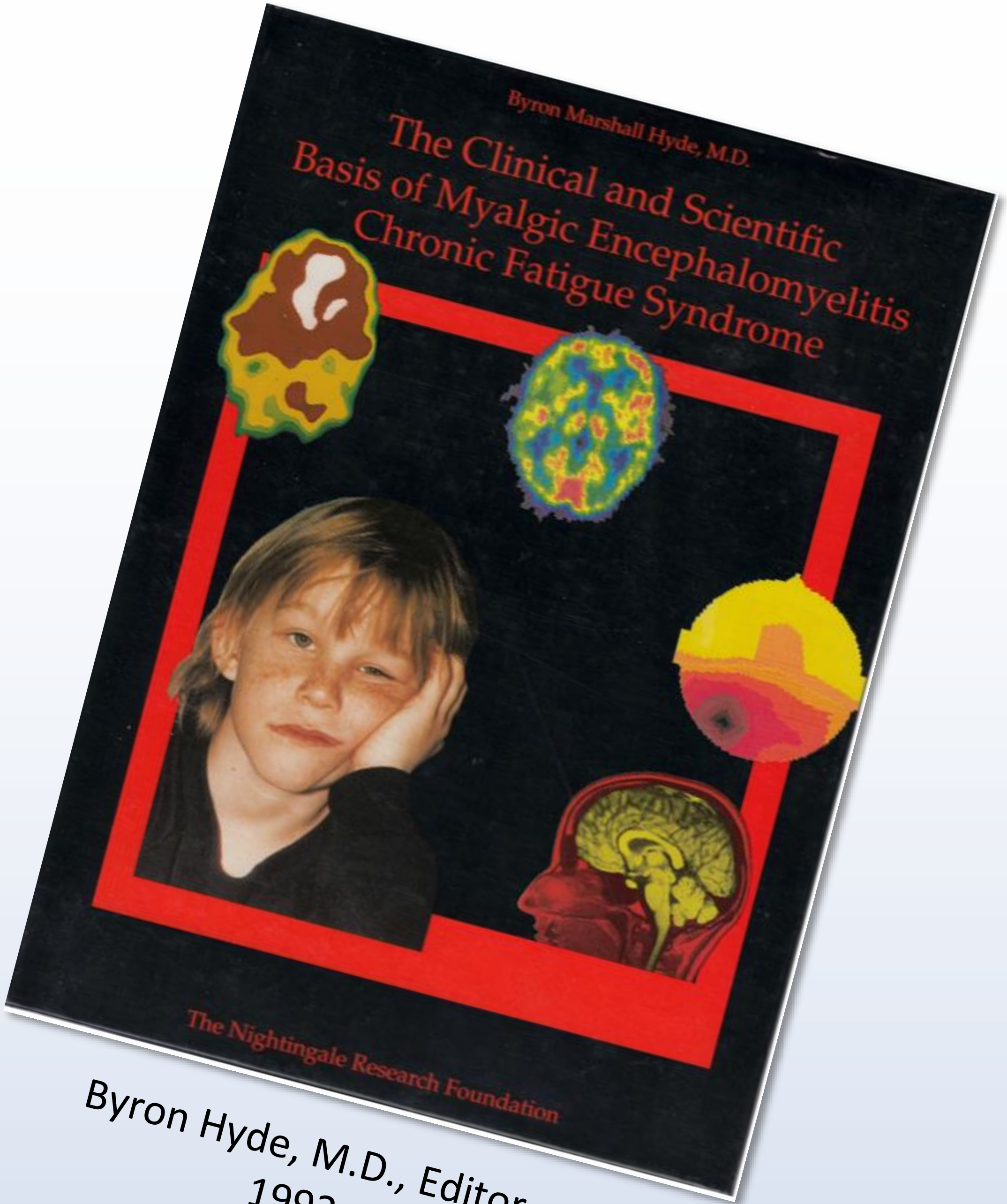
Chronic Fatigue/Immune Dysfunction Syndrome

by David S. Bell MD, FAAP

Also Known As

Chronic Fatigue Syndrome; CFS; Chronic Immune Activation Syndrome; CIAS; Chronic Immune Dysfunction Syndrome; CIDS; Fibromyositis; 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;

The Disease of A Thousand Names
David Bell, M.D. 1991



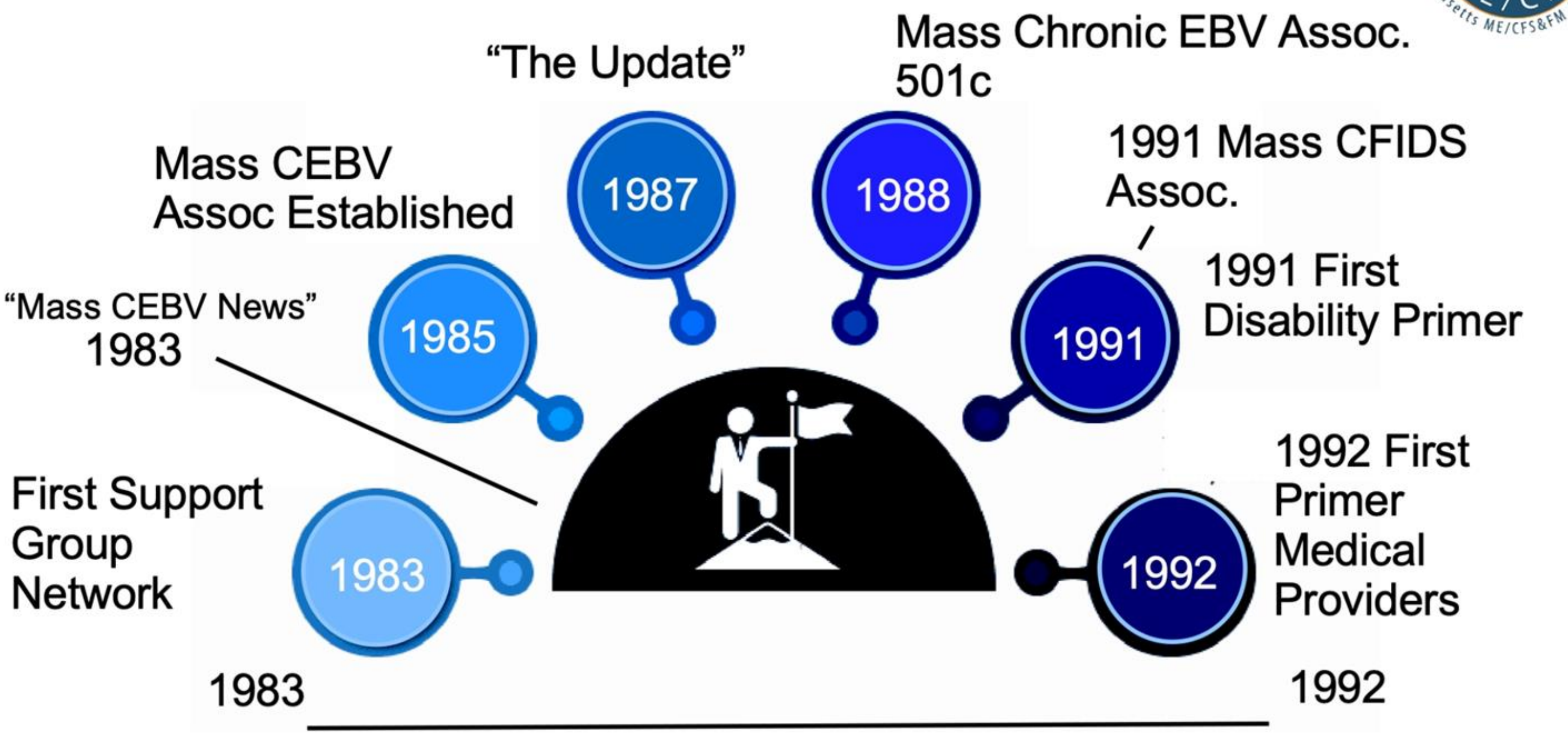
Byron Marshall Hyde, M.D.

The Clinical and Scientific Basis of Myalgic Encephalomyelitis Chronic Fatigue Syndrome

The Nightingale Research Foundation

Byron Hyde, M.D., Editor
1992

MassME/CFS & FM Association Achievements



First Support Group Network — 1983

"Mass CEBV News" 1983

Mass CEBV Assoc Established — 1985

"The Update" — 1987

Mass Chronic EBV Assoc. 501c — 1988

1991 Mass CFIDS Assoc.

1991 First Disability Primer

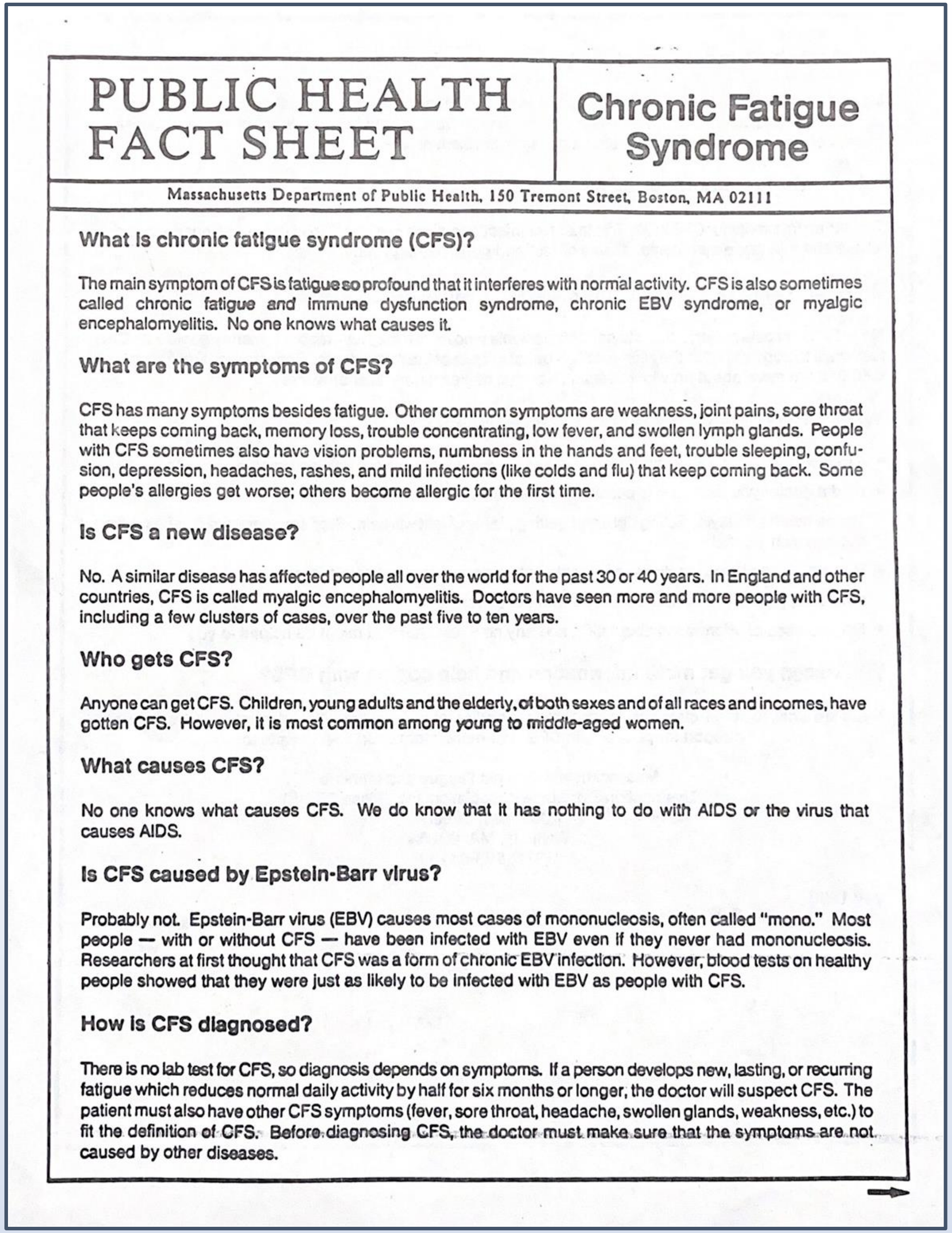
1992 First Primer Medical Providers

1983 — 1992

Support Groups

"Lending Library"

InfoLine Dial-in Support Communications



PUBLIC HEALTH FACT SHEET

Chronic Fatigue Syndrome

Massachusetts Department of Public Health, 150 Tremont Street, Boston, MA 02111

What is chronic fatigue syndrome (CFS)?

The main symptom of CFS is fatigue so profound that it interferes with normal activity. CFS is also sometimes called chronic fatigue *and* immune dysfunction syndrome, chronic EBV syndrome, or myalgic encephalomyelitis. No one knows what causes it.

What are the symptoms of CFS?

CFS has many symptoms besides fatigue. Other common symptoms are weakness, joint pains, sore throat that keeps coming back, memory loss, trouble concentrating, low fever, and swollen lymph glands. People with CFS sometimes also have vision problems, numbness in the hands and feet, trouble sleeping, confusion, depression, headaches, rashes, and mild infections (like colds and flu) that keep coming back. Some people's allergies get worse; others become allergic for the first time.

Is CFS a new disease?

No. A similar disease has affected people all over the world for the past 30 or 40 years. In England and other countries, CFS is called myalgic encephalomyelitis. Doctors have seen more and more people with CFS, including a few clusters of cases, over the past five to ten years.

Who gets CFS?

Anyone can get CFS. Children, young adults and the elderly, of both sexes and of all races and incomes, have gotten CFS. However, it is most common among young to middle-aged women.

What causes CFS?

No one knows what causes CFS. We do know that it has nothing to do with AIDS or the virus that causes AIDS.

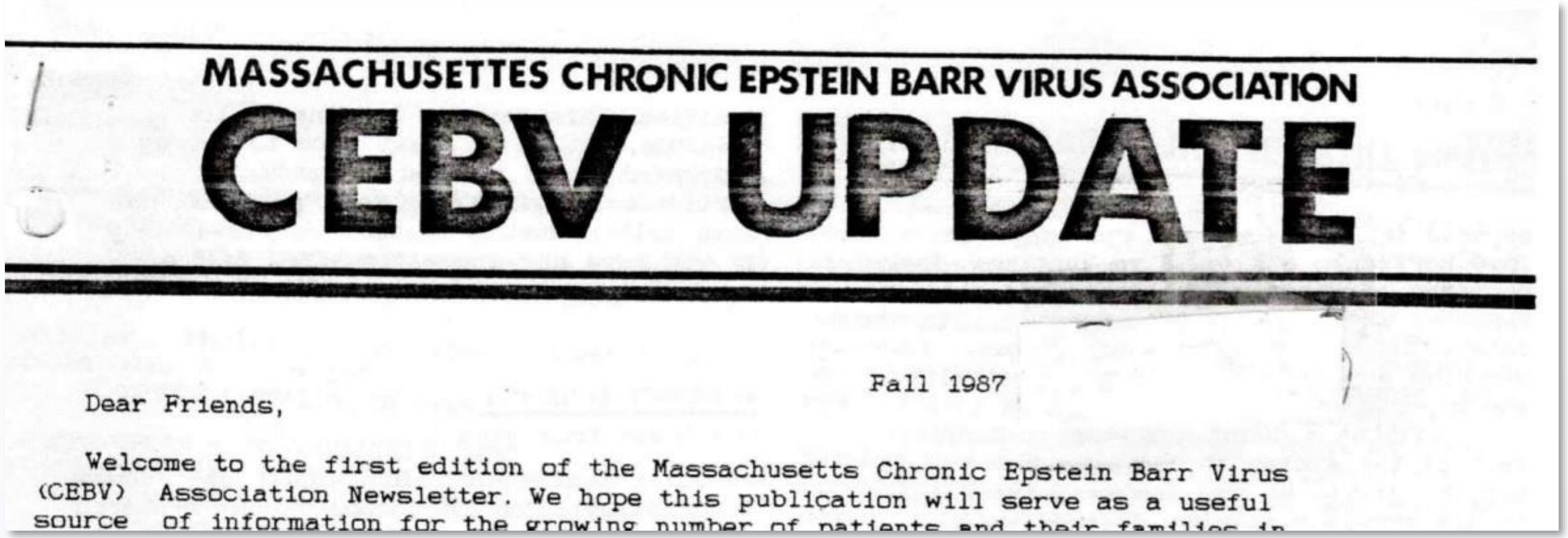
Is CFS caused by Epstein-Barr virus?

Probably not. Epstein-Barr virus (EBV) causes most cases of mononucleosis, often called "mono." Most people — with or without CFS — have been infected with EBV even if they never had mononucleosis. Researchers at first thought that CFS was a form of chronic EBV infection. However, blood tests on healthy people showed that they were just as likely to be infected with EBV as people with CFS.

How is CFS diagnosed?

There is no lab test for CFS, so diagnosis depends on symptoms. If a person develops new, lasting, or recurring fatigue which reduces normal daily activity by half for six months or longer, the doctor will suspect CFS. The patient must also have other CFS symptoms (fever, sore throat, headache, swollen glands, weakness, etc.) to fit the definition of CFS. Before diagnosing CFS, the doctor must make sure that the symptoms are not caused by other diseases.

→



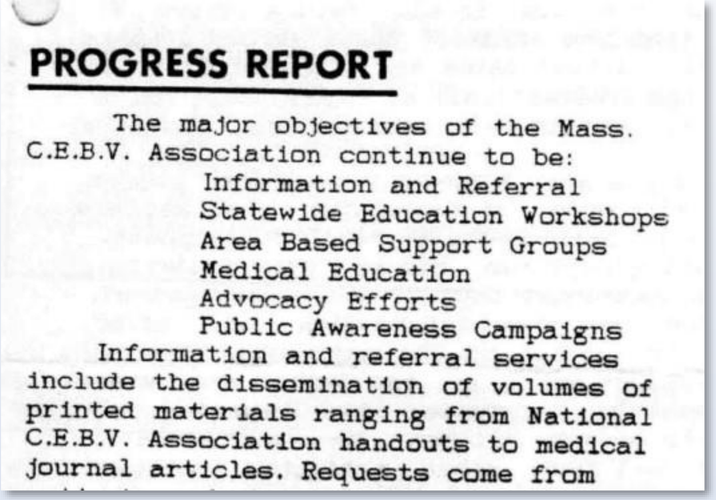
MASSACHUSETTES CHRONIC EPSTEIN BARR VIRUS ASSOCIATION

CEBV UPDATE

Fall 1987

Dear Friends,

Welcome to the first edition of the Massachusetts Chronic Epstein Barr Virus (CEBV) Association Newsletter. We hope this publication will serve as a useful source of information for the growing number of patients and their families in

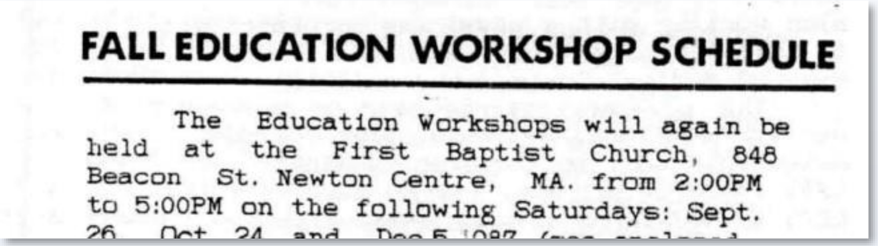


PROGRESS REPORT

The major objectives of the Mass. C.E.B.V. Association continue to be:

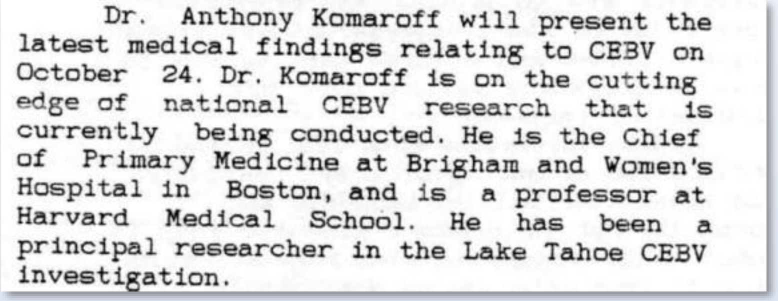
Information and Referral
Statewide Education Workshops
Area Based Support Groups
Medical Education
Advocacy Efforts
Public Awareness Campaigns

Information and referral services include the dissemination of volumes of printed materials ranging from National C.E.B.V. Association handouts to medical journal articles. Requests come from



FALL EDUCATION WORKSHOP SCHEDULE

The Education Workshops will again be held at the First Baptist Church, 848 Beacon St. Newton Centre, MA. from 2:00PM to 5:00PM on the following Saturdays: Sept. 26, Oct 24 and Dec 5 1987 (see enclosed

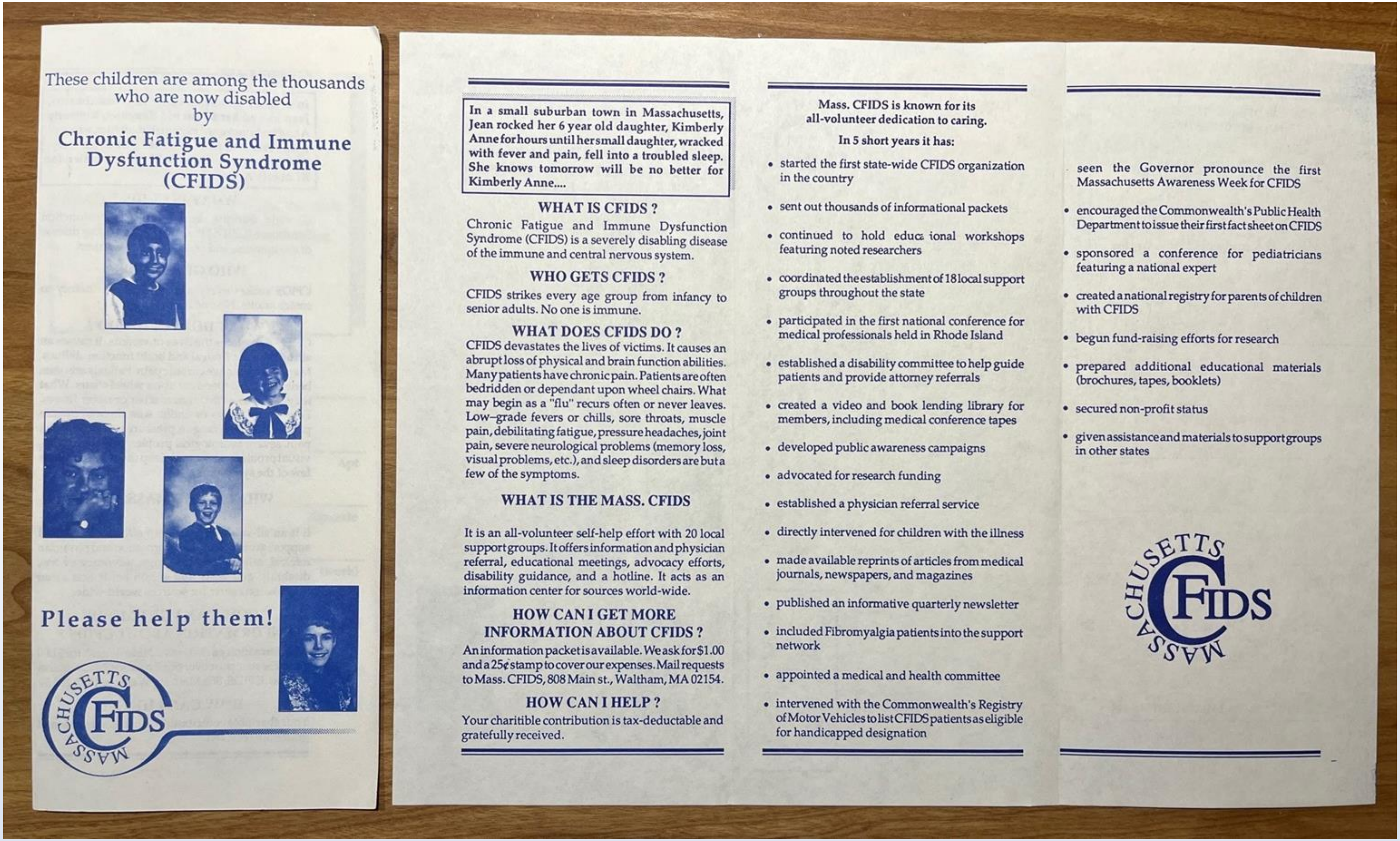


Dr. Anthony Komaroff will present the latest medical findings relating to CEBV on October 24. Dr. Komaroff is on the cutting edge of national CEBV research that is currently being conducted. He is the Chief of Primary Medicine at Brigham and Women's Hospital in Boston, and is a professor at Harvard Medical School. He has been a principal researcher in the Lake Tahoe CEBV investigation.

HOW TO APPLY FOR
SOCIAL SECURITY DISABILITY BENEFITS
IF YOU HAVE
CHRONIC FATIGUE SYNDROME

With Additional Information on Applying for Benefits if You Have Fibromyalgia

by Kenneth Casanova



These children are among the thousands who are now disabled by

Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS)

Please help them!

In a small suburban town in Massachusetts, Jean rocked her 6 year old daughter, Kimberly Anne for hours until her small daughter, wracked with fever and pain, fell into a troubled sleep. She knows tomorrow will be no better for Kimberly Anne....

WHAT IS CFIDS ?

Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) is a severely disabling disease of the immune and central nervous system.

WHO GETS CFIDS ?

CFIDS strikes every age group from infancy to senior adults. No one is immune.

WHAT DOES CFIDS DO ?

CFIDS devastates the lives of victims. It causes an abrupt loss of physical and brain function abilities. Many patients have chronic pain. Patients are often bedridden or dependant upon wheel chairs. What may begin as a "flu" recurs often or never leaves. Low–grade fevers or chills, sore throats, muscle pain, debilitating fatigue, pressure headaches, joint pain, severe neurological problems (memory loss, visual problems, etc.), and sleep disorders are but a few of the symptoms.

WHAT IS THE MASS. CFIDS

It is an all-volunteer self-help effort with 20 local support groups. It offers information and physician referral, educational meetings, advocacy efforts, disability guidance, and a hotline. It acts as an information center for sources world-wide.

HOW CAN I GET MORE INFORMATION ABOUT CFIDS ?

An information packet is available. We ask for $1.00 and a 25¢ stamp to cover our expenses. Mail requests to Mass. CFIDS, 808 Main st., Waltham, MA 02154.

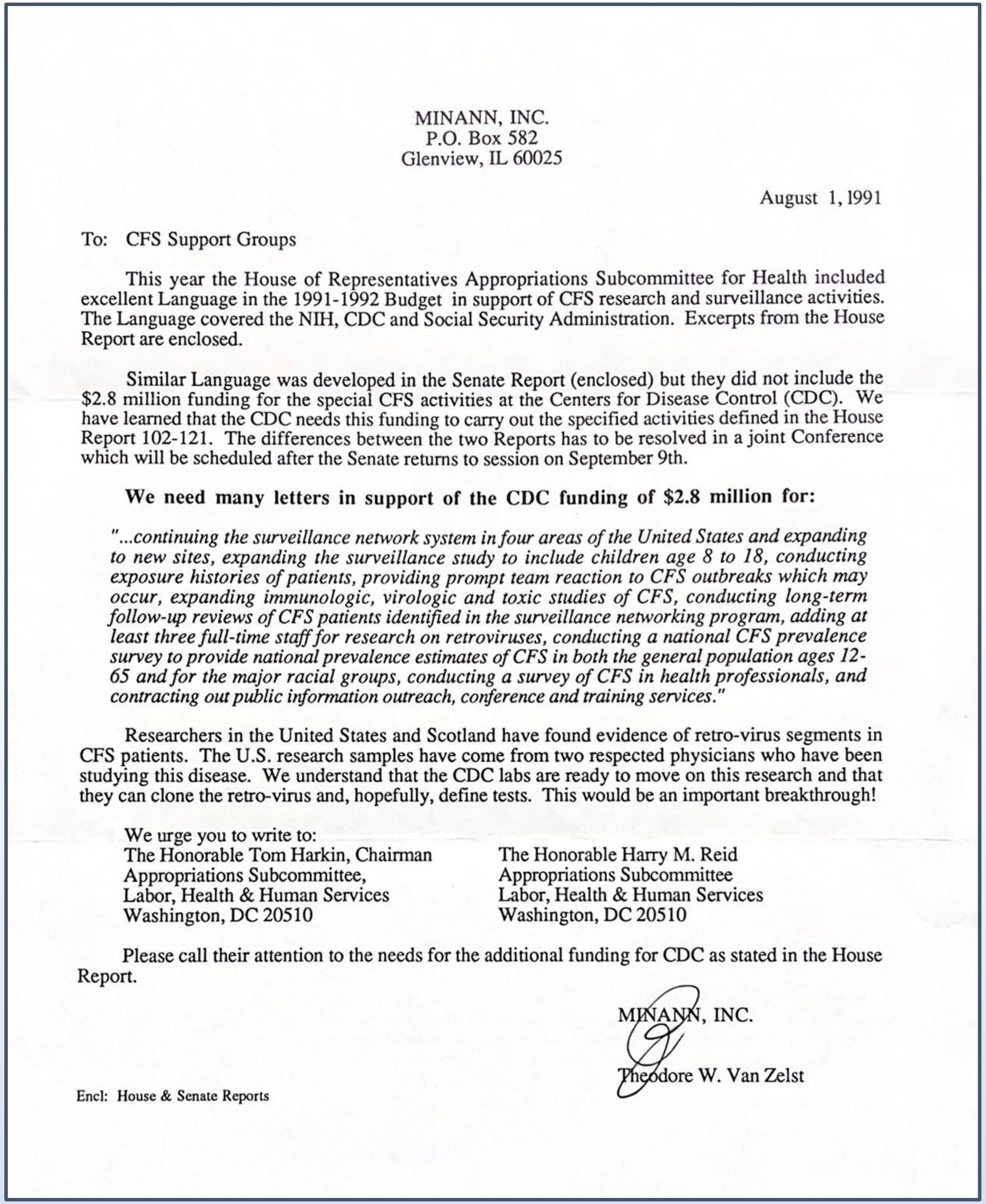
HOW CAN I HELP ?

Your charitible contribution is tax-deductable and gratefully received.

Mass. CFIDS is known for its all-volunteer dedication to caring.

In 5 short years it has:

- started the first state-wide CFIDS organization in the country
- sent out thousands of informational packets
- continued to hold educational workshops featuring noted researchers
- coordinated the establishment of 18 local support groups throughout the state
- participated in the first national conference for medical professionals held in Rhode Island
- established a disability committee to help guide patients and provide attorney referrals
- created a video and book lending library for members, including medical conference tapes
- developed public awareness campaigns
- advocated for research funding
- established a physician referral service
- directly intervened for children with the illness
- made available reprints of articles from medical journals, newspapers, and magazines
- published an informative quarterly newsletter
- included Fibromyalgia patients into the support network
- appointed a medical and health committee
- intervened with the Commonwealth's Registry of Motor Vehicles to list CFIDS patients as eligible for handicapped designation
- seen the Governor pronounce the first Massachusetts Awareness Week for CFIDS
- encouraged the Commonwealth's Public Health Department to issue their first fact sheet on CFIDS
- sponsored a conference for pediatricians featuring a national expert
- created a national registry for parents of children with CFIDS
- begun fund-raising efforts for research
- prepared additional educational materials (brochures, tapes, booklets)
- secured non-profit status
- given assistance and materials to support groups in other states



MINANN, INC.
P.O. Box 582
Glenview, IL 60025

August 1, 1991

To: CFS Support Groups

This year the House of Representatives Appropriations Subcommittee for Health included excellent Language in the 1991-1992 Budget in support of CFS research and surveillance activities. The Language covered the NIH, CDC and Social Security Administration. Excerpts from the House Report are enclosed.

Similar Language was developed in the Senate Report (enclosed) but they did not include the $2.8 million funding for the special CFS activities at the Centers for Disease Control (CDC). We have learned that the CDC needs this funding to carry out the specified activities defined in the House Report 102-121. The differences between the two Reports has to be resolved in a joint Conference which will be scheduled after the Senate returns to session on September 9th.

We need many letters in support of the CDC funding of $2.8 million for:

"...continuing the surveillance network system in four areas of the United States and expanding to new sites, expanding the surveillance study to include children age 8 to 18, conducting exposure histories of patients, providing prompt team reaction to CFS outbreaks which may occur, expanding immunologic, virologic and toxic studies of CFS, conducting long-term follow-up reviews of CFS patients identified in the surveillance networking program, adding at least three full-time staff for research on retroviruses, conducting a national CFS prevalence survey to provide national prevalence estimates of CFS in both the general population ages 12-65 and for the major racial groups, conducting a survey of CFS in health professionals, and contracting out public information outreach, conference and training services."

Researchers in the United States and Scotland have found evidence of retro-virus segments in CFS patients. The U.S. research samples have come from two respected physicians who have been studying this disease. We understand that the CDC labs are ready to move on this research and that they can clone the retro-virus and, hopefully, define tests. This would be an important breakthrough!

We urge you to write to:

The Honorable Tom Harkin, Chairman
Appropriations Subcommittee,
Labor, Health & Human Services
Washington, DC 20510

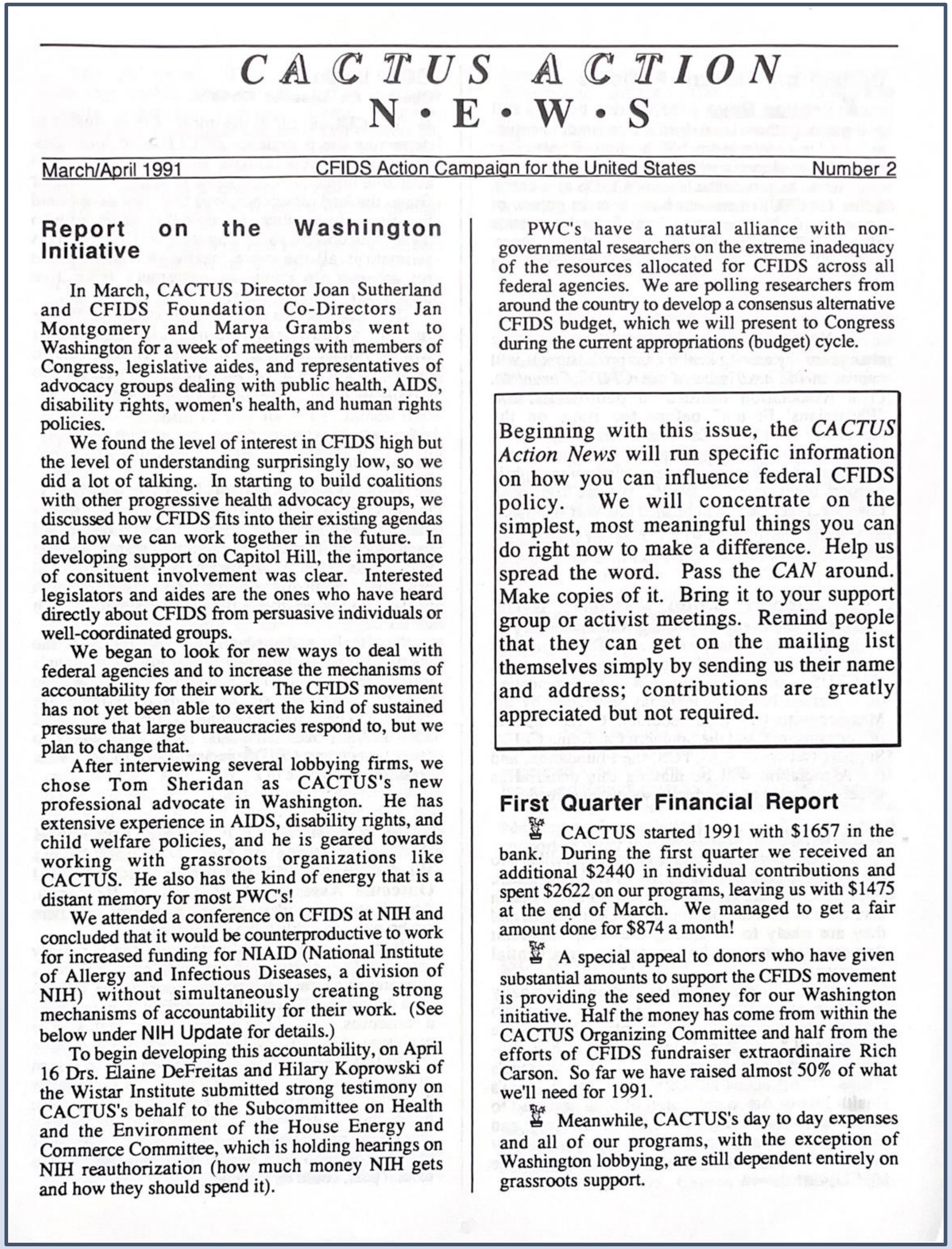
The Honorable Harry M. Reid
Appropriations Subcommittee
Labor, Health & Human Services
Washington, DC 20510

Please call their attention to the needs for the additional funding for CDC as stated in the House Report.

MINANN, INC.

Theodore W. Van Zelst

Encl: House & Senate Reports



CACTUS ACTION
N•E•W•S

March/April 1991 CFIDS Action Campaign for the United States Number 2

Report on the Washington Initiative

In March, CACTUS Director Joan Sutherland and CFIDS Foundation Co-Directors Jan Montgomery and Marya Grambs went to Washington for a week of meetings with members of Congress, legislative aides, and representatives of advocacy groups dealing with public health, AIDS, disability rights, women's health, and human rights policies.

We found the level of interest in CFIDS high but the level of understanding surprisingly low, so we did a lot of talking. In starting to build coalitions with other progressive health advocacy groups, we discussed how CFIDS fits into their existing agendas and how we can work together in the future. In developing support on Capitol Hill, the importance of consituent involvement was clear. Interested legislators and aides are the ones who have heard directly about CFIDS from persuasive individuals or well-coordinated groups.

We began to look for new ways to deal with federal agencies and to increase the mechanisms of accountability for their work. The CFIDS movement has not yet been able to exert the kind of sustained pressure that large bureaucracies respond to, but we plan to change that.

After interviewing several lobbying firms, we chose Tom Sheridan as CACTUS's new professional advocate in Washington. He has extensive experience in AIDS, disability rights, and child welfare policies, and he is geared towards working with grassroots organizations like CACTUS. He also has the kind of energy that is a distant memory for most PWC's!

We attended a conference on CFIDS at NIH and concluded that it would be counterproductive to work for increased funding for NIAID (National Institute of Allergy and Infectious Diseases, a division of NIH) without simultaneously creating strong mechanisms of accountability for their work. (See below under NIH Update for details.)

To begin developing this accountability, on April 16 Drs. Elaine DeFreitas and Hilary Koprowski of the Wistar Institute submitted strong testimony on CACTUS's behalf to the Subcommittee on Health and the Environment of the House Energy and Commerce Committee, which is holding hearings on NIH reauthorization (how much money NIH gets and how they should spend it).

PWC's have a natural alliance with non-governmental researchers on the extreme inadequacy of the resources allocated for CFIDS across all federal agencies. We are polling researchers from around the country to develop a consensus alternative CFIDS budget, which we will present to Congress during the current appropriations (budget) cycle.

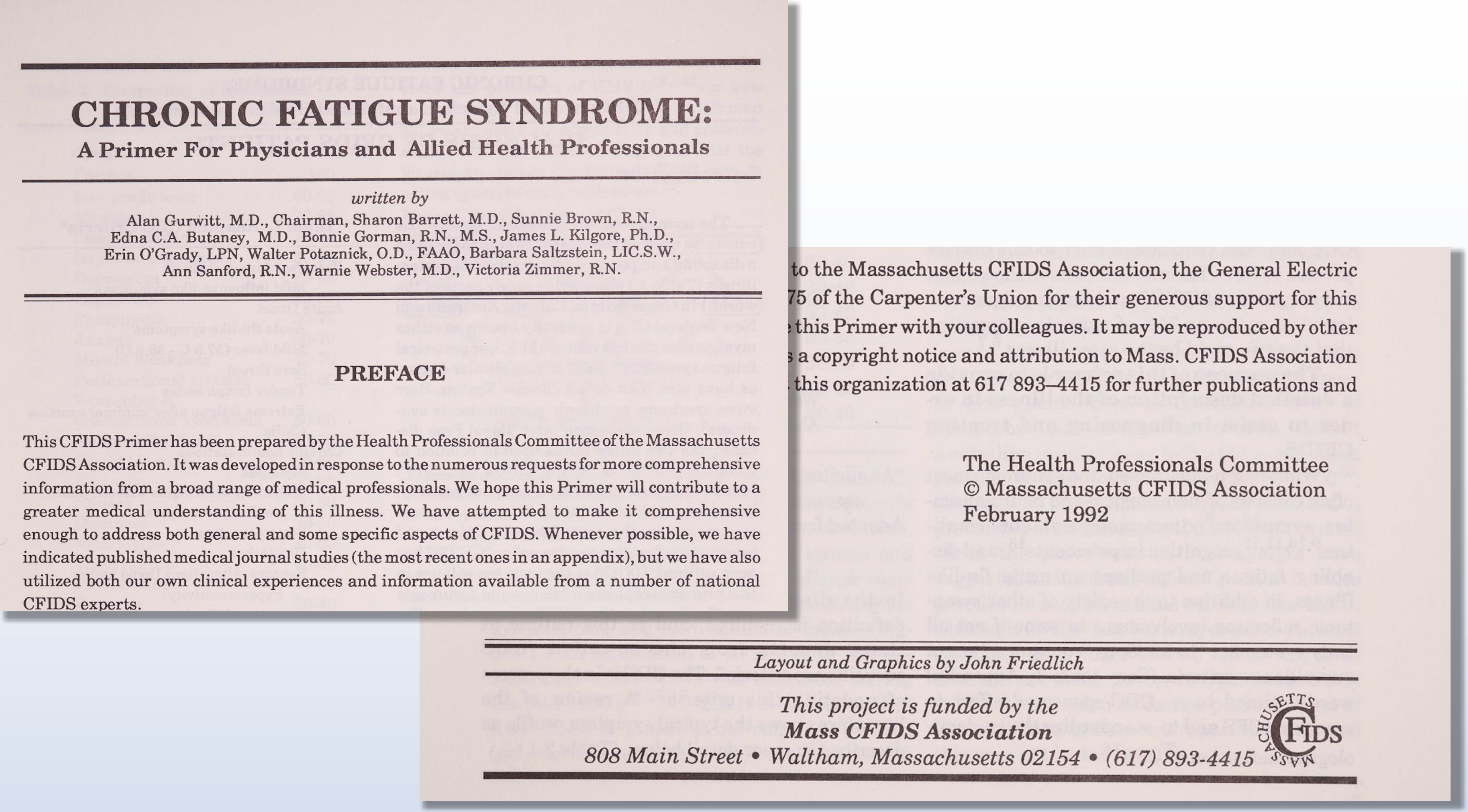
> Beginning with this issue, the *CACTUS Action News* will run specific information on how you can influence federal CFIDS policy. We will concentrate on the simplest, most meaningful things you can do right now to make a difference. Help us spread the word. Pass the *CAN* around. Make copies of it. Bring it to your support group or activist meetings. Remind people that they can get on the mailing list themselves simply by sending us their name and address; contributions are greatly appreciated but not required.

First Quarter Financial Report

CACTUS started 1991 with $1657 in the bank. During the first quarter we received an additional $2440 in individual contributions and spent $2622 on our programs, leaving us with $1475 at the end of March. We managed to get a fair amount done for $874 a month!

A special appeal to donors who have given substantial amounts to support the CFIDS movement is providing the seed money for our Washington initiative. Half the money has come from within the CACTUS Organizing Committee and half from the efforts of CFIDS fundraiser extraordinaire Rich Carson. So far we have raised almost 50% of what we'll need for 1991.

Meanwhile, CACTUS's day to day expenses and all of our programs, with the exception of Washington lobbying, are still dependent entirely on grassroots support.



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.

PREFACE

This CFIDS Primer has been prepared by the Health Professionals Committee of the Massachusetts CFIDS Association. It was developed in response to the numerous requests for more comprehensive information from a broad range of medical professionals. We hope this Primer will contribute to a greater medical understanding of this illness. We have attempted to make it comprehensive enough to address both general and some specific aspects of CFIDS. Whenever possible, we have indicated published medical journal studies (the most recent ones in an appendix), but we have also utilized both our own clinical experiences and information available from a number of national CFIDS experts.

to the Massachusetts CFIDS Association, the General Electric
75 of the Carpenter's Union for their generous support for this
this Primer with your colleagues. It may be reproduced by other
s a copyright notice and attribution to Mass. CFIDS Association
this organization at 617 893–4415 for further publications and

The Health Professionals Committee

February 1992

Layout and Graphics by John Friedlich

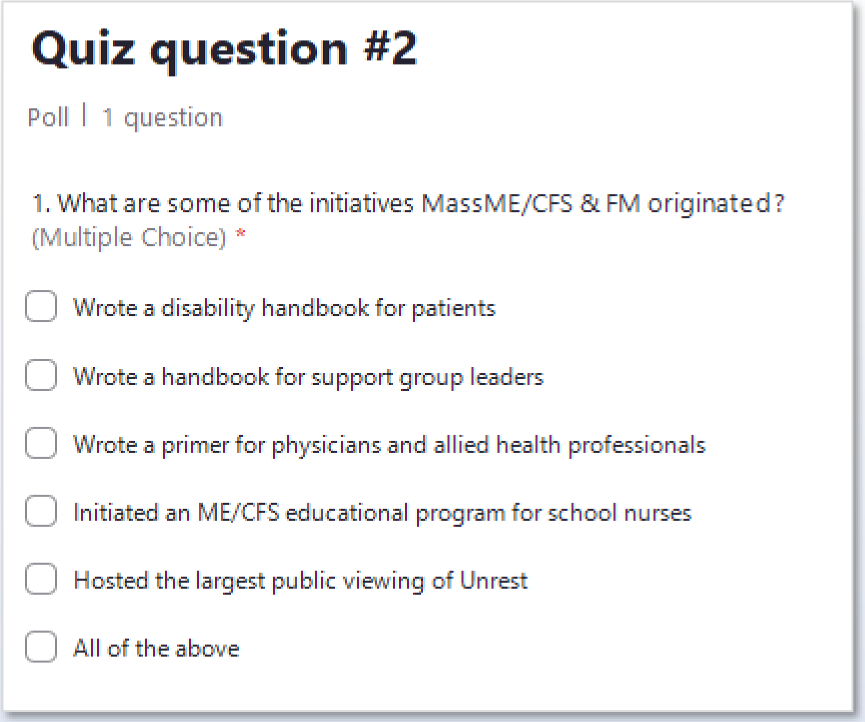
This project is funded by the
Mass CFIDS Association
808 Main Street • Waltham, Massachusetts 02154 • (617) 893-4415

Massachusetts ME/CFS & FM
ASSOCIATION
EDUCATION, SUPPORT & ADVOCACY SINCE 1985

Second Decade 1993-2002

National Politics Get Ugly, But the Association Stays Focused on Direct Service to Patients and Their Families.

Phil Chernin
MassME Co-President



Quiz question #2

Poll | 1 question

1. What are some of the initiatives MassME/CFS & FM originated? (Multiple Choice) *

- ☐ Wrote a disability handbook for patients
- ☐ Wrote a handbook for support group leaders
- ☐ Wrote a primer for physicians and allied health professionals
- ☐ Initiated an ME/CFS educational program for school nurses
- ☐ Hosted the largest public viewing of Unrest
- ☐ All of the above

1993 - 2002 WORLD EVENTS

1994 Fukuda Criteria

1994 UK National Task Force Report Published

1995 - 1998

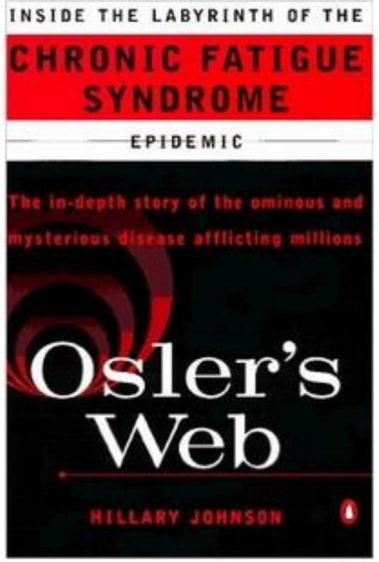
Congress allocates $27 million to research -only $9.8 million spent

1996

Osler's Web Hillary Johnson

1999

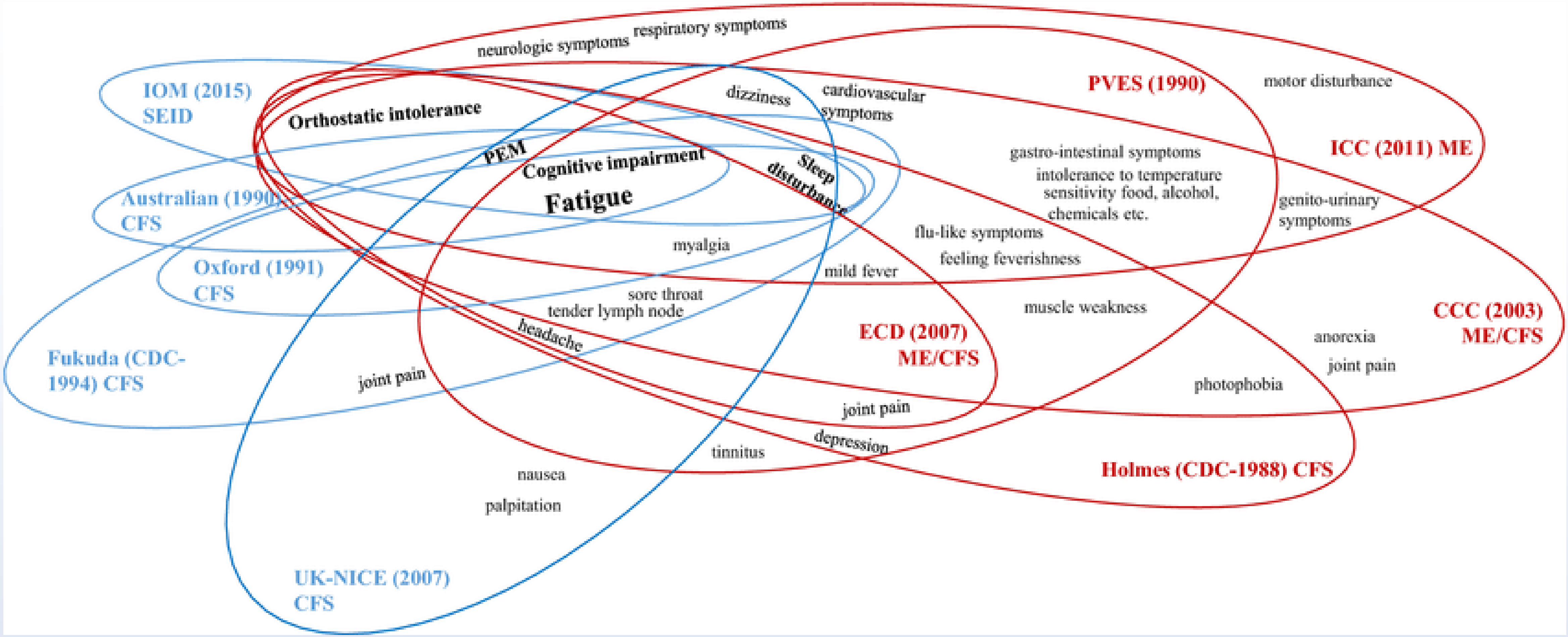
Senator Reid requests inquiry into missing research funds


INSIDE THE LABYRINTH OF THE
CHRONIC FATIGUE SYNDROME
EPIDEMIC
The in-depth story of the ominous and mysterious disease afflicting millions
Osler's Web
HILLARY JOHNSON

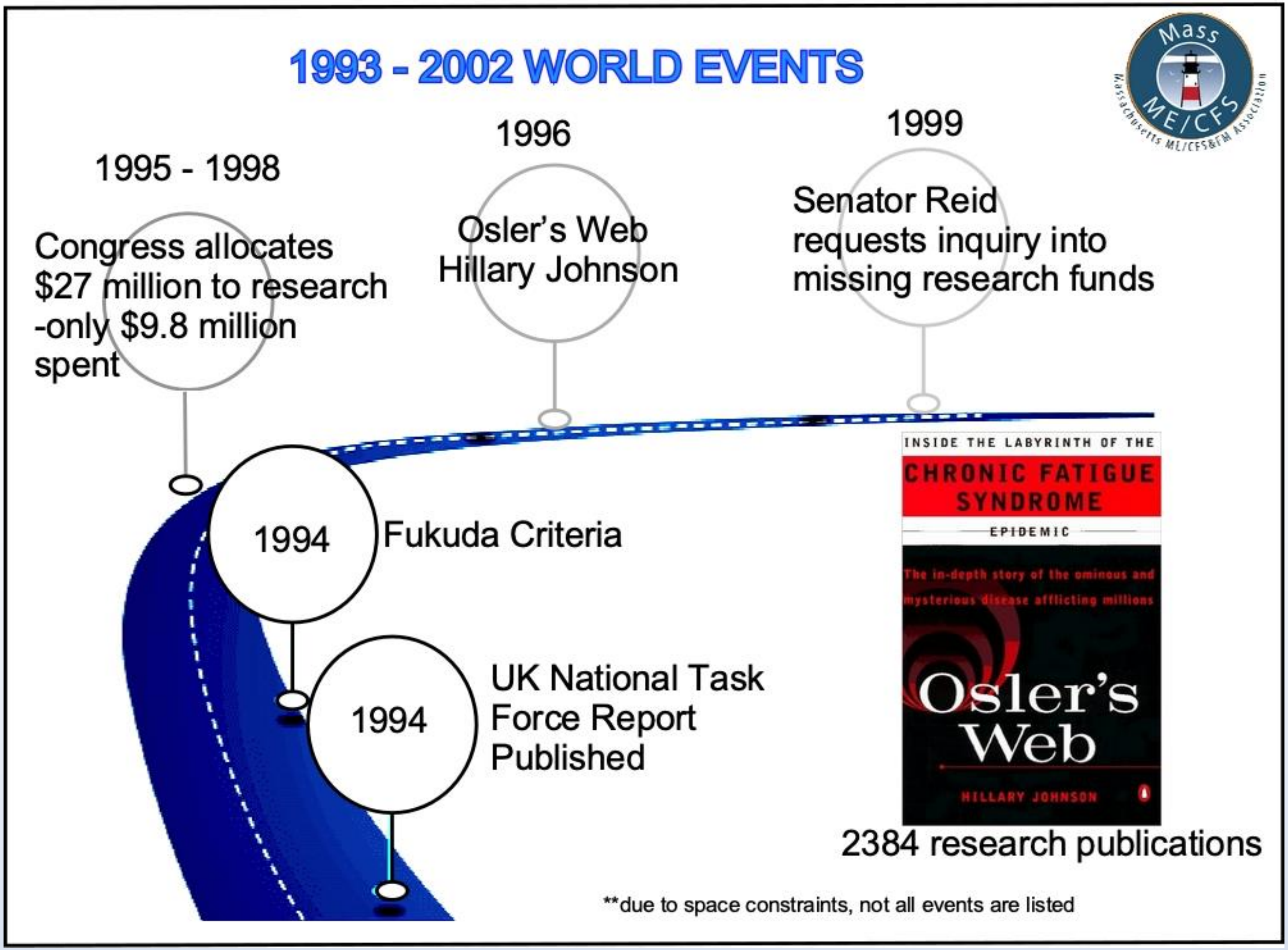
2384 research publications

**due to space constraints, not all events are listed

ME and CFS: Same or Different?



Lim, Eun-Jin & Ahn, Yo-Chan & Jang, Eun-Su & Lee, Si-Woo & Lee, Su-Hwa & Son, Chang-Gue. (2020). Systematic review and meta-analysis of the prevalence of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). Journal of Translational Medicine. 18. 10.1186/s12967-020-02269-0.



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HILLARY JOHNSON

2384 research publications

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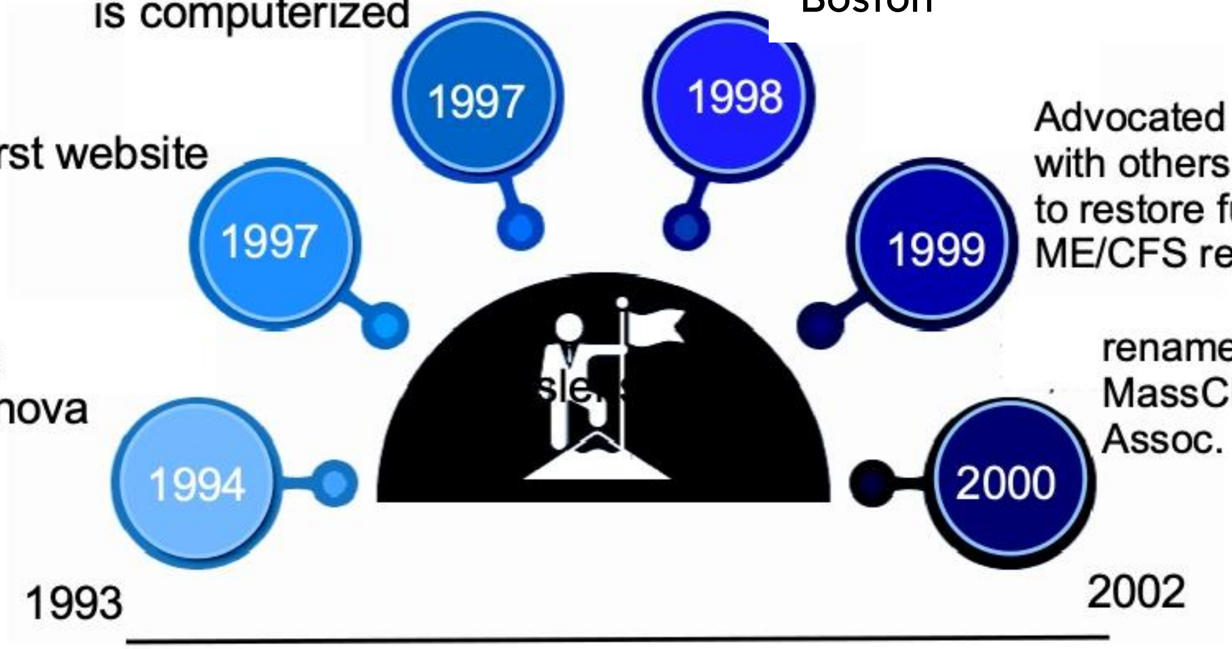
The Missing Funds Controversy

“the CDC since 1989, secretly diverted money Congress had appropriated for research into chronic fatigue syndrome and spent it on other programs. An inspector general's investigation confirmed in a report released in May that as much as $12.9 million approved for fighting the little-understood but debilitating disease was misspent or undocumented.” Washington Post, August 6, 1999

MassME/CFS & FM Association Achievements



1993

1994

Updated Disability Handbook Ken Casanova

1997

First website

1997

Physician Referral List is computerized

1998

AACFS Conference in Boston

1999

Advocated with others to restore funds to ME/CFS research

2000

renamed MassCFIDS & FM Assoc.

2002

Activities:

Support Groups

Public Events

Public Outreach

Advocacy

“Lending Library”

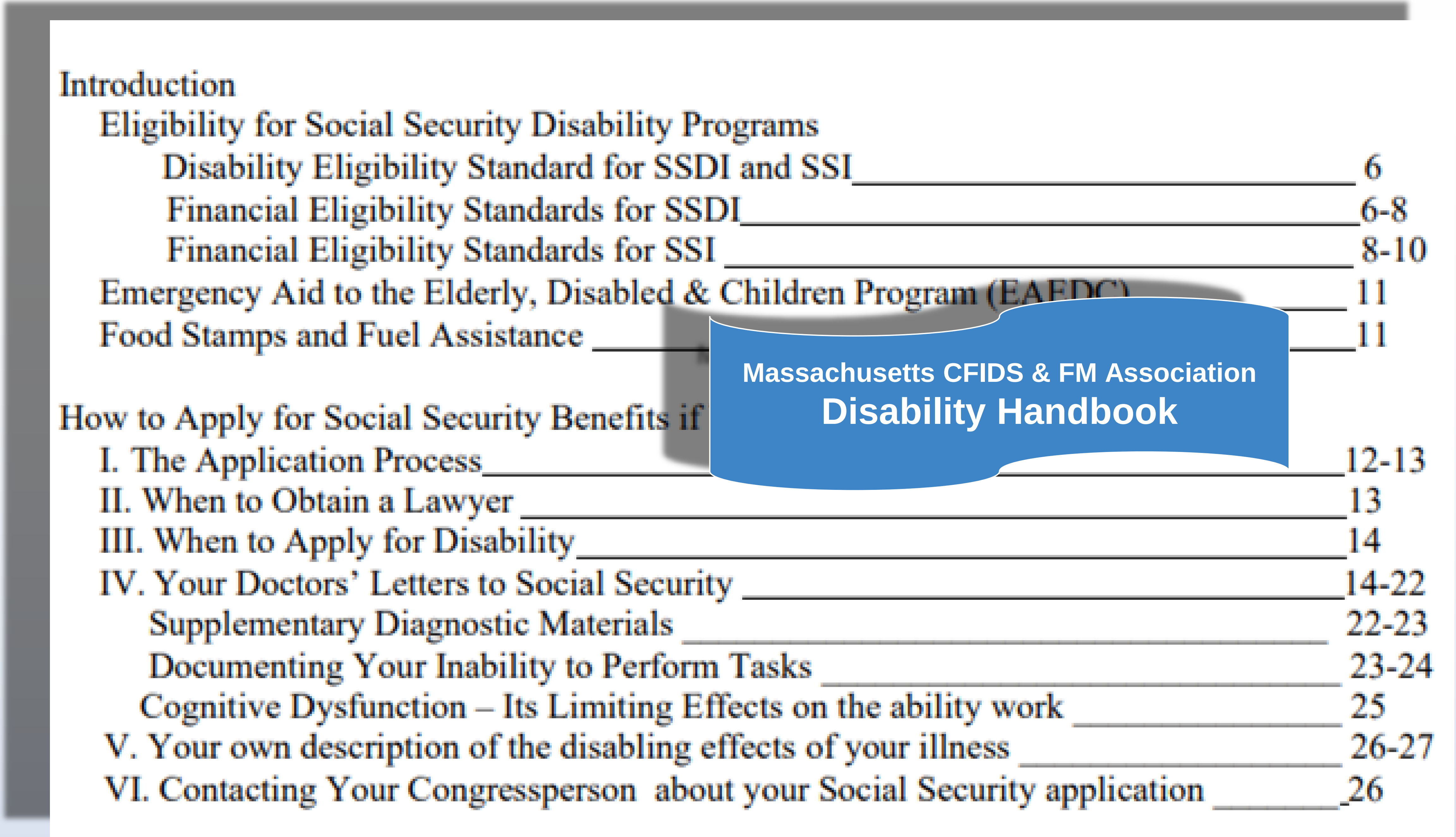
Communications

InfoLine

“The Update”

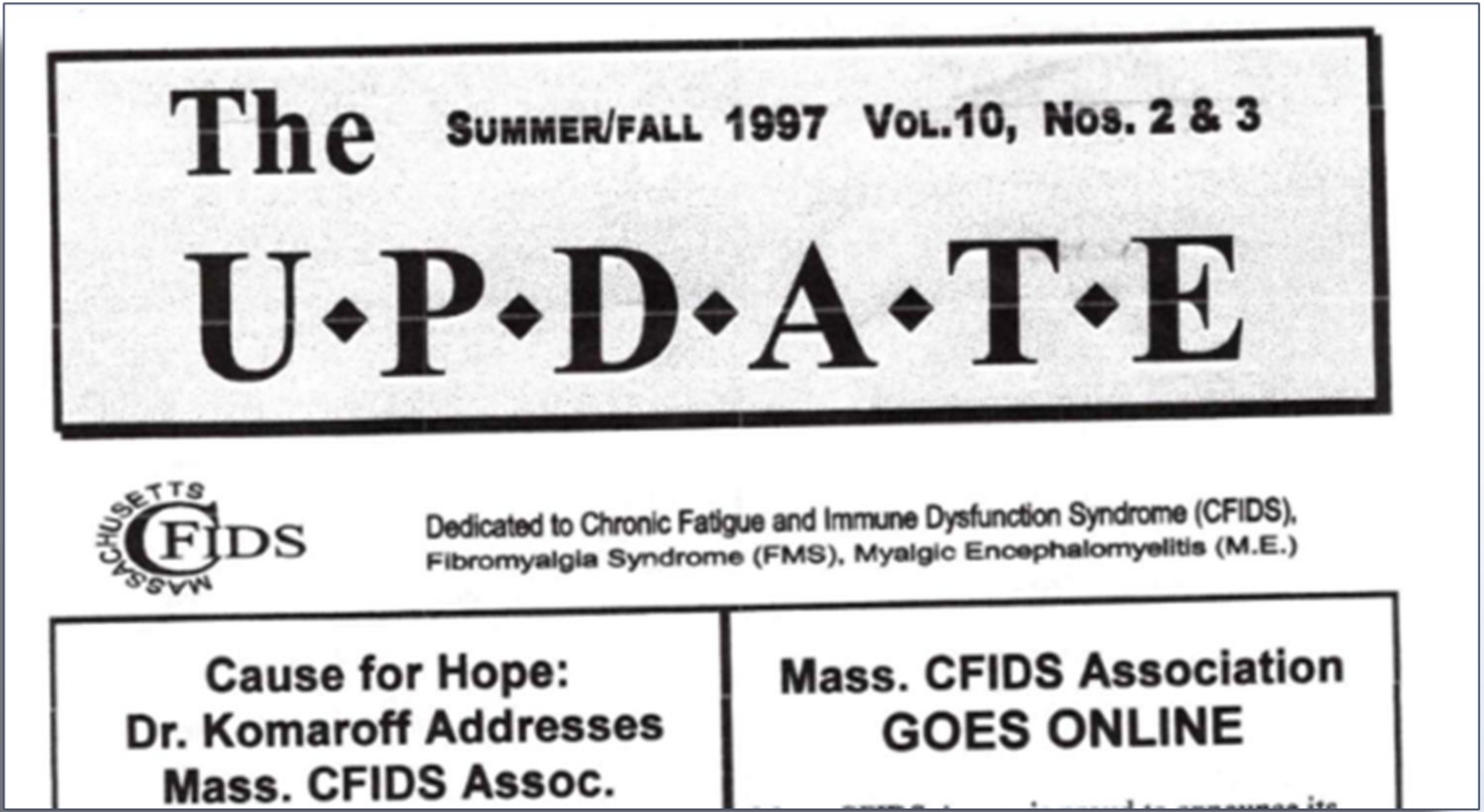
Massachusetts CFIDS & FM Association

Disability Handbook



Introduction

How to Apply for Social Security Benefits if



The U◆P◆D◆A◆T◆E

SUMMER/FALL 1997 VOL.10, NOS. 2 & 3

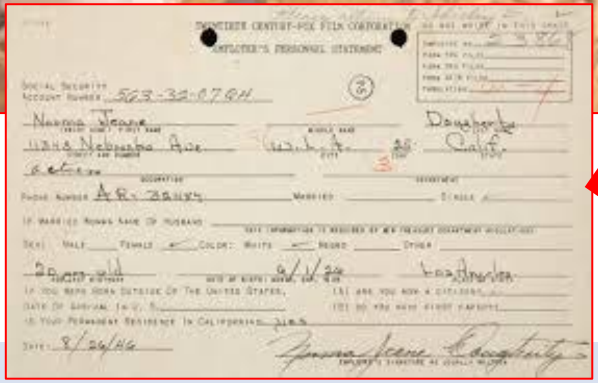
MASSACHUSETTS CFIDS

Dedicated to Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS), Fibromyalgia Syndrome (FMS), Myalgic Encephalomyelitis (M.E.)

Cause for Hope: Dr. Komaroff Addresses Mass. CFIDS Assoc.

Mass. CFIDS Association GOES ONLINE

Support Groups and Doctor Database



TWENTIETH CENTURY-FOX FILM CORPORATION

EMPLOYEE'S PERSONAL STATEMENT

SOCIAL SECURITY ACCOUNT NUMBER 563-32-0784

Norma Jeane Dougherty

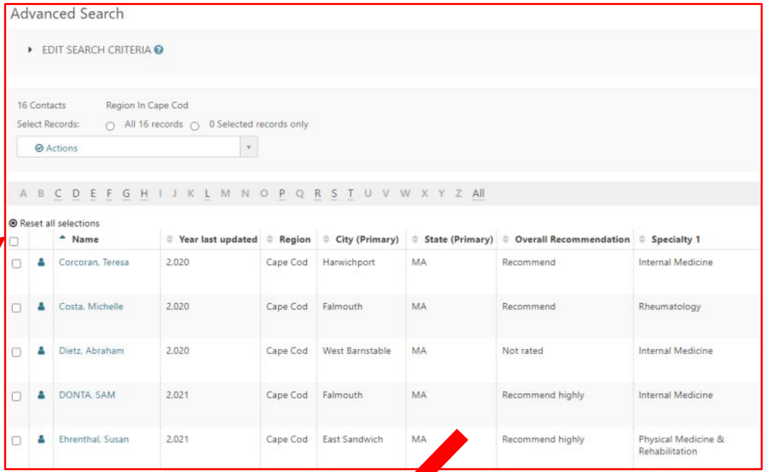
Calif.

PHONE NUMBER AR. 38484

Los Angeles

DATE: 8/26/46

Norma Jeane Dougherty

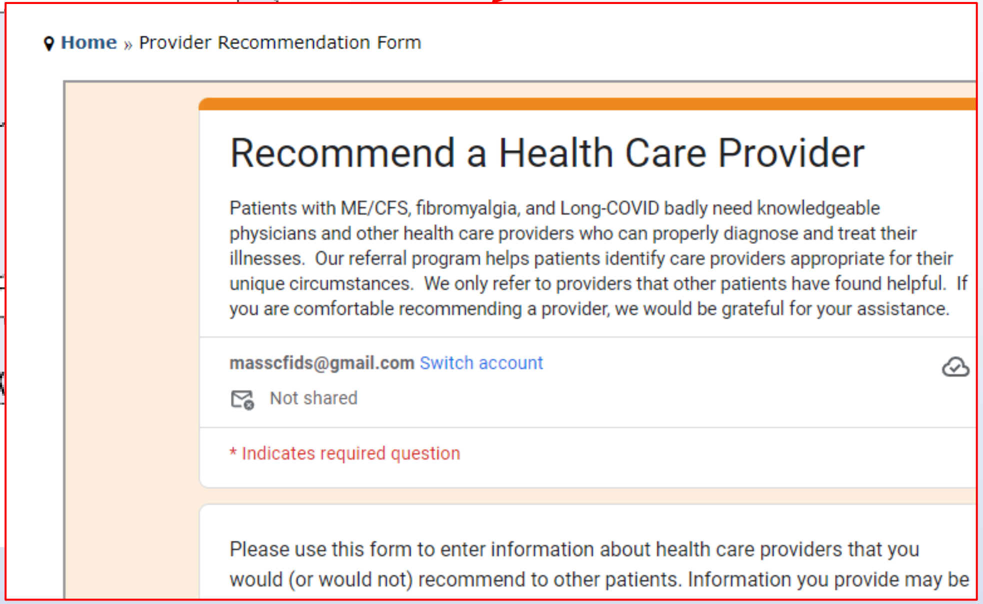


Advanced Search

16 Contacts Region In Cape Cod

Select Records: ○ All 16 records ○ 0 Selected records only

☐		Name	Year last updated	Region	City (Primary)	State (Primary)	Overall Recommendation	Specialty 1
☐		Corcoran, Teresa	2,020	Cape Cod	Harwichport	MA	Recommend	Internal Medicine
☐		Costa, Michelle	2,020	Cape Cod	Falmouth	MA	Recommend	Rheumatology
☐		Dietz, Abraham	2,020	Cape Cod	West Barnstable	MA	Not rated	Internal Medicine
☐		DONTA, SAM	2,021	Cape Cod	Falmouth	MA	Recommend highly	Internal Medicine
☐		Ehrenthal, Susan	2,021	Cape Cod	East Sandwich	MA	Recommend highly	Physical Medicine & Rehabilitation



Home » Provider Recommendation Form

Recommend a Health Care Provider

Patients with ME/CFS, fibromyalgia, and Long-COVID badly need knowledgeable physicians and other health care providers who can properly diagnose and treat their illnesses. Our referral program helps patients identify care providers appropriate for their unique circumstances. We only refer to providers that other patients have found helpful. If you are comfortable recommending a provider, we would be grateful for your assistance.

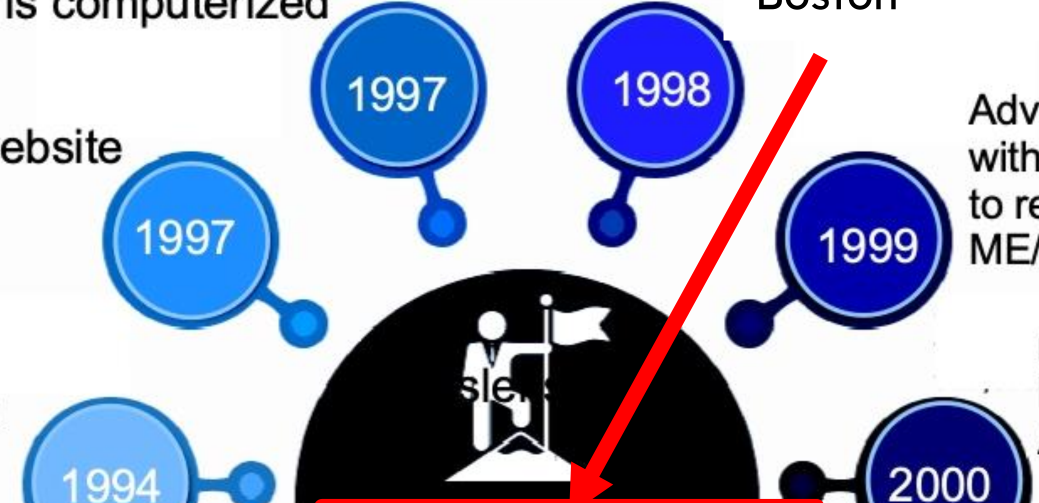
masscfids@gmail.com Switch account

Not shared

* Indicates required question

Please use this form to enter information about health care providers that you would (or would not) recommend to other patients. Information you provide may be

MassME/CFS & FM Association Achievements



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Updated Disability Handbook Ken Casanova

First website

Physician Referral List is computerized

AACFS Conference in Boston

Advocated with others to restore funds to ME/CFS research

renamed MassCFIDS & FM Assoc.

2002

International Association for

IACFS/ME

Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis

Activities:

Support Groups

Public Events

Public Outreach

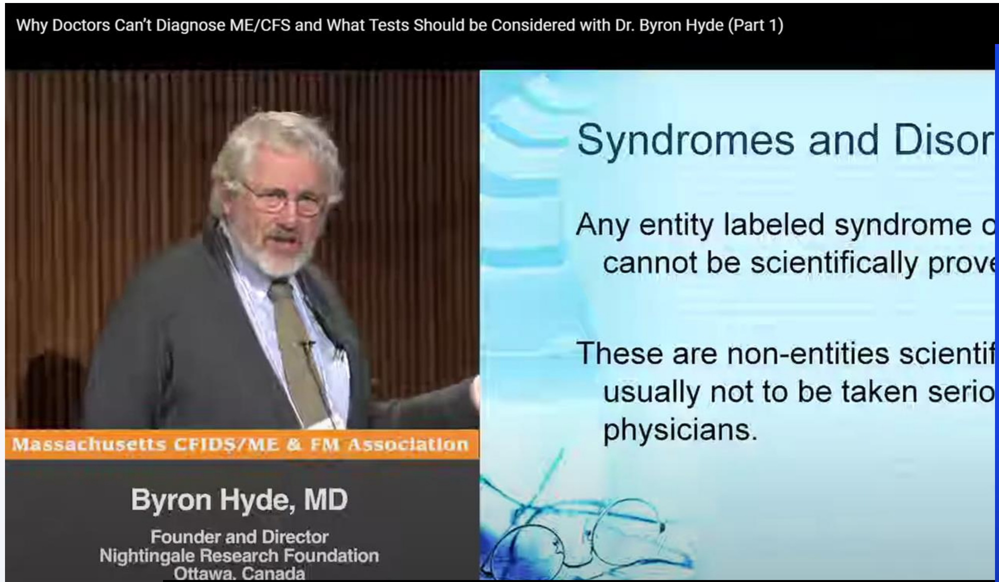
Advocacy

Communications

InfoLine

“The Update”

Statewide Lectures and Patient Panels



Why Doctors Can't Diagnose ME/CFS and What Tests Should be Considered with Dr. Byron Hyde (Part 1)

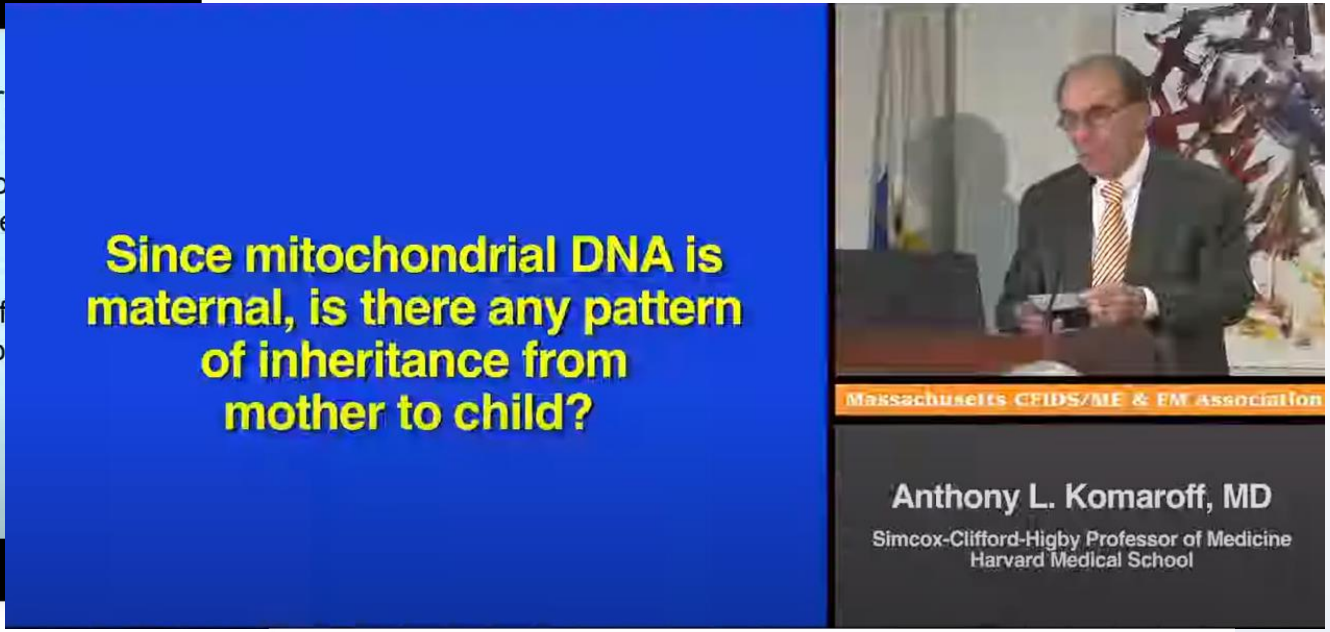
Syndromes and Disor

Any entity labeled syndrome o
cannot be scientifically prove

These are non-entities scientif
usually not to be taken serio
physicians.

Massachusetts CFIDS/ME & FM Association

Byron Hyde, MD
Founder and Director
Nightingale Research Foundation
Ottawa, Canada



Since mitochondrial DNA is maternal, is there any pattern of inheritance from mother to child?

Massachusetts CFIDS/ME & FM Association

Anthony L. Komaroff, MD
Simcox-Clifford-Higby Professor of Medicine
Harvard Medical School

New Research Linking Fibromyalgia and Small Fiber Polyneuropathy (SFPN)

Massachusetts CFIDS/ME & FM Association

Khosro Farhad, MD
Neurologist
Wentworth Health Partners

ON THE CUTTING EDGE

Anne Louise Oaklander, MD, PhD, Harvard Medical School and Massachusetts General Hospital

Fibromyalgia: New Research Helps Unravel the Mystery

WHAT IMPORTANT NEW STUDIES HAVE UNCOVERED: According to several studies published in 2013, one conducted by researchers at Massachusetts General Hospital, nearly half of people with fibromyalgia have evidence of a disease called *small-fiber polyneuropathy* (SFPN).

Bottom Line/Health | May 2014 |

An Unnerving Enigma

NEW CLUES TO FIBROMYALGIA'S ORIGINS COULD CRACK THE CASE OF CHRONIC PAIN
BY STEPHANI SUTHERLAND

SCIENTIFIC AMERICAN MIND
SEPTEMBER/OCTOBER 2014

One of those neurologists, Anne Louise Oaklander of Massachusetts General Hospital, began seeking collaborators to investigate the link, but she could not find a rheumatologist willing to embark on such a speculative, interdisciplinary project. Finally, Oaklander took matters into her own hands. To search for signs of nerve damage in people with fibromyalgia, her team used several tests, including a skin biopsy, in which a clinician punches out a small sample from the skin of the hand or leg and examines the tiny nerves within the sample under a microscope. "No one had really looked appropriately before at nerves," Oaklander says.

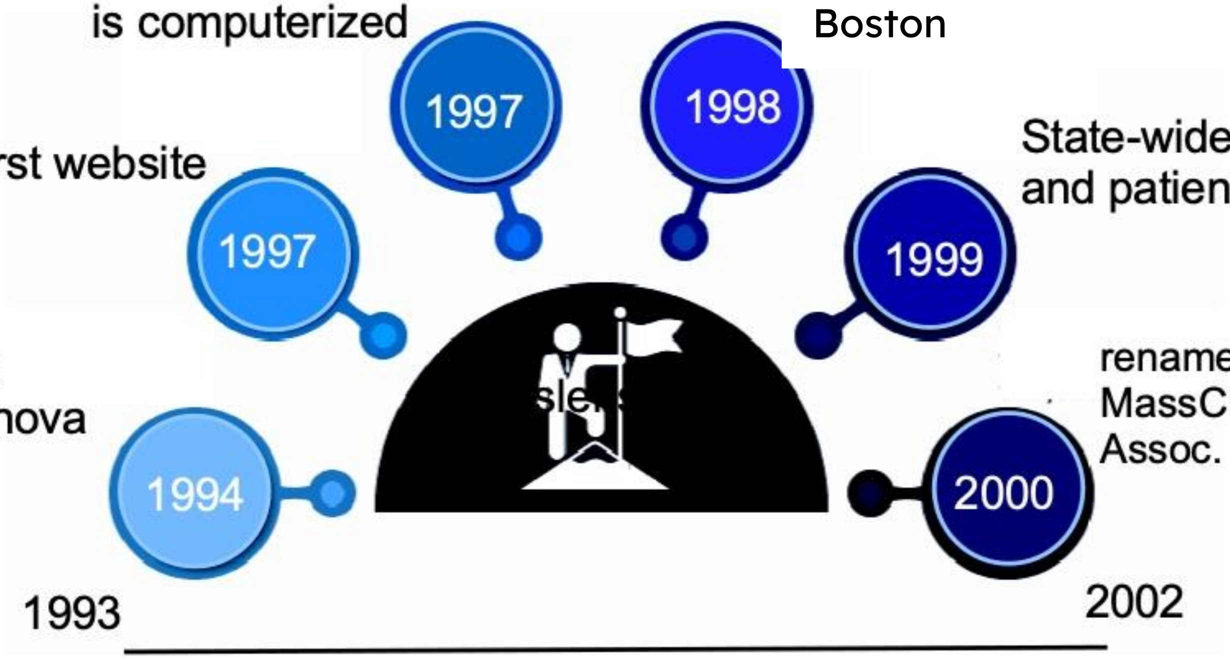
New research sheds light on mysterious fibromyalgia pain

Karen Weintraub, Special for USA TODAY*7:03 a.m. EST December 15, 2013*

This new understanding of fibromyalgia will hopefully lead to better treatments, doctors and researchers say.

"In 2013 there's been this absolute explosion of papers," says neurologist Anne Louise Oaklander at Massachusetts General Hospital in Boston. "The whole view on this has shifted."
Her lab published two studies in 2013 showing that roughly half of the cases of fibromyalgia are really a little-known condition affecting the nerves (neuropathy)

MassME/CFS & FM Association Achievements



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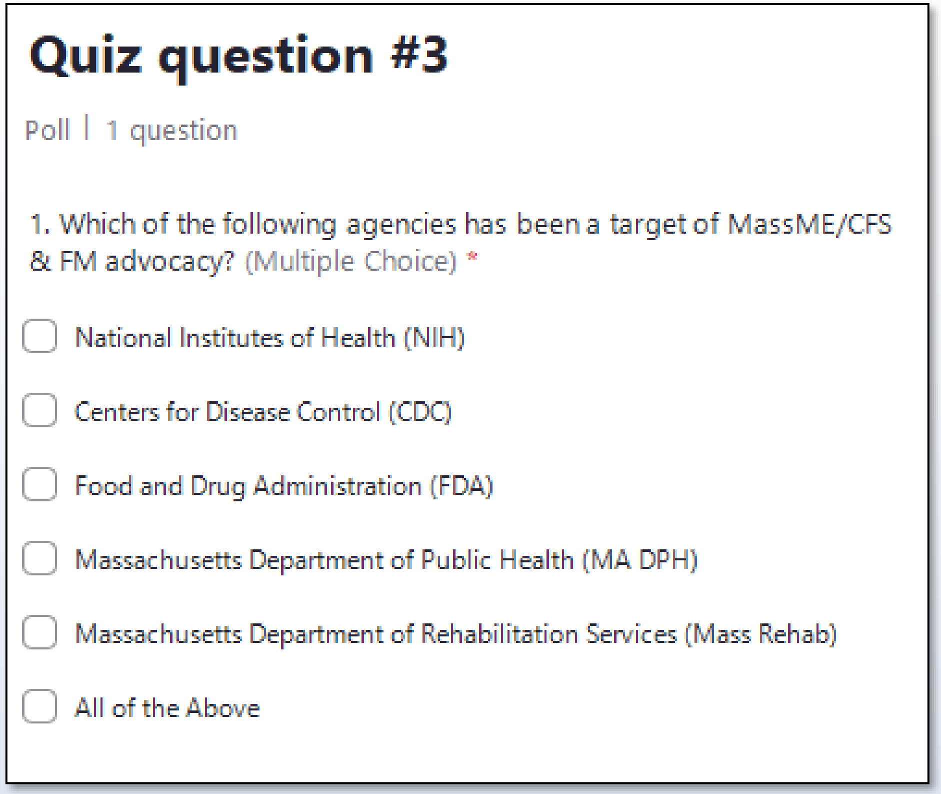
Massachusetts ME/CFS & FM
ASSOCIATION
EDUCATION, SUPPORT & ADVOCACY SINCE 1985

Third Decade 2003-2012

Struggles and Revitalization!



Quiz question #3

Poll | 1 question

1. Which of the following agencies has been a target of MassME/CFS & FM advocacy? (Multiple Choice) *

- ☐ National Institutes of Health (NIH)
- ☐ Centers for Disease Control (CDC)
- ☐ Food and Drug Administration (FDA)
- ☐ Massachusetts Department of Public Health (MA DPH)
- ☐ Massachusetts Department of Rehabilitation Services (Mass Rehab)
- ☐ All of the Above

Hayla Sluss
MassME Board Member

2003 - 2012 World Events

Interational Meetings

2003
Workwell Foundation
seminal paper
on 2 day CPET

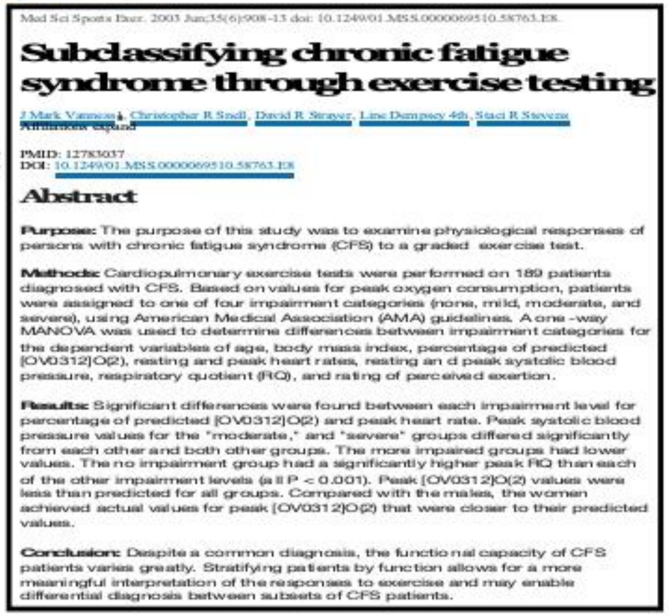
2006
Invest
in ME
UK

2007
IACFS

2011
ICC
criteria

DHHS
CFSAC
established
2003

CCC
criteria
2003



Med Sci Sports Exer. 2003 Jun;35(6):908-13 doi: 10.1249/01.MSS.0000069510.58763.E8.

Subclassifying chronic fatigue syndrome through exercise testing

J Mark Vanness, Christopher R Snell, David R Strayer, Line Dempsey 4th, Staci R Stevens
Affiliations expand

- PMID: 12783037
- DOI: 10.1249/01.MSS.0000069510.58763.E8

Abstract

Purpose: The purpose of this study was to examine physiological responses of persons with chronic fatigue syndrome (CFS) to a graded exercise test.

Methods: Cardiopulmonary exercise tests were performed on 189 patients diagnosed with CFS. Based on values for peak oxygen consumption, patients were assigned to one of four impairment categories (none, mild, moderate, and severe), using American Medical Association (AMA) guidelines. A one-way MANOVA was used to determine differences between impairment categories for the dependent variables of age, body mass index, percentage of predicted [OV0312]O(2), resting and peak heart rates, resting an d peak systolic blood pressure, respiratory quotient (RQ), and rating of perceived exertion.

Results: Significant differences were found between each impairment level for percentage of predicted [OV0312]O(2) and peak heart rate. Peak systolic blood pressure values for the "moderate," and "severe" groups differed significantly from each other and both other groups. The more impaired groups had lower values. The no impairment group had a significantly higher peak RQ than each of the other impairment levels (all $P < 0.001$). Peak [OV0312]O(2) values were less than predicted for all groups. Compared with the males, the women achieved actual values for peak [OV0312]O(2) that were closer to their predicted values.

Conclusion: Despite a common diagnosis, the functional capacity of CFS patients varies greatly. Stratifying patients by function allows for a more meaningful interpretation of the responses to exercise and may enable differential diagnosis between subsets of CFS patients.

3341 research publications
**due to space constraints, not all events are listed

2003 CFSAC: Chronic Fatigue Syndrome Advisory group

CFSAC's goal was to act as a liason to the Department of Health and Human Services (DHHS) and to offer recommendations on CFS. It included public input and interagency coordination including the FDA, CDC, SSA and the NIH. Over 15 years, the committee made important recommendations including: removal of a ME/CFS toolkit from the CDC website that was incorrect, increased funding for ME/CFS, improved SS disability access for patients. Some of recommendations were eventually followed, such as removal of the toolkit. Others were listed as completed but not actually completed. Members of our association attended the meetings and served as advocates. The CFSAC was disbanded unexpectedly in 2018, leading to more frustration.

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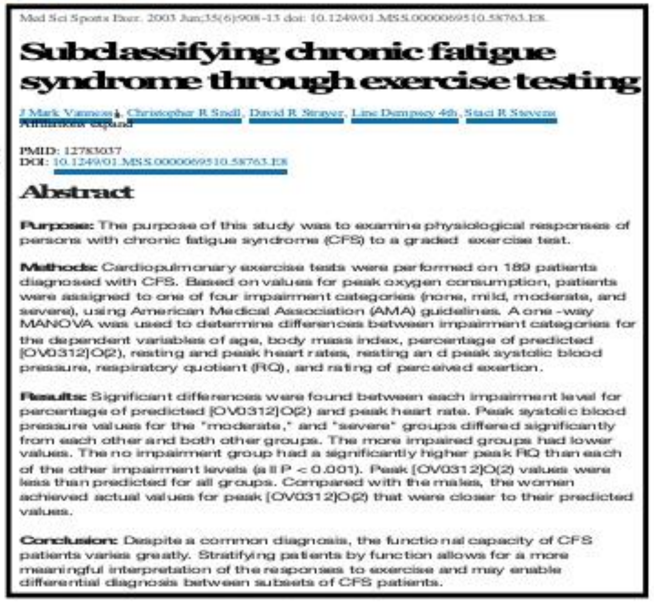

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CCC and ICC diagnosis criteria

CCC Requires PEM (post exertional malaise)

ICC requires PENE (post exertional neuroimmune exhaustion)

recognition can happen hours or days after overexertion

sudden, debilitating

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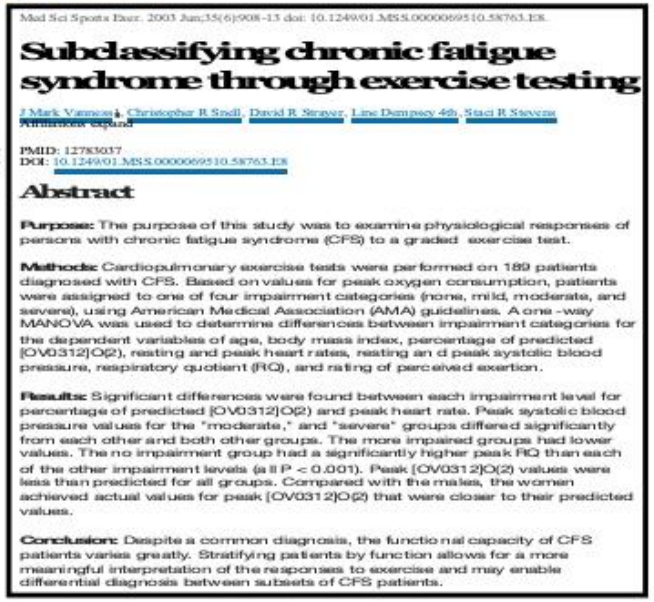

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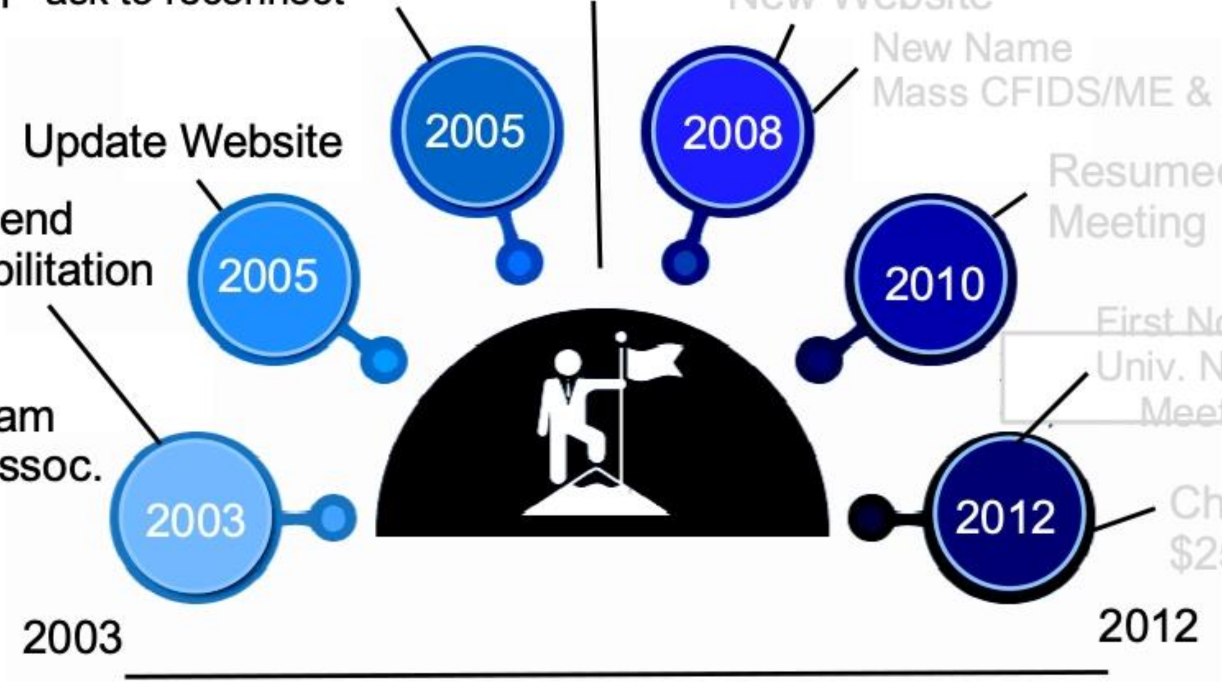
MassME/CFS & FM Association Achievements



Work with Conn. CFIDS

Mail all members- ask to reconnect

"Lean Years" 3 people

"Revitilization"

New Website

New Name Mass CFIDS/ME & FM

Update Website

Members attend Mass. Rehabilitation Conference

Transition team try to keep Assoc. going

Resumed Annual Meeting

First Northeastern Univ. Nurse Assoc Meeting.

Chase Grant $25,000

Activities:
Support Groups
Physican Referral
Disability Counseling
Advocacy
Fundraising

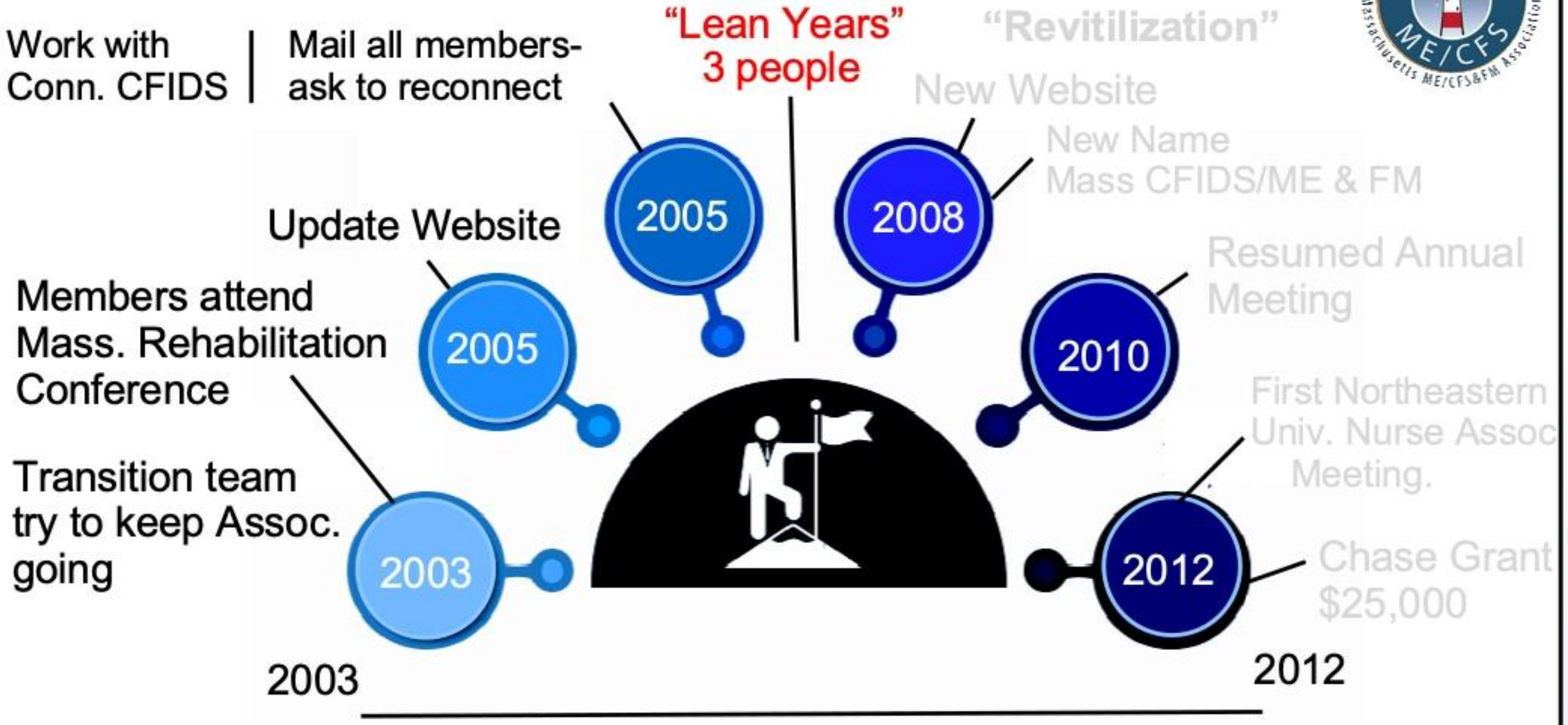
"Lending Library"

Communications

teleconference

e-newsletter
2008 - 2011
600 ppl

MassME/CFS & FM Association Achievements



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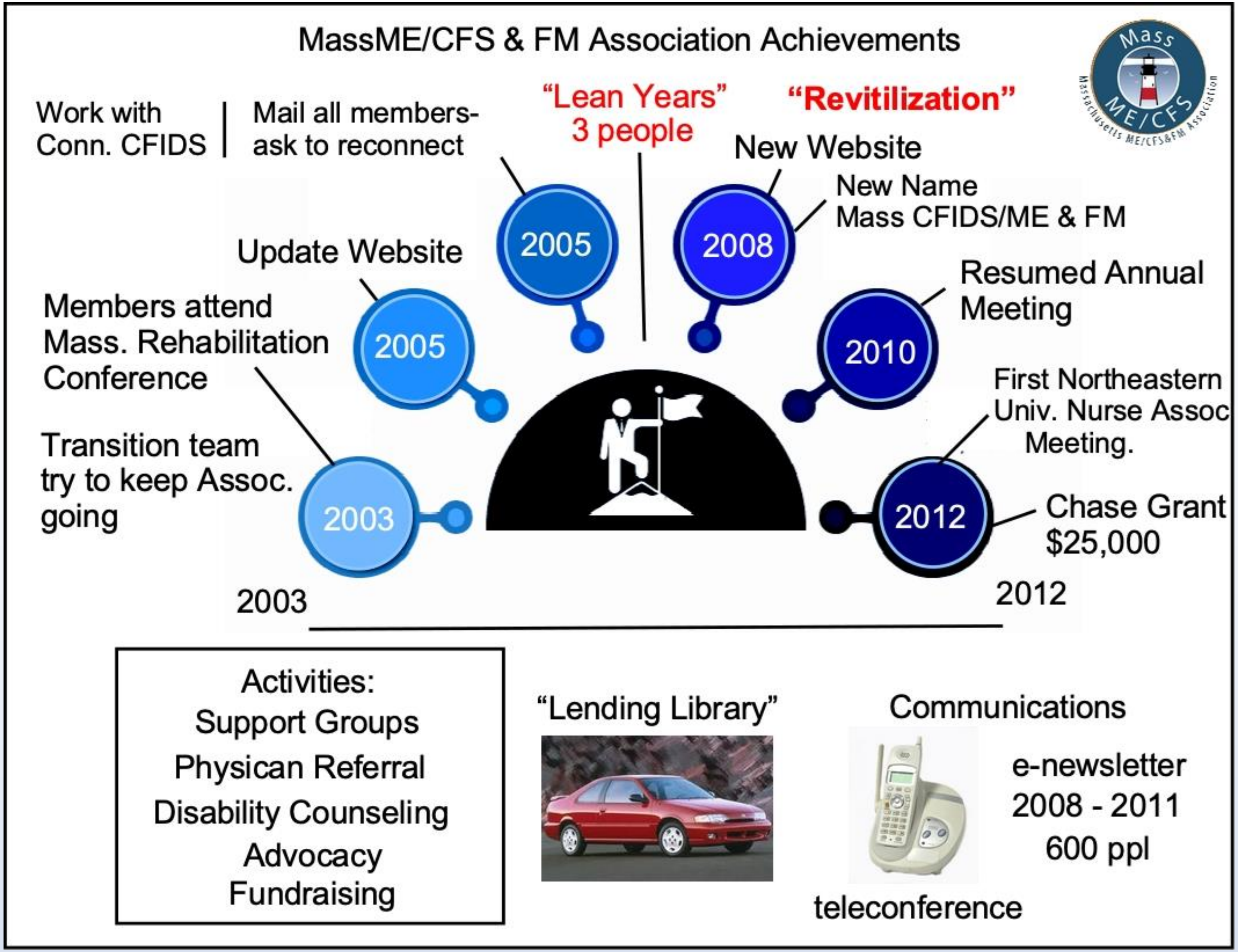

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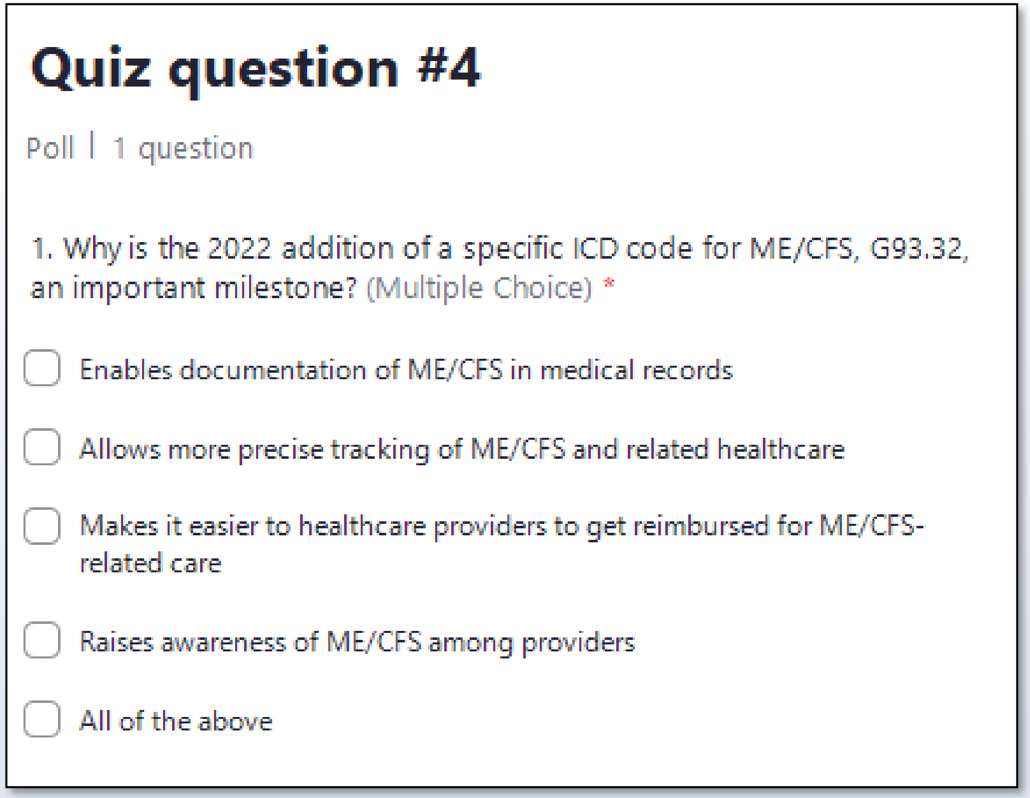
Massachusetts ME/CFS & FM
ASSOCIATION
EDUCATION, SUPPORT & ADVOCACY SINCE 1985

Fourth Decade 2013-2023

It's a New World!



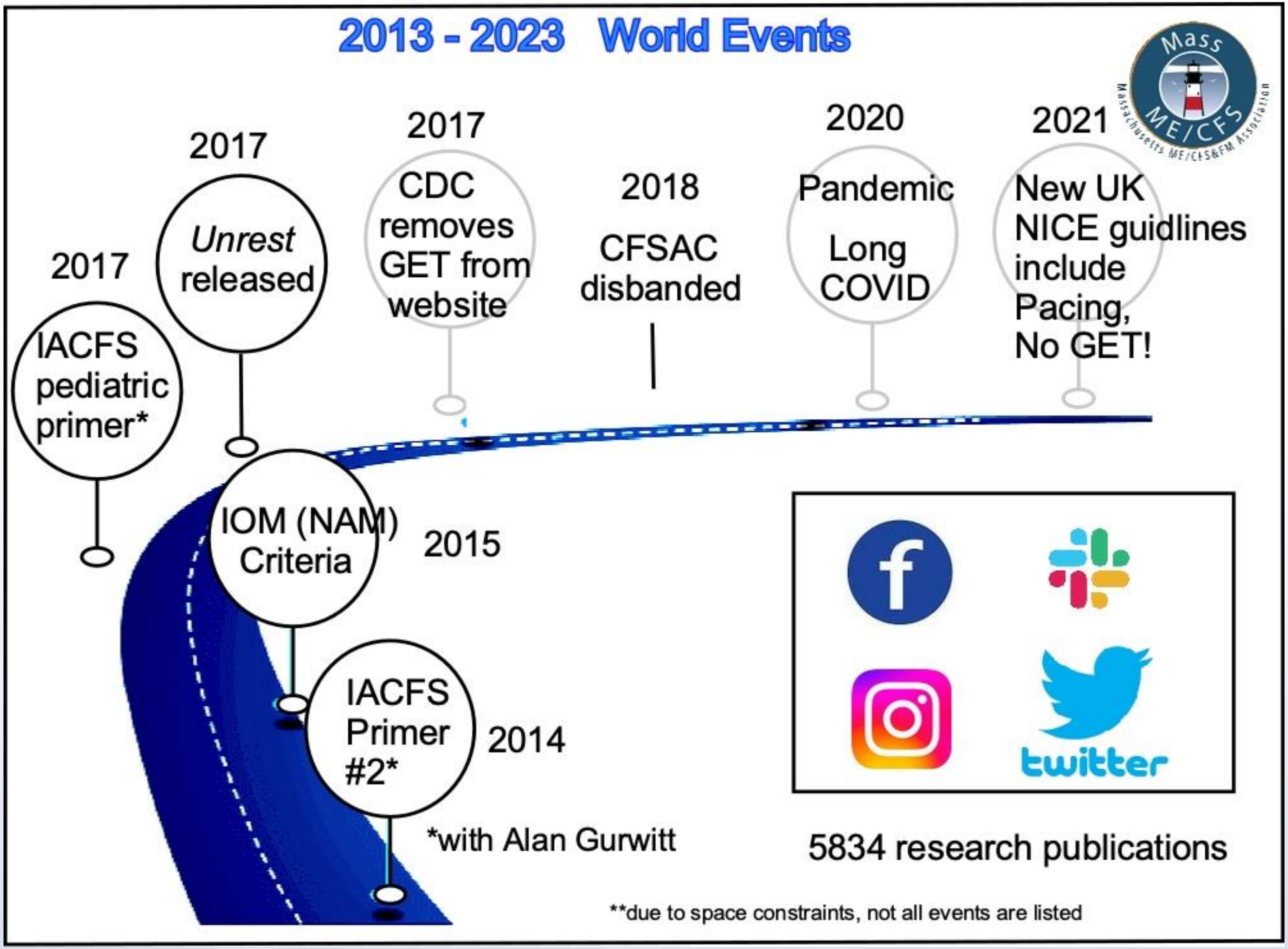
Quiz question #4

Poll | 1 question

1. Why is the 2022 addition of a specific ICD code for ME/CFS, G93.32, an important milestone? (Multiple Choice) *

- ☐ Enables documentation of ME/CFS in medical records
- ☐ Allows more precise tracking of ME/CFS and related healthcare
- ☐ Makes it easier to healthcare providers to get reimbursed for ME/CFS-related care
- ☐ Raises awareness of ME/CFS among providers
- ☐ All of the above

Helen McGunnigle
Sunday Conversations Team



2013 - 2023 World Events

2014
IACFS Primer #2*

2015
IOM (NAM) Criteria

2017
IACFS pediatric primer*

2017
Unrest released

2017
CDC removes GET from website

2018
CFSAC disbanded

2020
Pandemic
Long COVID

2021
New UK NICE guidlines include Pacing, No GET!

*with Alan Gurwitt

5834 research publications

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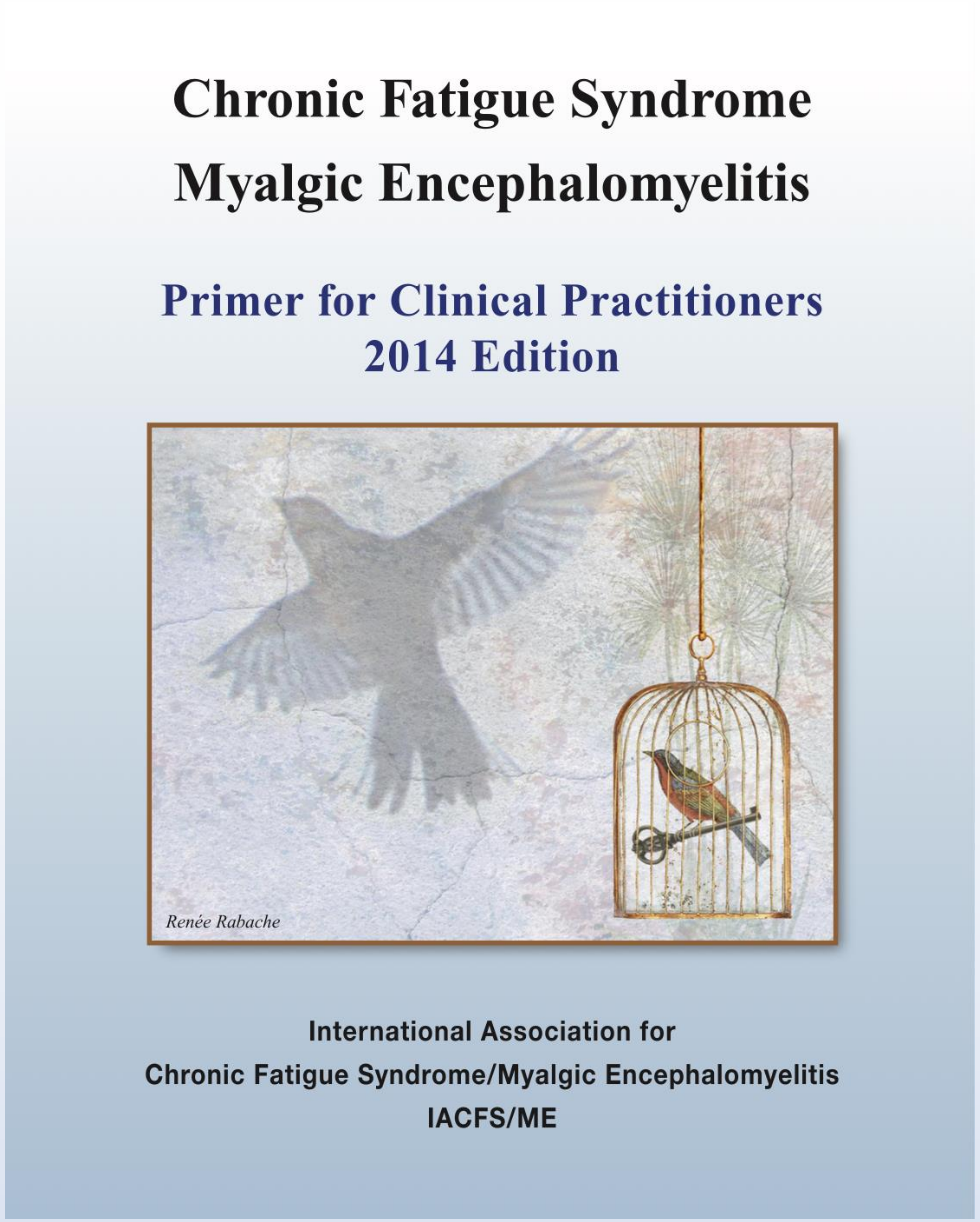
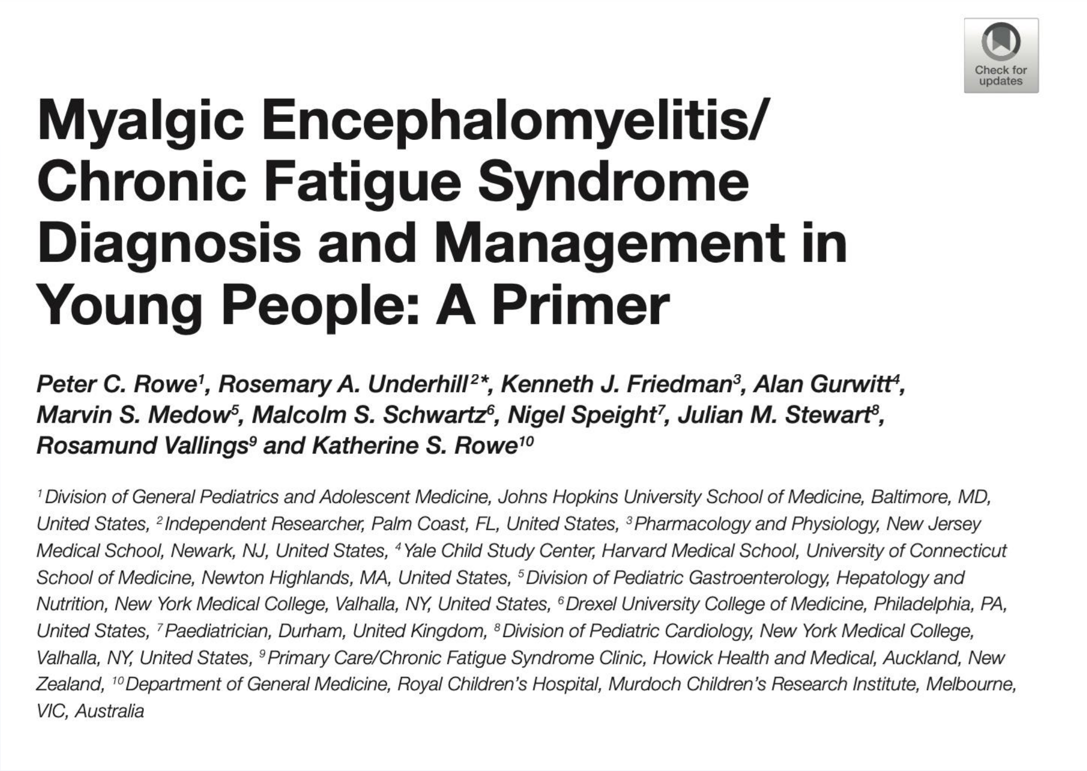


Chronic Fatigue Syndrome
Myalgic Encephalomyelitis

Primer for Clinical Practitioners
2014 Edition

Renée Rabache

International Association for
Chronic Fatigue Syndrome/Myalgic Encephalomyelitis
IACFS/ME

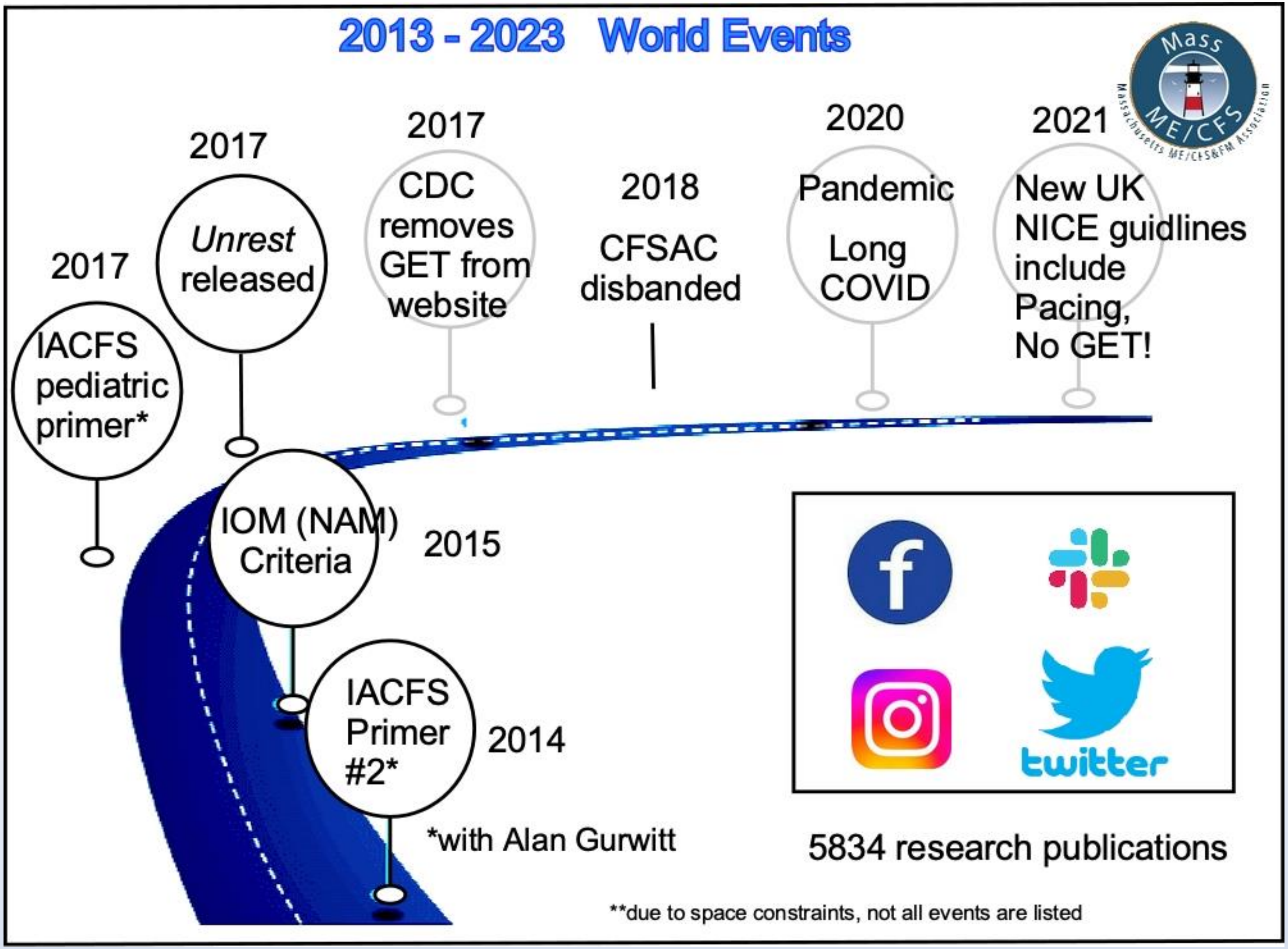


Check for updates

Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer

Peter C. Rowe[1], Rosemary A. Underhill[2]*, Kenneth J. Friedman[3], Alan Gurwitt[4], Marvin S. Medow[5], Malcolm S. Schwartz[6], Nigel Speight[7], Julian M. Stewart[8], Rosamund Vallings[9] and Katherine S. Rowe[10]

[1] *Division of General Pediatrics and Adolescent Medicine, Johns Hopkins University School of Medicine, Baltimore, MD, United States,* [2] *Independent Researcher, Palm Coast, FL, United States,* [3] *Pharmacology and Physiology, New Jersey Medical School, Newark, NJ, United States,* [4] *Yale Child Study Center, Harvard Medical School, University of Connecticut School of Medicine, Newton Highlands, MA, United States,* [5] *Division of Pediatric Gastroenterology, Hepatology and Nutrition, New York Medical College, Valhalla, NY, United States,* [6] *Drexel University College of Medicine, Philadelphia, PA, United States,* [7] *Paediatrician, Durham, United Kingdom,* [8] *Division of Pediatric Cardiology, New York Medical College, Valhalla, NY, United States,* [9] *Primary Care/Chronic Fatigue Syndrome Clinic, Howick Health and Medical, Auckland, New Zealand,* [10] *Department of General Medicine, Royal Children's Hospital, Murdoch Children's Research Institute, Melbourne, VIC, Australia*



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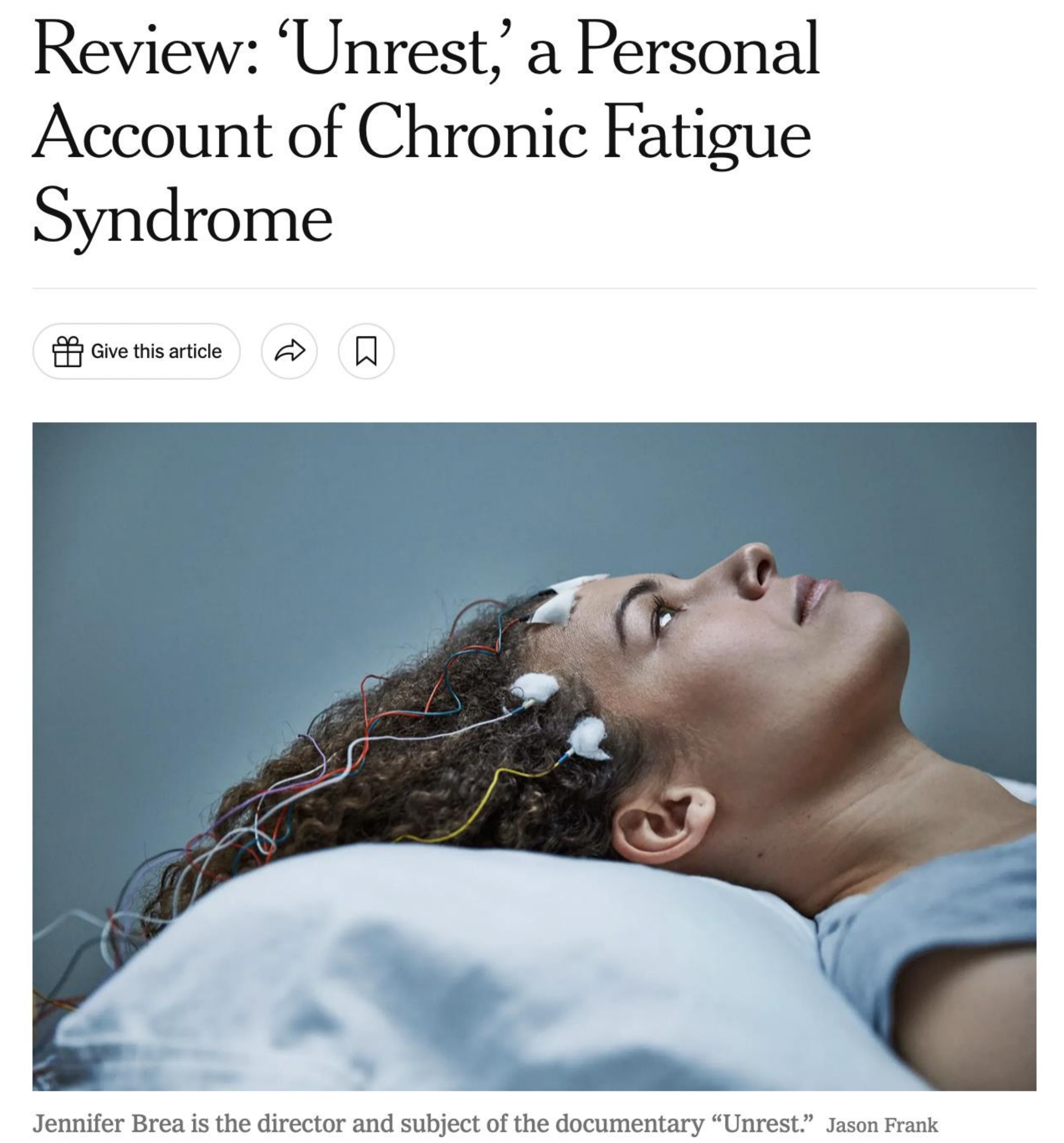
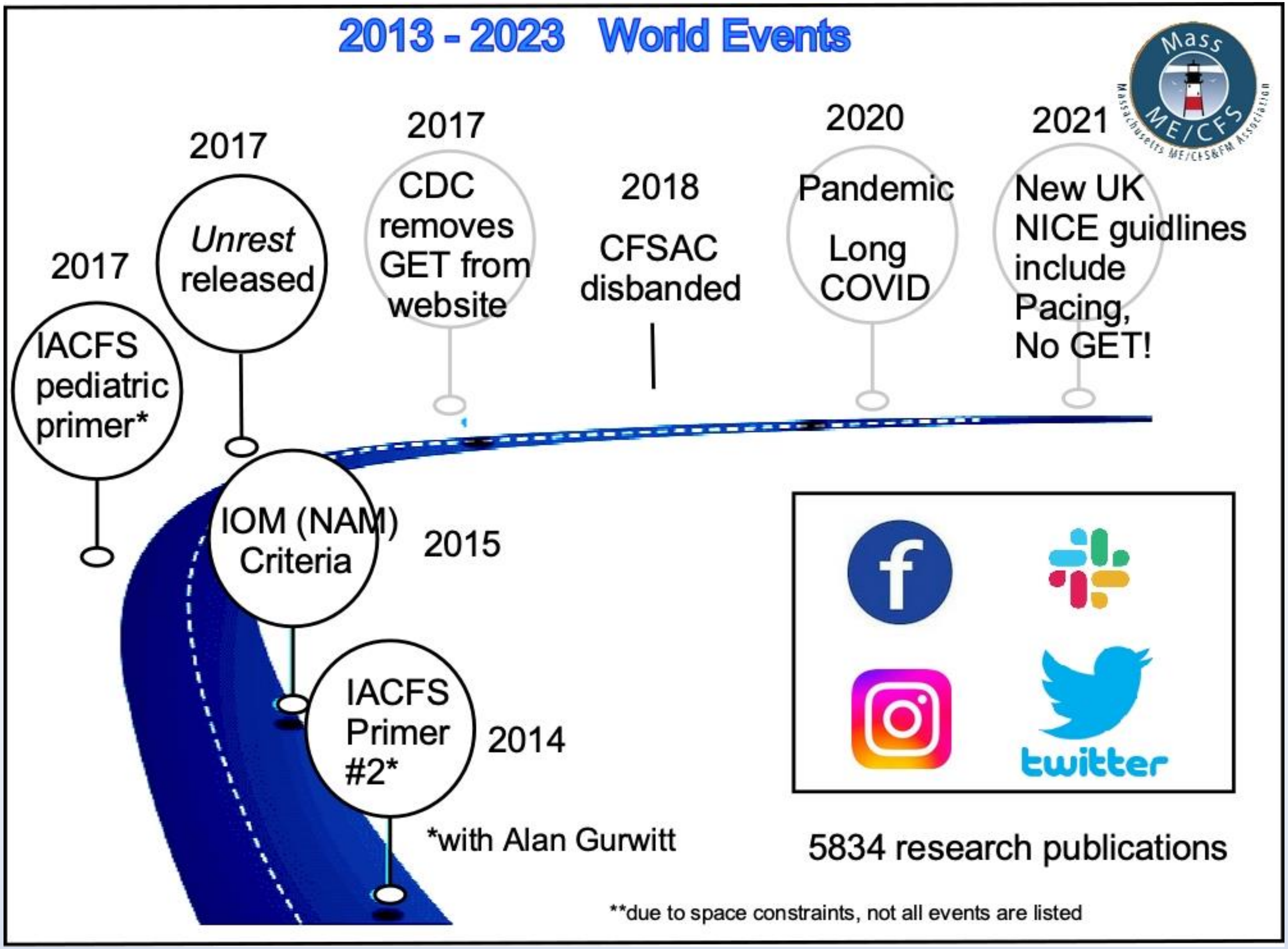


Review: ‘Unrest,’ a Personal Account of Chronic Fatigue Syndrome

Jennifer Brea is the director and subject of the documentary “Unrest.” Jason Frank



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NH HEALTH

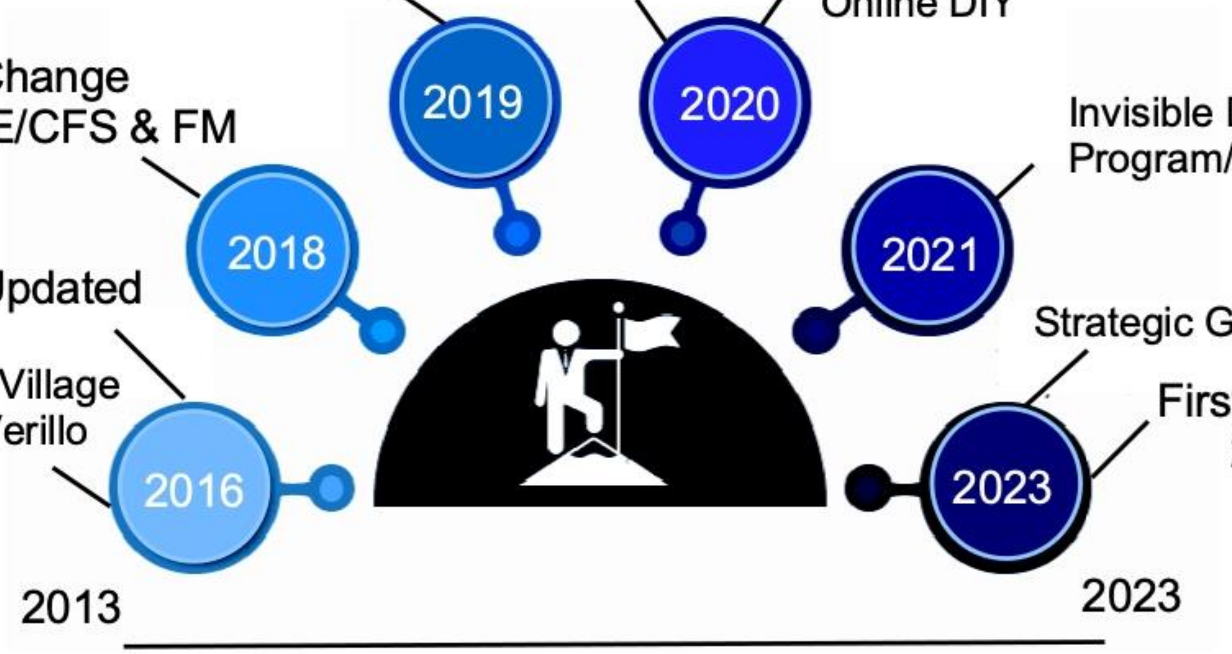
Learning to treat long COVID could help those struggling with Chronic Fatigue Syndrome, too

Some experts say the current crisis of long COVID is related to our government's neglect of similar post-acute infection chronic illnesses like ME/Chronic Fatigue Syndrome in decades past.

By **Amanda Gokee** Globe Staff, Updated May 23, 2023, 9:14 a.m.

Veronica "Ronnie" Dane watched a show while resting in bed at her home in Stratham, N.H. She suffers from Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and spends more than 20 hours in bed per day to save energy for picking her kids up from school and other daily tasks. CRAIG F. WALKER/GLOBE STAFF

MassME/CFS & FM Association Achievements



2013

2016
Sturbridge Village
Author Verillo
Website Updated

2018
Name Change
MassME/CFS & FM

2019
Annual Clinical Nursing
Conference, Worcester

2020
Social
Media
Strategic Plan Developed
Online Research Group
Online DIY

2021
Invisible Disabilities
Program/ Mass DPH

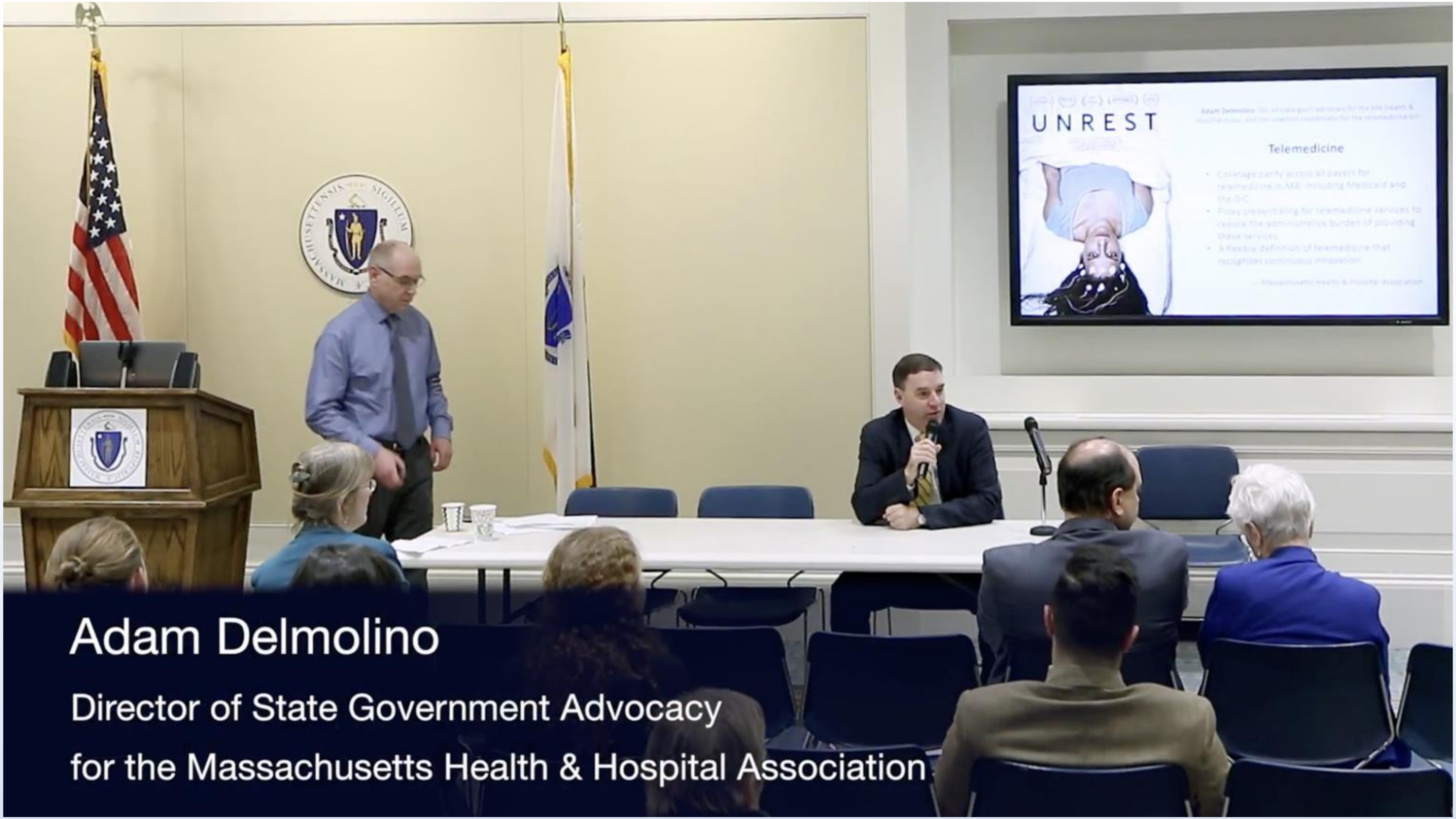
2023
Strategic Goals Updated
First paid staff-
2022

2023

Activities:
Support Groups
Physican Referral
Disability Counseling
Advocacy
Fundraising

Some examples- Many More!!

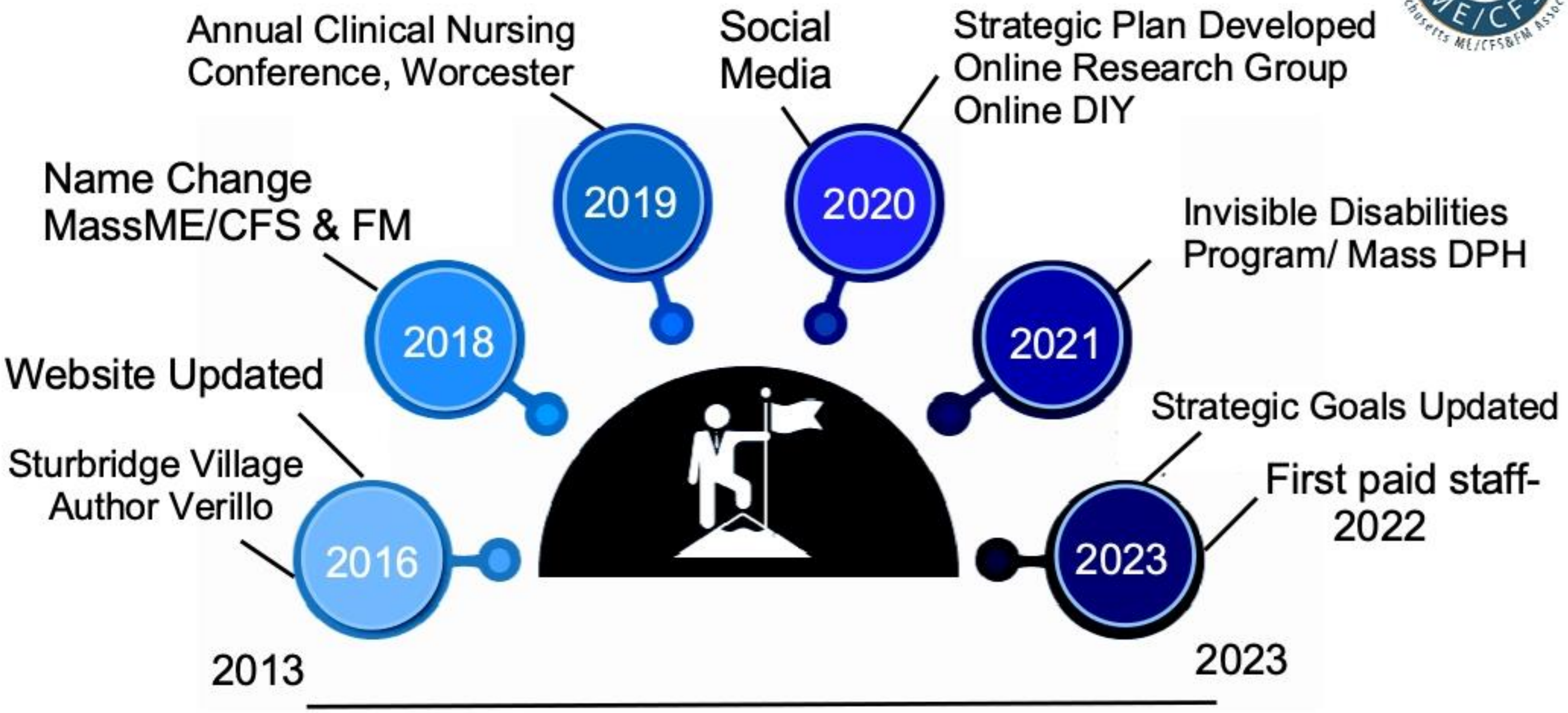
17 Unrest Events (org. Rivka Solomon), 2017 - 2019)
Monthly Sunday Conversations 2022 - ongoing
Online Support Groups 2022 - ongoing
Participation in Advocacy Week on Capitol Hill



Adam Delmolino

Director of State Government Advocacy
for the Massachusetts Health & Hospital Association

MassME/CFS & FM Association Achievements



2013

2016

Sturbridge Village
Author Verillo

Website Updated

2018

Name Change
MassME/CFS & FM

2019

Annual Clinical Nursing
Conference, Worcester

2020

Social
Media

Strategic Plan Developed
Online Research Group
Online DIY

2021

Invisible Disabilities
Program/ Mass DPH

2023

Strategic Goals Updated

First paid staff-
2022

2023

Activities:
Support Groups
Physican Referral
Disability Counseling
Advocacy
Fundraising

Some examples- Many More!!

17 Unrest Events (org. Rivka Solomon), 2017 - 2019)
Monthly Sunday Conversations 2022 - ongoing
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SEPTEMBER 15TH 12 NOON ET - ZOOM

INVISIBLE DISABILITIES

LONG COVID AND OTHER POST-INFECTIOUS CHRONIC ILLNESSES

CYNTHIA ADINIG
LONG COVID ADVOCATE

CLAUDIA CARRERA, MA
ME/CFS ACTIVIST

ALFRED DEMARIA JR., M.D.
MASS. DEPT. OF PUBLIC HEALTH

RODRIGO MONTERREY, MPA
MASS. DEPT. OF PUBLIC HEALTH

KAYLA SCHEINER
LYME ADVOCATE

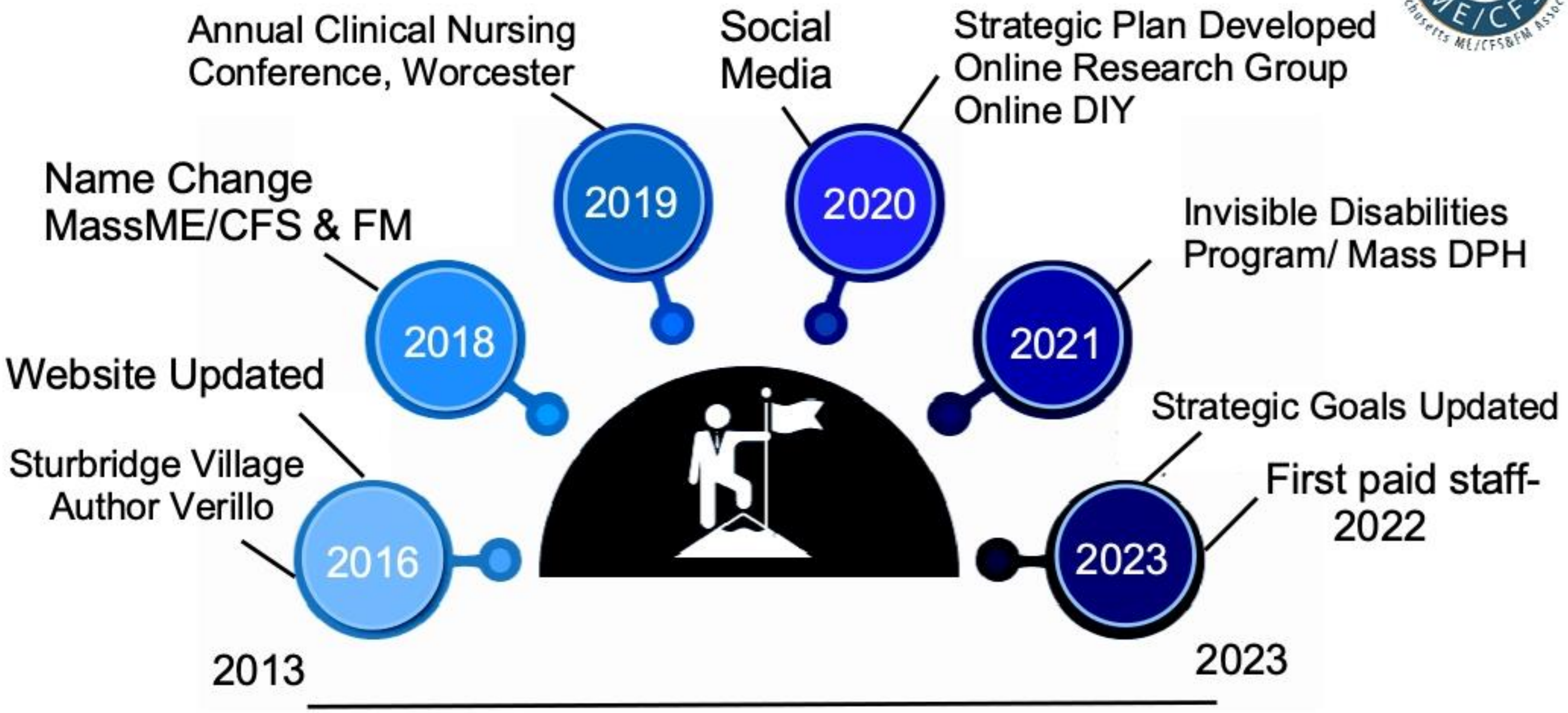
REGISTRATION & ZOOM AT: XXXXXXXXX.XXXXX

PRESENTED BY

THE HEALTH AND DISABILITY PARTNERSHIP
AT THE MASSACHUSETTS DEPARTMENT
OF PUBLIC HEALTH

WITH Massachusetts ME/CFS & FM ASSOCIATION

MassME/CFS & FM Association Achievements



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The Interview

Jehan Keziere interviews long-time member Ken Casanova

Thank you for zooming with us through the decades!

This was only a brief list of events and activities.

Due to time constraints, we couldn’t mention all the wonderful people involved,

but we honor everyone who contributed over the years.

Thank you to the following:

Concept: MassME Board members: Hayla Sluss, Pat Woods, Kathryn Ruhf

Opening/Closing: Susan Buckley, MassME Co-President

Decade 1: Charmian Proskauer, Past President

Decade 2: Phil Chernin, MassME Co-President

Decade 3: Hayla Sluss, Board member

Decade 4: Helen McGunnigle, Sunday Conversations team

Interview: Jehan Keziere, Volunteer; Ken Casanova, Past President, Patient Services Coordinator

Slides: Hayla Sluss, Board member

Zoom Production: Ben Erban, Sunday Conversations team

Help us celebrate our community and history!

MASSME@40

NEW LIGHT

The MassME@40 Campaign is gathering stories and documenting our history.

If you have archival materials, or a story to tell:

contact@massmecfs.org

or go to the 'Contact Us' page at massmecfs.org

We are only able to produce this speaker series through your membership and generous donations. Thank you!

massmecfs.org/**join**

massmecfs.org/**donate**

To join the Sunday Conversations team: volunteer@massmecfs.org

No Sunday Conversation in July
Resumes August 20…stay tuned!

Have a good summer!