Dear Secretary Sebelius,

We are writing as patient forum leaders, not-for-profit organization managers, scholars, authors, filmmakers, bloggers and other advocates working on behalf of individuals with the disease of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), to inform you that we stand united in support of the positions expressed in the letter to you dated September 23, 2013; updated October 25, 2013; and currently signed by 50 biomedical researchers and clinicians with expertise in ME/CFS.


As you know, the 1994 International Case Definition (Fukuda et al, 1994), commonly known as the Fukuda definition, was the primary case definition for ME/CFS for almost two decades.

However, as our experts wrote to you, in recent years expert researchers and clinicians have increasingly used the Canadian Consensus Criteria (CCC), as they have recognized that the CCC is a more scientifically accurate description of the disease. Unlike the Fukuda definition, the more up-to-date CCC incorporates the extensive scientific knowledge gained from decades of research, our experts explained.

As described in the letter from our experts, there is sufficient evidence and experience to adopt the CCC now for research and clinical purposes, and failure to do so will significantly impede research and harm patient care. This step will facilitate efforts to define the biomarkers, which will be used to further refine the case definition in the future, our experts agreed.

We strongly urge the Department of Health and Human Services (HHS) to follow our experts’ lead by using the CCC as the sole case definition for ME/CFS in all of the Department’s activities related to this disease.

In addition, we strongly urge you to abandon reliance on groups such as the Institute of Medicine (IOM) that lack the needed expertise to develop “clinical diagnostic criteria” for ME/CFS. Since the expert ME/CFS scientific and medical community has developed and adopted a case definition for research and clinical purposes, this effort is unnecessary and would waste scarce taxpayer funds that would be much better directed toward funding research on this disease. In addition, as our experts wrote, this
effort threatens to move ME/CFS science backward by engaging non-experts in the development of a case definition for a complex disease about which they are not knowledgeable.

ME/CFS patients who have been disabled for decades by this devastating disease need to see the field move forward and there is no time to waste. We believe that our experts’ consensus decision on a case definition for the disease will jump start progress and lead to much more rapid advancement in research and care for ME/CFS patients. We look forward to this accelerated progress and urge you to work with the people who know the most about this disease -- our experts -- in order to effectively increase scientific understanding of the pathophysiology of this disease, educate medical professionals, develop more effective treatments, and eventually find a cure.

Sincerely,

United States Signatories:

Michael S. Allen, Ph.D.
Ph.D., M.S., Syracuse University
Former Clinical Psychologist (disabled since 1993 at age 45)
Former Member of Board of Directors, Gay and Lesbian Alliance Against Defamation
Patient Advocate

Dave Asprey (Added November 9, 2013)
M.B.A., The Wharton School
Founder & CEO, The Bulletproof Executive
Vice President, Cloud Security, Trend Micro
Chairman, Silicon Valley Health Institute
Former CFS Patient
http://www.bulletproofexec.com/

Elisabeth Tova Bailey (Added November 9, 2013)
CFS patient for 21 years
Author of “The Sound of a Wild Snail Eating,” a CFS medical humanities/natural history memoir
www.elisabethtovabailey.com

Keith Baker
B.A., Psychology, University of Maine
Former Clinical Case manager, The May Institute (disabled)
Ill with CFS since 1987 (26 years)
Patient Advocate
Shari Boxer Baker *(Added November 9, 2013)*
President, JDS Group PR
Former Congressional Aide to Honorable Norman Y. Mineta (Former Member of U.S. Congress, U.S. Secretary of Commerce & U.S. Secretary of Transportation)
ME Activist

Lisa Frattaroli Baldwin, B.S.W., Q.D.D.P. *(Added November 9, 2013)*
Bachelor of Social Work, Mars Hill University, School Social Work License (NC State)
Parent of an adult son with severe ME/CFS
Family was subjected to horrible travesty of justice when at 17 years of age their son was taken wrongly into custody by North Carolina Child Protective Services
http://www.bringingryanhome.com/
Patient Advocate since 2004

Heidi Bauer
M.A., English Education, Indiana University of Pennsylvania
B.S., English Literature, Indiana University of Pennsylvania
Former Teacher (disabled starting in 1995)
Patient Advocate

Janis Bell, Ph.D., N.M.D., R.Y.T.
Ph.D., Brown University
Former Associate Professor, Kenyon College (disabled 1994 - present)
Grants from Fulbright, Harvard, American Academy in Rome
Extensive publications before becoming disabled
Currently Blogger, “Search for the Cure”
cfsmethylation.blogspot.com

Victoria Bell *(Added November 9, 2013)*
Former pianist; also formerly led telemark skiing, hiking, bicycle touring and river rafting expeditions
Former Creative & Legal Rights Agent (22 years); Director of Publicity and Marketing (14 years); Curator (12 years); Publisher and Managing Director (8 years)
Experienced ME viral onset and years of periodic disability alternating with attempts to work starting in 1989 at age 39
Not diagnosed until became permanently disabled in 2000
ME Advocate, 2003 to Present
http://www.linkedin.com/in/kivadancer
Katrina Berne, Ph.D.
Ph.D., Union Institute and University
M.C., Arizona State University
M.A., Montclair State College
B.A., Douglass College, Rutgers University
Ill with ME/CFS since 1984, disabled since 2001
Clinical Psychologist, College Instructor, Lecturer, Advocate.

Antonia (Toni) Bernhard, J.D.
Former Dean of Students and Faculty Member, University of California, Davis, School of Law, 1982-2004 (currently disabled)
Patient Advocate/Blogger at “Psychology Today” online. Name of Blog: "Turning Straw Into Gold"
Website: www.tonibernhard.com

Paul Beth
Disabled 24 years
Administrator, “CFS/ME/CFIDS: Feel Great Destinations”
http://health.groups.yahoo.com/group/CFS_CFIDS_ME/

Gina Bettor (Added November 9, 2013)
Studied Insurance Management, Boward College
Formerly worked for Prudential Financial, Progressive Insurance and Eastern Airlines
Patient Advocate
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Howard Bloom (Added November 9, 2013)
Former Core Faculty Member, The Graduate Institute
Recent Visiting Scholar, Graduate Psychology Department, New York University
Founder and Chairman, Space Exploration Asia
Founder, International Paleopsychology Project
Founder, Space Development Steering Committee
Member Of Board Of Governors, National Space Society
Founding Board Member, Epic of Evolution Society
Founding Board Member, The Darwin Project
Founder, The Big Bang Tango Media Lab
Member, New York Academy of Sciences, American Association for the Advancement of Science, American Psychological Society, Academy of Political Science, Human Behavior and Evolution Society, International Society for Human Ethology
Scientific Advisory Board Member, Lifeboat Foundation
Advisory Board Member, The Buffalo Film Festival
Board of Editors, The Journal of Space Philosophy
Howardbloom.net
http://www.youtube.com/user/howbloom

Valentina Bodina-Cohen, J.D. (Added November 9, 2013)
J.D., Universita' degli Studi, Milano, Italy
Disabled by ME since 1981 at age 14
Since then never been able to have a career or lead a normal life
Patient Advocate

Andrew Bokelman (Added November 9, 2013)
M.A., Education, California State University Northridge
Former Senior Administrative Analyst, Los Angeles Unified School District
Disabled since 2005

Wendy Boutilier (Added November 9, 2013)
B.A., Fine Arts, Art History & Anthropology, Western University & University of West Indies
Former Resort Manager in Caribbean for 19 years
Disabled in 2009 with ME
Patient Advocate
wendy1953@myopera.com
Jennifer Brea  
Harvard Ph.D. student on medical leave (disabled at age 28)  
A.B. Princeton University  
Director & Producer, “Canary in a Coal Mine”  
www.canaryinacoalminefilm.com

Jeannette Burmeister, J.D.  
J.D., Free University Berlin School of Law  
LL.M., University of San Francisco School of Law  
Former Attorney at Baker & McKenzie, LLP (disabled at age 34)  
Attorney at Law and Rechtsanwältin, licensed to practice law in California and Germany  
Patient Advocate/Blogger, “Thoughts About M.E.”  
www.thoughtsaboutme.com

Christopher Cairns (Added November 9, 2013)  
Professor Emeritus, Haverford College  
Patient Advocate

Terri Campbell, Ph.D.  
Ph.D., Pacifica Graduate Institute  
M.A., John F. Kennedy University  
Former Psychologist in San Francisco (disabled at age 42)  
Patient Advocate/Blogger, “Three Miles at a Time (ME/CFS Warrior)”  
http://cfswarrior.blogspot.com

Meg Carlson, M.A.  
M.A., Psychology, Sonoma State University  
B.A., Women’s and Gender Studies, Sonoma State University  
Trained as Volunteer Hospital Chaplain and Domestic Violence Advocate  
Somatic Experiencing Practitioner (trauma therapy)  
Chronically ill since 1982 at age 29  
Patient Advocate/Support Group Facilitator

Rik Carlson  
Illness Survivor  
Director, ImmuneDysfunction.org (The Vermont CFIDS Association)

Rich Carson (Added November 9, 2013)  
B.A., UC Santa Barbara  
Former Stockbroker (totally disabled 1987 at age 31)  
Owner, ProHealth (largest number of likes for any ME/CFS group or individual (100,000+) and largest number of ME/CFS Twitter followers (5000+))  
http://www.prohealth.com/
Patricia Carter, J.D.
J.D., University of Florida College of Law (with Honors)
B.A., Public Administration and Political Science, University of Central Florida (Magna Cum Laude)
Florida Bar Association Member No. 198528
Former Assistant Professor, University of Central Florida
Former Partner, Carter & Stalnaker, Attorneys at Law, Winter Park, Florida (disabled at age 41 in 1986)
Administrator, “ME CFS Forums” (currently 6820 members)
www.mecfsforums.com

Kenneth Casanova (Added November 9, 2013)
B.A., Hamilton College, 1968
Former Community Organizer, Legislative Advocate, and Program Developer, State of Massachusetts
Disabled with ME/CFS in 1981
Patient Advocate and Support Group Leader, 1987-2013
Past President, Massachusetts CFIDS/ME & FM Association
Author, "How to Obtain Social Security Disability Benefits if You Have Chronic Fatigue Syndrome"
Author of numerous articles on ME/CFS

Nicole Castillo
B.A., University of Georgia
Director, The Blue Ribbon Foundation

Ann Cavanagh
M.B.A., Johns Hopkins University
B.S., Journalism and Mass Communications, Drake University
Director, Sales, Fortune 500 company (disabled in 2008 at age 30)
Patient Advocate

Ray Colliton
B.A., Philosophy, St. Paul's College, Washington, D.C.
Former Systems Administrator (disabled with ME/CFS in 1988)
Managing Owner, “The Co-Cure Project”
http://www.co-cure.org/

JoAnn (Joni) Comstock (Added November 9, 2013)
Cosmetologist
Former Salon Owner & Operator (closed Dec. 2004 due to disability)
Former Office Manager
Chronically ill since 1997 at age 33
Patient Advocate, May 12 International Awareness Day Events
www.May12.org
Robert Courtney *(Added November 9, 2013)*
Former Health Worker
Became ill in 2003
Patient Advocate

Jamie Deckoff-Jones, M.D.
M.D., The Albert Einstein College of Medicine
A.B., Harvard University
Patient Advocate, "X Rx"
http://blogspot.x-rx.net/

Michael Dessin *(Added November 9, 2013)*
B.S., University of Cincinnati
Former Sales Executive
Disabled and very severely ill with ME/CFS in 2006, now mostly recovered
Patient Advocate

Arlyn DeWees *(Added November 9, 2013)*
A.B., University of Florida, 1960
Former Editor of Legal Newsletters and Scientific Journals
Acquired CFS/ME in 1984, primarily housebound since 2009
Patient Advocate

Mary Dimmock
B.A., Connecticut College
Retired Scientist and Business Analyst, Pfizer Pharmaceuticals
Patient Carer and Advocate

John Dodson *(Added November 9, 2013)*
B.S.E., Industrial Education
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Susan Dodson *(Added November 9, 2013)*
M.A., B.A., Speech Pathology, Texas Tech University
Former Division Director, Early Childhood Intervention, State of Texas, Austin
Ill with ME/CFS since June 19, 1988
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Pat Fero, M.E.P.D.
Master of Education and Professional Development, University of Wisconsin - Whitewater
Executive Director, Wisconsin ME and CFS Association, inc.
http://www.wicfs-me.org/
Barbara Fifield *(Added November 9, 2013)*
Long Term Patient, Caregiver and Advocate

Robin Funk *(Added November 9, 2013)*
Degree, Business Administration, Columbia College
Diagnosed at age 34 in 1988 (Outbreak in Sonora, California)
Former Paralegal (housebound since 2011)
Patient Advocate
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Martha Gandelman *(Added November 9, 2013)*
B.S., Natural Science, Worcester State College
Patient Advocate

Gaston Gingues *(Added November 9, 2013)*
B.S., Science, University of New Hampshire
Former Chemist (disabled at age 33)
Became permanently ill after a bout of mono
Patient Advocate

Maureen Goggins
B.S., University of Illinois at Urbana-Champaign
Gradual onset disability
Patient Advocate

Karen Goode *(Added November 9, 2013)*
B.S., Life Sciences, Pennsylvania State University (Capital College Honors Program Graduate)
Former Aspiring Medical Student
Ill with ME since 2002 at age 21, disabled since 2009
Gradual Onset Disability
ME Advocate and Guinea Pig

Julie Murray Goodlaxson *(Added November 9, 2013)*
B.F.A. Design, The University of Iowa
Former Special Projects Assistant, City of Iowa City, Water Division of Public Works
Became ill with ME/CFS in September 2005
Became unable to work 2009 and bedridden in 2011
Former community organizer (local, state, and national) for issues concerning Education, Special Education, the ADA, Autism Awareness, and Educating Children with Autism
Campaign Officer for several local campaigns.
Patient Advocate for ME/CFS

Bonnie Gorman, R.N. *(Added November 9, 2013)*
Founder, Massachusetts CFIDS/ME & FM Association
Lillian Greeley, Ed.D. (Added November 9, 2013)
Ed.D., Harvard University
Disabled with ME/CFS in 1986
Patient Advocate
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Joan Grobstein, M.D. (Added November 9, 2013)
M.D., University of California Davis School of Medicine
A.B., Harvard University
Former Neonatologist at Children's Hospital of Philadelphia (disabled since 2000)
Patient Advocate

Lisa Hansen (Added November 9, 2013)
Afflicted with ME for 22 years
Patient Advocate

Jean Harrison
A.B., Wellesley College
Former Museum Conservator for Oil Paintings (disabled since 1994)
Founder MAME (Mothers Against ME) in 1999

Heidi Hayward (Added November 9, 2013)
Sick for 9 Years
Patient Advocate

John Herd
Degree, Beth Israel Hospital School of Biomedical Photography
Lowell Institute Program, Massachusetts Institute of Technology
Former medical photographer and business owner (disabled at age 37)
Member of several program planning and selection committees and a name change workgroup for Chronic Fatigue Syndrome for the US Department of Health and Human Services (1996-2003)
ME/CFS Author and Advocate

Rev. Bernard F. Hillenbrand (Added November 9, 2013)
Former Executive Director, National Association of Counties
Elder in United Methodist Church
Father of a daughter who is a 25-year victim of CFS
Advocate

Eileen Holderman
B.S., Radio-TV-Film, University of Texas at Austin
Former profession: radio broadcaster, public relations (NYC)
ME Advocate
Carol Houseman *(Added November 9, 2013)*  
M.B.A., California State University Sacramento  
Former Management Consultant/University Lecturer  
Disabled at 55 years old in 2002  
Patient Advocate  
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Suzan L. Jackson *(Added November 9, 2013)*  
B.S., Chemical Engineering (with a concentration in Technical Communications), Clarkson University  
Acquired CFS in 2002. Mother of two sons who first became ill with the disease as young children.  
Freelance Writer (including articles about CFS)  
Patient Advocate, "Learning to Live with CFS"  
http://www.livewithcfs.blogspot.com/

Cort Johnson  
Patient Advocate

Erik Johnson  
1985 Incline Village "Tahoe Mystery Illness" survivor  
Participant, Holmes et al CFS definition patient study group  
Former Hang Gliding and Windsurfing Instructor  
Author, Chapter 23, "Mold at Ground Zero for CFS" in Dr. Ritchie Shoemaker's book, "Mold Warriors"

Hillary Johnson  
M.S., Columbia University (Graduate School of Journalism) 1975  
B.S., U.C. Berkeley 1974  
Author, "Osler's Web: Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic" (Crown Publishing Group, New York, 1996)  
Assistant Professor, Journalism, Marist College, NY 2000-2003  
Myalgic Encephalomyelitis: March 1986-present

Jill Justiss *(Added November 9, 2013)*  
Chronically ill for 12 years  
Patient Advocate

Gail R. Kansky  
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Former Teacher (disabled)  
President, National CFIDS Foundation (all-volunteer charity that has funded close to $2 million to advance research)  
www.NCF-NET.org
Ward Karns (Added November 9, 2013)
B.S., Mechanical Engineering, Rochester Institute of Technology
Former Research Engineer and Scientist, Xerox PARC (Disabled 1987)
Patient Advocate

Mary A. Kindel (Added November 9, 2013)
B.S., Industrial Design, University of Cincinnati
Former Industrial/Graphic/Web Designer, Technical Writer, Musician, Luthier
Disabled in 2000 at age 37
Patient Advocate

Roger King
Ph.D., Agricultural Economics, University of Reading, England
M.S., University of Massachusetts Amherst
B.S., Food Science, University of Nottingham, England
Former University Professor (stopped teaching as a result of ME/CFS)
Novelist, “Love and Fatigue in America”

Mindy Kitei
M.S., Northwestern University (Medill School of Journalism)
B.A., University of Pennsylvania
Magazine editor, bestselling health-book author and advocate for a good friend who
died from this disease
Blogger, “CFS Central”
www.cfscentral.com/

Gabby Klein
Former Vice President of Administration for an Insurance Company
Disabled for the past 10 years
Patient Advocate

Steven P. Krafchick, J.D., M.P.H. (Added November 9, 2013)
M.P.H., University of Michigan
J.D., University of Puget Sound (now Seattle University School of Law)
Attorney at Law representing ME/CFS patients in private-disability-insurance and
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B.S., California Polytechnic University at San Luis Obispo
Former Senior Staff Counsel CA Department of Insurance (disabled at age 51)
Patient Advocate
Margaret Lauritson-Lada (Added November 9, 2013)
Public Health Administrator (retired)
ME/CFS survivor and advocate

Rosemary Lee (Added November 9, 2013)
B.A., Political Science/English, University of California, Los Angeles
Former Corporate Broker, Woodside Homes (disabled since 2009)
Patient Advocate/Blogger, "Seeking Equilibrium"
www.rosemaryl.blogspot.com

Carol Lefelt (Added November 9, 2013)
M.Ed., Rutgers University
B.A., Douglass College
Former High School English Teacher and Humanities Supervisor
Disabled 1999 at age 55 after a flu shot
Blog, "But You Don't Look Sick" at Health Rising
www.cortjohnson.org

Diane Lewis, LCSW-C (Added November 9, 2013)
Patient Advocate

Anne LiConti, R.N. (Added November 9, 2013)
Nursing Degree, College of Staten Island, CUNY
Former CCU and Operating Room Registered Nurse
Disabled from ME/CFS since age 30
Symptoms of ME since 1965
Vice President of MAME (Mothers Against ME)
ME Patient Advocate

Denise Lopez-Majano
Parent of two young men with severe ME (CFS)
Patient Advocate
Developer of “Speak Up About ME"
http://speakupaboutme.wordpress.com/

Kathleen Manganaro
Master Equivalency, Speech Pathology, Indiana State University
B.S., Speech Pathology, Pennsylvania State University
Former School Speech/Language Pathologist for 30 years
Disabled since 2007
Patient Advocate

Craig Maupin (Added November 9, 2013)
The CFS Report
www.cfidsreport.com
Beth Mazur  
B.S., Electrical Engineering and Computer Science, MIT  
Patient Advocate  

S. Siobhan McElwee  
Former Artist/ Owner of Talkingfox Studios  
Became Ill in 1978. Completely disabled since 2006  
ME Activist  

Courtney Miller  
B.A., Cum Laude, Yale University  
Wife of Longtime ME/CFS Patient  
Obama Promise to Elevate ME/CFS  
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Robert Miller  
ME/CFS Patient & Advocate  
Former Fire Boss Coal-Miner Certified - EMT trained (Became ill with ME/CFS in 1982)  
Ampligen - FDA clinical trial participant  
11 Day Hunger-Striker for Treatments, January 2013  
NIH State of Knowledge Workshop participant  
ME/CFS FDA Drug Development Workshop panelist  
bobmiller42@msn.com  

Billie Moore  
B.A., Pennsylvania State University  
Advocate for deceased 46-year old son who committed suicide after having ME for 20 years and despairing of no treatments  
Advocate for other sufferers  

Jacqueline McBride Nance (Added November 9, 2013)  
Former Professional Artist  
Permanently Disabled with ME at age 40 (more than 22 years)  
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Disability Insurance Attorney  
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Faith Newton, Ed.D. *(Added November 9, 2013)*  
Ed.D., College of William & Mary  
Associate Professor of Education, Delaware State University  
ME/CFS Education Initiative  
ME/CFS Parent Advocate

Matina Nicholson  
M.B.A., Dartmouth College (The Tuck School of Business)  
B.S., International Business Management, Goldey Beacom College  
Executive Program in Pharmaceutical Marketing  
Former VP Marketing and Director of E-marketing at Leading NYC Pharmaceutical Advertising Agency (disabled at age 38)  
Patient Advocate

Linda R. Oldershaw, R.N. *(Added November 9, 2013)*  
R.N., St. Luke's Hospital School of Nursing  
Former Director of Medical Services, Blue Cross Blue Shield  
Disabled since 2007  
Patient Advocate

Anita Patton *(Added November 9, 2013)*  
Secretarial Degree  
Former Word Processor at Physical Science Laboratory, New Mexico State University  
Ill since 1986  
Patient Advocate

Donna Pearson  
Former Management Executive (disabled at age 48)  
Vice President, Massachusetts CFIDS/ME & FM Association  
Patient Advocate

Ella Peregrine *(Added November 9, 2013)*  
Cheraga (Interfaith Minister), Sufi Ruhaniat International  
B.A., Humanities, University of Louisville  
Former Research Coordinator, Neurodevelopmental Sciences Laboratory, University of Louisville  
Severely disabled in 2008 at age 42  
Patient Advocate, Administrator of U.S. Campaign for Myalgic Encephalomyelitis

Lisa Petrisin, Ph.D.  
Ph.D., Marketing, Kellogg School of Management, Northwestern University  
M.S., B.S., Medill School of Journalism, Northwestern University  
Former Tenure-Track Professor, Loyola University Chicago (disabled at age 36)  
Executive Director, Paradigm Change  
www.paradigmchange.me
Elizabeth C. Potter (Added November 9, 2013)
B.A., Mathematics, Secondary Education and Computer Sciences, New England College
Senior Systems Analyst at Wang Laboratories in Manufacturing Production and Finance
Disabled with ME/CFS in 1985 at age 32
Board of Directors for Massachusetts CFIDS/ME & FM Association
Patient Advocate

Shirley Powers, M.S. (Added November 9, 2013)
M.S., San Francisco State University
Former Assistant Director, Citywide Case Management, UCSF Department of Psychiatry
Formerly in private practice
Co-author, “Clinical Case Management”
Ill for 15 years
Patient Advocate
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Ryan Prior
B.A., University of Georgia
President, The Blue Ribbon Foundation

Justin Reilly, J.D.
J.D., Georgetown University Law Center
B.A., Brown University
Former Attorney at Senn, Lewis & Visciano, Denver, Colorado (disabled at age 30)
Patient Advocate

T. Gorman Reilly, J.D. (Added November 9, 2013)
J.D., New York University
B.A., Fordham University
Former FDA Attorney
Former Federal Prosecutor in SDNY
Commander (retired), US Navy Intelligence
Partner (retired), Hahn & Hessen, New York, NY
Patient Advocate

Katherine Reynolds (Added November 9, 2013)
M.F.A., Creative Writing, Vermont College
M.A., Creative Writing, University of Houston
B.S., Education, Kent State University
Former Professor of English, Lone Star College Tomball, Texas (1989-2010)
Ill with ME since 2009. Disabled since 2010.
Patient Advocate
katherinereynoldswriter.blogspot.com
Judith A. Richman, Ph.D.
Ph.D., Columbia University
Professor of Epidemiology in Psychiatry, University of Illinois at Chicago
Author of many journal articles on this illness

Andrea Runyan
B.S., Math, Stanford University (Goldwater Scholar)
Marketing Researcher
Disabled at age 23, now partly recovered
Video Blogger, “Grow Your Life”
http://www.youtube.com/user/Xicota85

Diana Saba (Added November 9, 2013)
Disabled Retired Nurse
Founder and Editor, Women and Children of CFIDS + Men + ME

Mary Schweitzer, Ph.D.
Ph.D., Johns Hopkins University
Former Professor of History, Villanova University (disabled)
Author and Patient Advocate

George Segerman
M.B.A., M.I.S., City University
Human Resource Management, University of Washington
University of Puget Sound Law School, Tacoma, WA
B.P.A., Public Affairs, Seattle University
Criminal Justice, Washington State Patrol Academy
GCS Associates Management Organizational Development
Manager/Consultant Worldwide Technology Center, Weyerhauser
Manager Windows PSS Division, Microsoft
Patient Advocate Research Funding, Member of the Microsoft Alumni Foundation

Carol Sieverling (Added November 9, 2013)
M.Div. and M.A.C.E., Union Presbyterian Seminary
B.A., Math, Sterling College
Former High School Math Teacher, Associate Pastor
Ill and disabled since 1987, on Long Term Disability since 1996
Treasurer and Former President of the CFS/FM Support Group of DFW (Dallas/Ft. Worth)
Nancy Smith (Added November 9, 2013)
Degree in Fashion Design
Former Small Business Owner
Disabled for 39 years with ME/CFS
Patient Advocate, Support Group Leader
National TV and Radio experience in raising CFS/ME awareness
Board Member of MassCFIDS/ME & FM Association for 21 years
Previous Educational Lecture Chairperson for MassCFIDS/ME & FM Association
Author of "CFIDS, An Owner's Manual" and numerous articles on ME/CFS

Kim A. Snyder (Added November 9, 2013)
M.A., Johns Hopkins School of Advanced International Studies
Film Director/Producer, “I Remember Me”

Rivka Solomon, M.S.
Writer, playwright
Advocate for ME/CFS Patients

Pat Sonnett (Added November 9, 2013)
B.B.A., University of Miami
Former Legal Administrator
Have had ME/CFS since January 1986
Patient Advocate, Miami ME/CFS Support & Advocacy Group

Jay Spero (Added November 9, 2013)
Patient Advocate

Jerrold Spinhirne, S.E.
B.Arch., University of Illinois at Chicago
B.A., University of Chicago
Licensed Structural Engineer
Former Senior Project Engineer at Thornton Tomasetti (disabled since 1996)
Patient Advocate, U.S. Campaign for Myalgic Encephalomyelitis (ME)
https://www.facebook.com/groups/624505110934978/

Maryann Spurgin, Ph.D.
Ph.D., M.A., Philosophy, The University of Texas at Austin
B.A., Languages and Philosophy, LSU Baton Rouge
Formerly taught philosophy
Ill with Myalgic Encephalomyelitis since March 2, 1982 (became too sick to teach in mid-30’s)
Author of over 10 articles and reviews on topics in science and medical politics
Wrote and constructed the M.E. Society of America website
www.cfids-cab.org/MESA/
Kathryn Stephens  
Served in U.S. Army, 1974-80  
Social work student when stricken with CFS in 1987  
Sick for 26 years (since age 46)  
Newsletter Editor/Author  
Patient Advocate/Support Group Leader  

Cheryl Stromberg, P.T. (Added November 9, 2013)  
B.S., Physical Therapy, University of New Mexico  
B.S., Communicative Disorders/Sign Language Interpreting, University of New Mexico  
Former Physical Therapist, Yoga Instructor, Sign Language Instructor, Certified Childbirth Instructor  
Disabled by ME/CFS (including POTS) in 2012 at age 48  
Mother of a child with the same symptoms  
Patient Advocate  

Susan Thomas (Added November 9, 2013)  
B.A., Duke University  
Residency--Clinical Pastoral Education, University of Alabama Hospital  
Former Hospital Chaplain (disabled since 2006)  
Patient Advocate  

Jane Tompkins, Ph.D. (Added November 9, 2013)  
Ph.D., Yale University  
B.A., Bryn Mawr College  
Former Professor of Literature, Duke University (disabled in 2005)  
Patient Advocate  

Suellen Tritt (Added November 9, 2013)  
B.A. Eq., English, Art and Political Science, Brooklyn College  
Former Artificial Intelligence Consultant, Senior Knowledge Engineer, System Designer, Quality Assurance Project Manager and Wall Street Executive (with “Who’s Who” professional recognition)  
Disabled for 23 years starting at age 38  
Patient Advocate (international and national): three HHS testimonies; creator of the “Impact Book”; former New Jersey CFS Association board member; facilitated the development of viral research in ME/CFS by encouraging Dr. Ian Lipkin and Dr. Susan Levine to become collaborators in the late 1990’s; founder and facilitator of New York Support Network; board member of cfsADVOCACY  
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Bachelor’s in Business Administration, UC Berkeley  
Former Consultant  
Patient Advocate  
Board of Directors for “The Blue Ribbon: ME/CFS and the Future of Medicine”
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Former Artist and Owner, Knothome Designs
Former Author and Photographer
Web Designer and Co-Owner, Replay Publishing/Sports Games
Disabled by ME in 1996 at age 37
Co-Founder, Web Design & Content, National Alliance for Myalgic Encephalomyelitis
ME Advocate
www.name-us.org

Erica Verrillo
M.A., Syracuse University
B.A., Tufts University
Author, “Chronic Fatigue Syndrome: A Treatment Guide”
Editor, ProHealth
Patient Advocate, "Onward Through The Fog"
ww.cfstreatment.blogspot.co.uk/

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A.A.S., Architectural/Construction Technology, Baker College
Disabled at age 18
Patient Advocate

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J.D., University of Virginia School of Law
B.A., Brown University
Former Senior Associate Counsel, UMWA Health & Retirement Funds
Disabled since 1991
Patient Advocate

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D.V.M., The Ohio State University,
Former Veterinarian (worked for 10 years)
Became very ill at age 33, permanently disabled at age 35
Patient Advocate

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Author, The Kafka Pandemic
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M.B.A., Finance and International Business, New York University (with Honors)
B.A., Architectural Sciences, Harvard University (with Honors)
Former Journalist
Former Wall Street Analyst, Oil & Gas Industry
Ill with ME/CFS since 1989
Co-Founder and Reporter, “ME/CFS Alert”
http://www.youtube.com/user/MECFSAlert

Sara Whitestone
Became ill in 2010 at age 16
Current Student, University of Cincinnati
Patient Advocate

Annette Whittemore
Founder, President and CEO, Whittemore Peterson Institute for Neuro-Immune Disease
www.wpinstitute.org

Andrea Whittemore-Goad
Chronically ill for 25 years
Social Media, Donor Relations and Patient Advocacy, Whittemore Peterson Institute for Neuro-Immune Disease
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Laura A. Willoughby-Snow
M.A., Washington State University
Former Art Director/Designer, Major Jewelry Company
Disabled in the Incline Village/Lake Tahoe epidemic 29+ years ago at the age of 20
Patient Advocate (letters, videos, paintings, poetry, etc.)
Patient Volunteer, Simmaron Research Foundation, 2011

Danny Zee
Disabled at Age 21
Patient Advocate

International Signatories:

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Grad. Dip., Applied Business Administration, Swinburne University
Grad. Dip., Applied Social Psychology, Swinburne University
B.A., Dip., Social Work, University of Melbourne
Former Superannuation Regulation Officer (disabled for 14 years)
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Australia
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M.Sc., Economics, University of Amsterdam
Former Recruitment Manager at global US IT company (disabled at age 39)
ME Advocate: ME TV interviews for documentaries and news items, speaker at Dutch
ME press conference etc., initiator International ME conference 2014 in the Netherlands
Netherlands

Wilfried P. Bieger M.D., Ph.D. (*Added November 9, 2013*)
Munich Clinic for Stress Medicine and Clinical Immunology
18 years of Specialization in ME/CFS
Germany

Natalie Boulton (*Added November 9, 2013*)
Carer for daughter (a severe ME patient) for over 22 years.
Artist, book and film maker, “Lost Voices from a Hidden Illness” and “Voices from the
Shadows”
www.voicesfromtheshadowsfilm.co.uk
England

Sally Burch (*Added November 9, 2013*)
B.Sc., Zoology, PGCE, Queen's University Belfast
Formerly Lecturer of Biological Sciences at Belfast Metropolitan College
Sudden onset illness March 2012 at age 49. Now disabled and unable to work.
Patient Advocate.
Northern Ireland

Suzy Chapman (*Added November 9, 2013*)
Dip.A.D., Graphic Design and Communication, Canterbury College of Art
Patient Advocate since 1999 for young person with ME
Former Internet ME Support Group Leader
Dx Revision Watch (monitoring the development of DSM-5 and ICD-11)
www.dxrevisionwatch.com
England

Regina Clos
Former teacher at Frankfurt University (Germany) and translator (disabled since age 33)
Translated many ME/CFS-related documents (including the Canadian Consensus
Criteria (CCC)) from English into German
Official photographer at Invest in ME (London) since 2007
Patient Advocate since 2001
www.cfs-aktuell.de
Germany
Jane Colby *(Added November 9, 2013)*
B.A. (First-Class Honors), Cert Ed
Former School Principal, Lecturer and Author
Co-Author of “Long Term Sickness Absence due to ME/CFS in UK Schools: An Epidemiological Study With Medical and Educational Implications,” Dowsett and Colby, Journal of Chronic Fatigue Syndrome 1997
Executive Director of “The Young ME Sufferers Trust,” www.tymestrust.org
Holder of the Queen's Award for Voluntary Service: the MBE for Volunteer Groups
Former severe ME sufferer from Coxsackie B infection
www.methenewplague.net
England

Kathy Collett *(Added November 9, 2013)*
Patient Advocate
Australia

Kati Debelic, R.N., B.S.N.
R.N., B.S.N., Universite de Montreal
Former Oncology Nurse (disabled at age 39)
Patient Advocate
Canada

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Masters Degree in Science, NUI Galway, Ireland
Graduate Diploma in Systems Analysis and Design, NUI Galway, Ireland
Diploma in Computer Science, University of Oxford, England
Systems Analyst, Computer programmer, University Tutor, Charities Worker
Campaign for an Irish ME clinic
http://www.me-ireland.com
Ireland

Michael Evison *(Added November 9, 2013)*
Degree, Sheffield Hallam University
Former Engineer (disabled in 2009)
Patient Advocate
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England
Katherine (Krystal) Gault (Added November 9, 2013)
M.A., Film Production, University of Central Lancashire
Former Film and Video Director/Producer, Event Curator, Lecturer, Workshop Teacher and Consultant
Became ill suddenly in 2008. Continued to freelance part time until 2011 when degenerated to mostly housebound/bedbound.
Patient Advocate
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Flicker: flickr.com/photos/kitschmonkey
England

Maria Gjerpe, M.D. (Added November 9, 2013)
Crowd-funded $475,000 in 90 days to secure a clinical Rituxan trial in Norway with 140 ME patients meeting the Canadian Consensus Criteria (CCC)
Blogger at Marias Metode, www.mariasmetode.no
www.meyou.no
Norway

Carlos Gonzalez (Added November 9, 2013)
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Sick since 2005
Patient Advocate
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Spain

Simon Goodwin (Added November 9, 2013)
CFS/ME onset in 1990 at age 12
Have never worked due to disability
CFS/ME Advocate
Australia

Chris Heppner, Ph.D., (Added November 9, 2013)
Taught English Literature at McGill University, 1961-1995
Came down with ME in 2007
V.P., local support group, Victoria, BC, Canada. Have written brief essays on research and treatment for the group newsletter, "InforME Magazine"
Canada
Peter Kemp, M.A. *(Added November 9, 2013)*  
NCFE dip Integrative Counseling, Masters Counseling and Psychotherapy Research, Thames Valley University  
Head Groundsman until 1988  
Patient Advocate and ME and CFS Research Analyst and Commentator  
http://counsellingme.com/poster/poster.html  
England

Angela Kennedy, M.A. (also retired R.G.N.)  
Associate Lecturer, Open University and Independent Academic Researcher  
Carer and parent of disabled woman who became ill at 12 years of age.  
England

Eddy Keuninckx *(Added November 9, 2013)*  
ICT Project Leader of very large accounts (Total, GSK Biologicals, etc.)  
Problem Manager for the roll-out of the Belgian Electronic Identity Card  
Disabled since December 2011  
Patient Advocate  
Belgium

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Germany

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B.A., Events Management, De Montfort University, Leicester, UK (with Honors)  
Former Marketing Manager  
Ill since age 26  
Neuroimmune Alliance CEO  
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England

Vanessa Li *(Added November 9, 2013)*  
Former Student, University of London (disabled)  
Patient Advocate  
ruolin@Gmail.com  
England
Priscilla Ling *(Added November 9, 2013)*
Bachelor of Applied Science, Occupational Therapy, Lincoln Institute of Health Sciences (later amalgamated with Latrobe University, Victoria)
Former occupational therapist in rehabilitation, community and mental health with government and private organizations (disabled since 1995)
Patient Advocate (letters, raising ME awareness).
www.mecfshints.com
Australia

Countess of Mar *(Added November 9, 2013)*
Independent Member of the UK House of Lords since 1975
Farmer
Organophosphate poisoning in 1989 with ongoing autonomic effects
Chairman of Forward-ME
Patron of many ME/CFS charities
Campaigner on behalf of people with ME, OP victims including aircrew and farmers, Gulf War Veterans, Lyme disease and others with "medically unexplained physical symptoms"
England

Penelope McMillan *(Added November 9, 2013)*
Former Psychologist and Teacher (disabled in 2000)
Patient Advocate
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Australia

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City & Guilds, Professional Cookery, Hospitality and Catering Management
Former School Meals Organiser for Education Board (disabled since 1999)
Founder, Newry & Mourne ME/FMS Support Group
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Advocate
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Northern Ireland

Giles Meehan, M.A. M.Eng. (Cantab)
Masters Degree in Engineering, University of Cambridge, England
Former Engineer (disabled at age 22)
Journalist/TV Producer/Blogger, “Get Well From ME”
www.getwellfromme.com
England
Cristina Montané *(Added November 9, 2013)*  
Degree, Public Relations, University of Barcelona  
Board Member, Plataforma FM - CFS (Association of Relatives of people suffering from Fibromyalgia and Chronic Fatigue Syndrome)  
Advocate for FM/ME/CFS Patients since 2004  
http://www.plataformafamiliars.org/  
Spain

Sophie Neville *(Added November 9, 2013)*  
B.A., Anthropology, University of Durham (with Honors)  
Acquired ME/CFS in 1991  
Lost her job directing TV drama serials at BBC due to ME/CFS  
Now Writer and Producer, Witness Films  
Author, "Funnily Enough" (award-winning memoir about coping with ME/CFS)  
http://sophieneville.net/  
England

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Diploma, Art, Duncan of Jordanstone College of Art, Dundee, Scotland  
Former Office Administrator (Disabled)  
Patient Advocate, Campaigner, Fundraiser for ME Research  
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Scotland

Leela Play  
Professional  
Disabled since 2001  
Patient Advocate  
Canada

Danielle Pratt, B.S.R., M.B.A. *(Added November 9, 2013)*  
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B.S.R., University of British Columbia (Vancouver, BC, Canada)  
Former president and owner of a health strategy company (disabled in 2004)  
Ill with ME since 1997  
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Canada

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ME/CFS Expert  
Charité Berlin Mitte  
Germany
Nicole Spillmann Al Kumrawi *(Added November 9, 2013)*  
Pediatric Nurse and Social Worker  
Ill since 2005 with ME/CFS  
Chair of the Swiss ME/CFS Association since 2009  
www.verein-me-cfs.ch  
Switzerland

Martina Stark *(Added November 9, 2013)*  
Disabled since 1996 at age 29  
Patient Advocate  
Germany

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Bachelor of Applied Economic Sciences, University of Antwerp  
Former Manager, Database Management Department, Graydon Belgium  
Ill since 2001  
Patient Advocate and Member of WUCB Advocacy Group for ME Patients  
Belgium

Jan van Roijen  
Alumnus, The Theater Academy (cum laude)  
Former Teacher  
Former Actor (performing in classical and modern stage and television productions)  
Disabled in 1983, currently completely housebound  
Patient Advocate and Publisher of the “Help ME Circle” Email Bulletin (with scientific and advocacy information circulated in 25 countries)  
Netherlands

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Family Physician/GP and ME expert  
Osnabrück  
Germany

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M.B., B.A., B.Ch, B.A.O., Trinity College, Dublin, Ireland  
Fellow of the Royal Australian College of Physicians  
Specialist Consultant in Internal Medicine & Infectious Diseases, ME/CFS Specialist  
Australia

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Chairman, ME/cvs Vereniging Nederland  
Active Member of Project 'Wetenschap voor Patiënten' / Science for Patients  
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Netherlands
Margaret Williams *(Added November 9, 2013)*  
Patient Advocate  
England

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Bachelor’s Degree, Oxford University, UK  
Former Teacher (permanently disabled by Myalgic Encephalomyelitis (ME) in 1981)  
Advocate since 1987  
England

Alex Young *(Added November 9, 2013)*  
B.Sc., Biochemistry, University of Queensland  
B.Inf., Artificial Intelligence, Griffith University  
Former Ph.D. candidate, former part-time university lecturer  
Diagnosed under Holmes criteria in 1989  
Blogger, Patient Advocate,  
Writing a book on psychogenic medicine  
http://forums.phoenixrising.me/index.php?blog/alex3619.786/  
Australia

Cc:  
Barack Obama, President of the United States of America  
Senator Tom Harkin, Chairman, Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies  
Senator Jerry Moran, Ranking Member, Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies  
Jack Kingston, Chairman, U.S. House of Representatives Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies  
Rosa DeLauro, Ranking Member, U.S. House of Representatives Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies  
Lucille Roybal-Allard, U.S. House of Representatives Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies  
Barbara Lee, U.S. House of Representatives Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies  
Mike Honda, California, U.S. House of Representatives Committee on Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Danile R. Levinson, Inspector General, U.S. Department of Health and Human Services

Adam Trzeciak, Inspector General, U.S. Government Accountability Office

Dr. Harvey Fineberg, President, Institute of Medicine

Dr. Howard Koh, Assistant Secretary for Health, Department of Health and Human Services

Dr. Wanda Jones, Principal Deputy Assistant Secretary for Health, Department of Health and Human Services

Dr. Richard Kronick, Director, Agency for Healthcare Research and Quality

Dr. Thomas Frieden, Director, Centers for Disease Control and Prevention

Ms. Marilyn Tavenner, Administrator, Centers for Medicare and Medicaid Services

Dr. Margaret Hamburg, Commissioner, U.S. Food and Drug Administration

Dr. Mary Wakefield, Administrator, Health Resources and Services Administration

Dr. Francis Collins, Director, National Institutes of Health

Dr. Harold Varmus, Director of the National Cancer Institute

Dr. Anthony Fauci, Director of the National Institute for Allergy and Infectious Diseases

Ms. Carolyn W. Colvin, Commissioner, Social Security Administration

The 50 Expert Signatories of the Open Letter to Secretary Sebelius, Dated September 23, 2013, and Updated October 25, 2013