

More than ever before, 2015 has been a year that has brought fresh hope to Myalgic Encephalomyelitis (ME) patients. The Institute of Medicine (IOM) and NIH Pathways to Prevention (P2P) reports confirmed the neglect and disbelief that have held the disease hostage for decades and strongly recommended action to improve patient care. Publications from Stanford, Columbia and Haukeland (Norway) Universities brought new insights into the biology. World-renowned scientists have joined the fight. Stories about severely ill patients like Ron Davis's son have created more public awareness. And the Tuller series brought greater exposure to the concerns with the PACE trial and psychogenic theories.

For the first time, there's a sense that we have huge opportunities to change the future for ME patients. And just as importantly, there's a sense that if we want to turn those opportunities into reality, then we need to find new ways to work together across the community to increase the impact of our voices.

To that end, a number of organizations, bloggers and independent advocates, listed below, have started having discussions to identify those areas where they can agree on goals and work together to achieve what is needed for patients.

Thus far, we have identified common goals to focus on, including the need to **dramatically increase funding, to advance the research agenda, to resolve the definitional challenges, and to improve clinical care through quality medical education.** We expect that this will lead to actions directed toward Congressional leaders, HHS and its agencies, and public awareness through the media.

To achieve these goals, we are going to need broad participation across the community. We will leverage the Groups feature on the MEAction.net platform to get input on these goals and to share proposals for joint actions. Because we are working as a loose collaboration, groups and individuals will be given the opportunity to opt in or opt out of specific actions.

Working in this way and at this scale is new for all of us and we will be learning as we go. We also know that we won't all agree on every tactic or policy direction. But we believe there is power in numbers and coordination and are all committed to taking advantage of every opportunity that we can to regain our future.

Please join us and share your ideas and enthusiasm. If you are interested in participating and providing input, you can join in the discussion on MEAction Groups here: <http://www.meaction.net/us-action-working-groups/>

Signed

Patient Organizations

Connecticut CFIDS Association, Inc.
ImmuneDysfunction.org dba The Vermont CFIDS Association, Inc
Massachusetts CFIDS/ME & FM Association
The Myalgic Encephalomyelitis Action Network (#MEAction)
Open Medicine Foundation (OMF)
New Jersey ME/CFS Association, Inc.
Pandora Org
Phoenix Rising
Simmaron Research
Solve ME/CFS Initiative
Wisconsin ME and CFS Association, Inc.

Patient blogs

Health Rising (Cort Johnson)
OccupyCFS (Jennifer Spotila)
Onward Through the Fog (Erica Verrillo)
Race to Solve ME/CFS (Claudia Goodell)
Speak Up About ME (Denise Lopez-Majano)

Independent Advocates

Lily Chu, MD, MSHS
Mary Dimmock
Steve Krafchick, MPH, JD
Robert and Courtney Miller
Donna Pearson
Staci R. Stevens, MA