

Testimony

Toby Vokal

WHEN?

When are the people with the authority to help people with M.E. (Myalgic Encephalomyelitis) going to do so? When is the CDC going to change their website to be accurate? When is the NIH going to give research dollars to M.E. as they do to comparative diseases (\$150 million annually minimum immediately)? When is there going to be a branch of the NIH for just M.E.? When is the CFSAC going to become the MEAC? When are we going to realize that this affects men, women, and children? When will people understand that estimates as high as 4 million Americans and 20 million worldwide and growing have M.E. ? When are doctors going to be educated? When is it going to be in every single medical school and books? When are researchers going to be drawn to this field? I can tell you there would be no shortage of interest if the funding was there. When is there going to be a national awareness campaign? Not one that makes the public put off by M.E., however respects it and its seriousness?

These questions are not rhetorical, they are serious. Anyone can tell you that these are measures that should have been put into place years ago. It is unacceptable the way we have been and still are treated. In this day and age which is full of technology we should as a nation should be leaders. British Columbia, Canada just opened a Center of Excellence. When is the U.S.A.? I thought we were supposed to have 5 regional research and care center's up and running by now. **Can someone please tell me the given dates in realistic time goals? Or better yet post them on a website for everyone to see and track progress.**

Meanwhile people with M.E. wait. Their lives are altered in ways unimaginable to someone healthy. We try our best to help awareness,

however we are limited by our condition. I do commend the committee on holding meetings twice a year and giving some time to the public. This is not enough. We need to step it up now!