



Massachusetts CFIDS/ME & FM Association

Education, Support and Advocacy since 1985

Presentation to the Chronic Fatigue
Advisory Committee

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October 4, 2012



About our Association

- The oldest patient-run advocacy group for CFS/ME
- Established in 1985, grew out of patient support groups begun in 1983
- Mission: **Education, support, advocacy**
- Added Fibromyalgia in the '90s
- Published “The Update” for many years; now maintains website www.masscfids.org with electronic newsletter
- All-volunteer; registered non-profit charity 501(c)3



Some highlights

- Co-authored
 - First Physician's Primer for CFS, published in 1992
 - Pediatric Case definition (Jason *et al.* 2006)
 - IACFS/ME Primer (now on Revisions Committee)
- Website - www.masscfids.org
 - Global reach
 - Dr. Komaroff's April 2010 lecture has been translated into 4 languages, has reached "influencers" and patients around the world
 - Disability Handbook is highly regarded and used extensively
- Outreach to other state/regional/international associations
 - Work collaboratively with other groups in our region
 - Participate in national advocacy efforts
 - Attend IACFS/ME meetings
 - We helped Japan start a national association which just had its first conference with 200+ attendees



Current projects

- Health Care Provider education
 - Distributing the IACFS/ME Primer
 - Exhibiting at medical conferences
- Outreach to children and youth
 - Beginning with school nurses
 - Pediatric ME/CFS Resources CD
- Outreach to the 80% who are undiagnosed



Challenges

- Provider “uninformed ignorance” or “willful rejection” of what is known about ME/CFS
 - Harm done to patients from discredited treatments (“CBT” and “GET”)
 - Severe shortage of knowledgeable providers
- Education of providers and the medical establishment – facts and attitudes
- Needed:
 - Clear, unambiguous message from CDC and NIH
 - Funding commensurate with seriousness and prevalence of the illness



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Thank you.