

# ME/CFS Researcher and Clinician-Scientist Recruitment Workgroup

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and

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# Outline

- Goals of the group
- Members & Contributors
- Discussions to date
  - Fred's data
  - Suzanne's presentation
- Progress
  - Work accomplished
- Moving forward

# Members & Contributors

- Dane Cook
- Jordan Dimitrakoff
- Fred Friedberg
- K. Kim McCleary
- Adrian Casillas
- Suzanne Vernon
- Steve Krafchick
- Susan Maier
- Deborah Willis-Fillinger
- Beth Collins-Sharp
- Ermias Belay
- Janine Clayton
- Joyce Grayson

# Mandates of the Workgroup

- Identify gaps in the recruitment and retention process of researchers and clinician scientists to the field of ME/CFS
  - Increase awareness
  - Increase opportunities
- End-goal: Provide an actionable set of evidence-based recommendations to the Secretary

# Charge

- “...increasing awareness among basic and clinical researchers about ME/CFS research and suggesting strategies to increase the number of interested researchers who will apply for current and future research funding opportunities”

# Initial brainstorm session

(May 2013)

- Little or no access to well-defined clinical populations
- Lack of confidence making the diagnosis and/or applying case definition
- Heterogeneity of condition
- Uncertain contribution of co-morbid and/or frequently co-occurring conditions (IBS, FM, TMJ, POTS, migraine, etc.)
- Lack of experience/access to other disciplines needed to study multisystem, multifactorial condition



# Initial brainstorm session cont.

(May 2013)

- Perceptions about lack of appropriate expertise among reviewers evaluating applications
- Weak institutional support for investigators entering emerging fields vs. established fields
- Insecurities about the level of current and future funding available to reliably staff and sustain lab/clinical research effort
- No established target, agent or tissue of interest



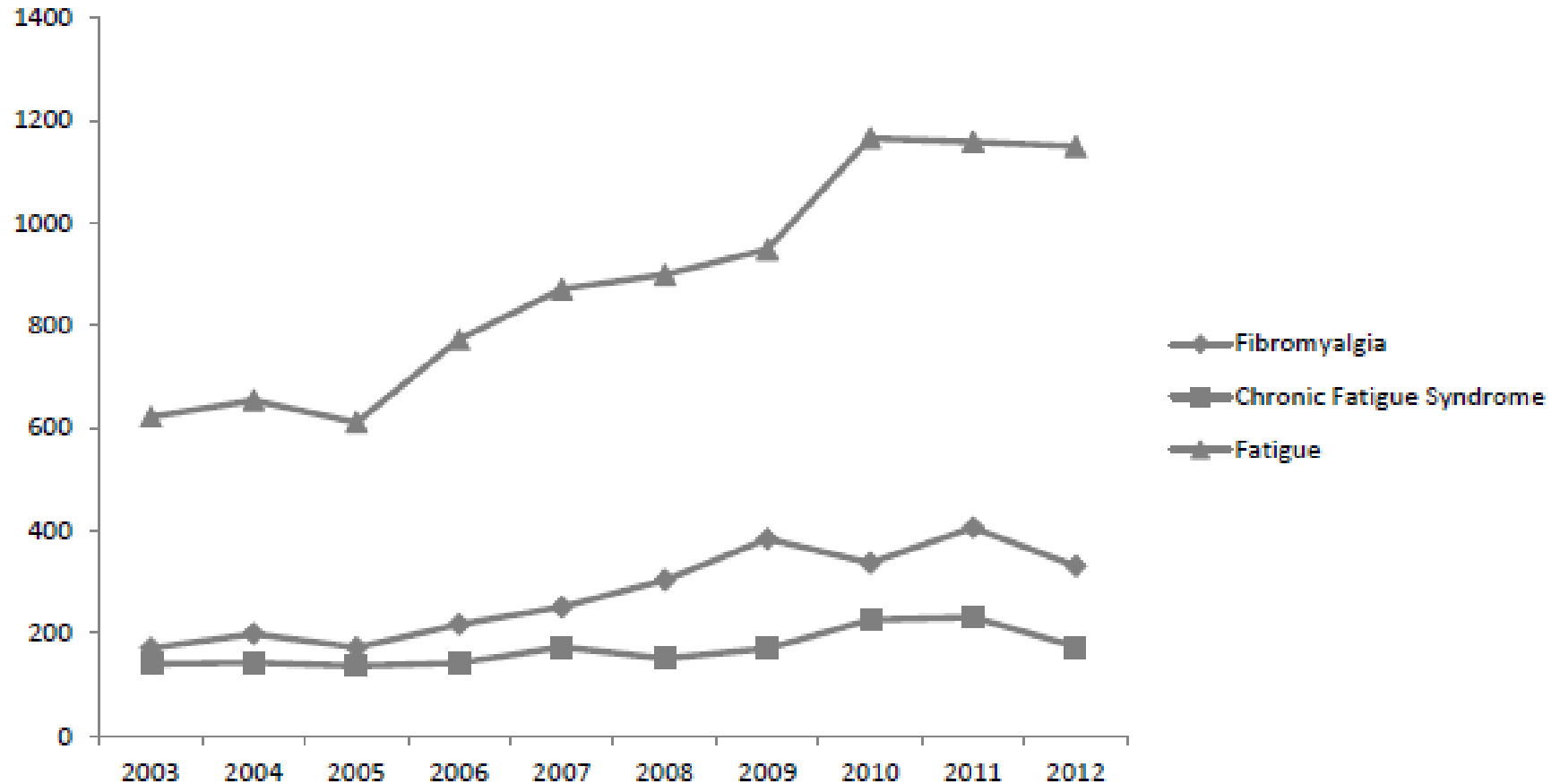
# Initial discussion items of the established workgroup

June 2013

- National Institutes of Health ME/CFS Special Emphasis Panel issues
- Low number of researchers and reduced publications
- Access to a big database
- How to bring together diverse & complimentary expertise to study ME/CFS
  - Poor marketing of research opportunities
  - Lack of knowledge & communication among the scientific community
- Identifying the critical barriers to increasing CFS research
- Case definition issues



# Report on peer reviewed ME/CFS publications (Fred Friedberg)



Annual Publication Frequencies for Fatigue, Fibromyalgia, and Chronic Fatigue Syndrome

# Poor marketing of research opportunities

## (Suzanne Vernon)

- Barriers:
  - Lack of knowledge concerning CFS
  - Lack of partnerships
  - Lack of a supportive infrastructure and data sharing
- Potential Solutions:
  - Education
  - Continuing to recruit investigators from diverse areas
  - Facilitate communication among investigators
  - Providing the seed funding necessary to go for bigger dollars
  - Creating a targeted marketing effort for CFS research
  - Community involvement
  - Consolidating existing registries and bio-banks for research and subject recruitment

# Working Decision

- Request for Applications (RFA)
  - One that would be dedicated to CFS research yet broad enough to attract a diverse set of investigators.
    - The idea of including a registry component was also mentioned
  - We are currently discussing the structure and feasibility of this as an actionable recommendation to the Secretary