ME/CFS Researcher and Clinician-Scientist Recruitment Workgroup

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Members & Contributors

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Outline

- Reminder of mandate and charge
- Recap of previous progress
- Original working decision for a RFA
- Evolution of the recommendation
- Work still to be accomplished

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"

Recap of initial discussion items

- Low number of researchers and reduced publications
- Barriers to research & potential solutions
- How to bring together diverse & complimentary expertise to study ME/CFS

Poor marketing of research opportunities

(Suzanne Vernon)

- Barriers:
  - Lack of knowledge concerning CFS
  - Lack of partnerships
  - **Lack of a supportive infrastructure and access to a big database**
    - **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
  - **Harnessing of existing registries and bio-banks for research and subject recruitment (A federation of data and people)**

Original 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

Evolution of the Recommendation

- 2010 - State-of-the-Knowledge Workshop
  - What recommendations would help inform the Research Work Group?
- Several initiatives in process that will help inform a RFA for ME/CFS
  - Trans-NIH ME/CFS Research Working Group
  - Pathways to Prevention (P2P) Program for ME/CFS
  - Institute of Medicine (IOM) initiative to evaluate current clinical diagnostic criteria for ME/CFS
- **Necessity of infrastructure**

2010 - State-of-the-Knowledge Workshop Report

- **Moving Forward**
  - "To capture the extensive information from such studies (clinical trials), a centralized interactive database, using common data elements and accessible to everyone, is **sorely needed** to collect, aggregate, store, and analyze results."
  - "The study of ME/CFS can benefit from an interdisciplinary collaborative approach using well-connected clinical and research networks. Moreover, additional highly qualified investigators must be attracted to study ME/CFS."

http://orwh.od.nih.gov/research/mecfs/pdfs/ORWH_SKW_Report.pdf

Trans-NIH ME/CFS Research Working Group

- A partnership:
  - NIH institutes and centers
  - The Office of Research on Women's health (ORWH)

- To promote research on ME/CFS
  - Does not have grant making authority
  - Informs NIH Centers & Offices & works to leverage resources for ME/CFS research
  - Considers unique ways to support ME/CFs research

Pathways to Prevention Program for ME/CFS

- P2P evidence-based methodology workshop goals:
    - Identify research gaps and methodological and scientific weaknesses in a scientific area
    - Suggest research needs
    - Move the field forward through an unbiased, evidence-based assessment of a complex health issue

- A Request for Applications (RFA) for ME/CFS should be informed by the report and recommendations from this workshop

http://www.iom.edu/~/media/Files/Activity%20Files/Disease/MECFS/Maier%20IOM%20MECFS%20Presentation.pdf

IOM Consensus Study
(Diagnostic Criteria for ME/CFS)

- Comprehensively evaluate the current diagnostic criteria for ME/CFS:
  - Conduct a study to identify the evidence for various diagnostic clinical criteria of ME/CFS using a process with stakeholder input, including practicing clinicians and patients;
  - Develop evidence-based clinical diagnostic criteria for ME/CFS for use by clinicians, using a consensus-building methodology;
  - Recommend whether new terminology for ME/CFS should be adopted;
  - Develop an outreach strategy to disseminate the definition nationwide to health professionals.

- A Request for Applications (RFA) for ME/CFS should be informed by the report and recommendations from this effort

Primacy of Infrastructure for ME/CFS Research

- Research infrastructure is critical for accelerating discovery, providing pathways for collaboration and attract the best and brightest researchers to study ME/CFS
- National Database for Autism Research (NDAR) example

NDAR

- Infrastructure
  - a data sharing platform to create a large database
  - a common data dictionary and data standards that can be applied across studies
  - protection of patient privacy
  - protection of investigator intellectual property

- Success of NDAR
  - Contains data from over 70,000 patients

A Roadmap for ME/CFS

- Development of a clear research agenda
  - Based on information and recommendations from the P2P and IOM reports
  - Communicated and championed by the Trans NIH ME/CFS working group
  - Supported by strong infrastructure

- This is the path to:
  - Increase awareness among basic and clinical researchers
  - Increase collaboration
  - Increase applications for funding

- Move the field forward

Discussion