Interagency ME/CFS Working Group

February 25, 2021
1:00–5:00 pm Eastern Time

1:00 – 2:45 pm

1. Welcome – Inger Damon (CDC) and Walter Koroshetz (NIH)

2. Goals of the Working Group and meeting – Inger Damon

3. ME/CFS Health Care Workforce Development: Documentation of Need
   a. Introduction
   b. Joint Presentation from Patient Advocacy Groups – Massachusetts ME/CFS & FM Association, #MEAction, New Jersey ME/CFS Association, Solve ME/CFS Initiative – Oved Amitay
   c. Discussion

4. Challenges from Clinician Viewpoint
   a. Introduction
   b. Survey from Clinician Coalition – Mary Dimmock
   c. Discussion (including Nancy Klimas)

2:45 – 2:55 pm Break

2:55 – 4:25 pm

5. Description of Current Initiatives to Address
   a. Introduction: CDC – Elizabeth Unger
   b. K awards and fellowships: NIH – Vicky Whittemore
   c. Medical school education: Quinnipiac University – Howard Selinger
   d. Educating nurses: National Association of School Nurses – Erin Maughan

6. Discussion – All
   a. Suggestions
   b. Workplan – subcommittee

7. Other business
   a. Status & limitations of Systematic Review – Nanda Issa
   b. NIH planned meeting on Clinical Trial Design – Vicky Whittemore
   c. Discussion

4:25 – 5:00 pm

8. Q&A

9. Brief preview of Friday’s topic and adjournment – Inger Damon
Interagency ME/CFS Working Group
February 26, 2021
1:00–3:00 pm Eastern Time

1:00 – 2:20 pm
1. Welcome & goal of meeting – Inger Damon (CDC) and Walter Koroshetz (NIH)
2. What We’re Learning about Long COVID – Alfonso Hernandez-Romieu (CDC)
3. Research on Long COVID
   a. CDC ongoing studies – Sharon Saydah
   b. New research program on Post-Acute Sequelae of COVID-19 – Walter Koroshetz
4. Other Activities – Jennifer Cope (CDC)
5. Cross-agency collaboration – Andrea Lerner (NIH)
6. Long COVID Alliance – Sadie Whittaker

2:20 – 2:30 pm Break

2:30 – 3:00 pm
7. Discussion/Q&A
8. Wrap up and adjournment – Inger Damon

Meeting Participants

Agencies
1. Inger Damon, MD, PhD, CDC – co-chair
2. Elizabeth Unger, MD, PhD, CDC
3. Alfonso Hernandez-Romieu, MD, MPH, CDC
4. Sharon Saydah, PhD, CDC
5. Jennifer R. Cope, MD, MPH, CDC
6. Nanda Issa, MD, CDC
7. Christine Pearson, CDC
8. Walter Koroshetz, MD, NIH – co-chair
9. Vicky Whittemore, PhD, NIH
10. Andrea Lerner, MD, MS, NIH
11. Alayna Ness, SSA
12. Megan Butson, SSA
13. Karen Block, PhD, VA
14. Kathryn Argue, PhD, DoD
15. Shari Ling, MD, CMS

Invited Guests
16. Charmian Proskauer, Massachusetts ME/CFS & FM Association
17. Ben HsuBorger, #MEAction
18. Ken Friedman (Feb. 25) & Pat LaRosa (Feb. 26), New Jersey ME/CFS Association
19. Oved Amitay, Solve ME/CFS Initiative
20. Sadie Whittaker, PhD, (Feb. 26) Long COVID Alliance
21. Erin Maughan, PhD, RN, NASN
22. Howard Selinger, MD, Quinnipiac University
23. Mary Dimmock, ME/CFS Clinician Coalition
24. Nancy Klimas, MD, Nova Southeastern University