Online workshops to stimulate clinical research in ME/CFS invitation to participate

We are organising a series of online workshops to stimulate clinical research in ME/CFS. The workshops are connected with the Research Working Group, set up by the UK Clinical Research Collaboration. The workshops aim to raise the profile of ME/CFS clinical research, increase collaboration, attract new researchers and formulate research priorities in this area of huge unmet need.

The workshops are listed below. Please click the Eventbrite link for full details of speakers and to register for each workshop.

1. Clinical trial design in people with ME/CFS $-\,4^{\rm th}$ June 13:00 to 15:30

The speakers and discussions will look at clinical trial design in people with ME/CFS – how to optimise it, possibilities for a core outcome set and lessons from other disease areas. Eventbrite link for more information and to register:-<u>Clinical Trial Design in People with ME/CFS Tickets, Tue 4 Jun 2024 at 13:00 | Eventbrite</u>

2. Clinical trial platform studies – 6th June 11:00 to 12:00

An online discussion about two Platform studies, the Octopus multi-arm, multi-stage treatment trial for multiple sclerosis, and STIMULATE-ICP, the multi-site study of long COVID examining current care, developing an integrated care pathway and drug repurposing clinical trial. Are there lessons for clinical research in ME/CFS, particularly for drug repurposing studies? Eventbrite link for more information and to register:-

Clinical Trial Platform Studies and Lessons for ME/CFS research Tickets, Thu, Jun 6, 2024 at 11:00 AM | Eventbrite

3. Drug repurposing clinical trials in people with ME/CFS – 26^{th} June 13:00 to 15:30

The speakers and discussions will look at drug repurposing including clinical use and research findings, study design, and potential drugs such as low dose naltrexone (LDN). Eventbrite link for more information and to register:-Drug Repurposing Clinical Trials in People with ME/CFS Tickets, Wed, Jun 26, 2024 at 1:00 PM | Eventbrite

4. ME/CFS research and underserved groups - 16th July 10:00 to 12:30

This workshop will look at three areas, and will include breakout groups for discussion in each of these areas;-

a) improving diagnosis and health care provision in people with ME/CFS particularly those who are already minoritized or socially disadvantaged in society.

b) disadvantaged groups within ME/CFS - the severely affected and children and young adults. c) widening recruitment and participation in clinical trials for ME/CFS.

Eventbrite link for more information and to register:-

ME/CFS Research and Underserved Groups Tickets, Tue, Jul 16, 2024 at 10:00 AM | Eventbrite

There is separate information available for this workshop as well, which we want to circulate widely. Please email<u>underserved-groups@serafina3.me.uk</u> if you have ideas for people or groups who may be interested in this workshop.

In order to stimulate discussion we want to attract a wide range of researchers and health care workers both from within and outside the field of ME/CFS care and research. Although the workshops are primarily aimed at researchers and clinicians, we encourage people with ME/CFS to attend to share their views.

Full details of speakers are listed on the Eventbrite page for each workshop. Each workshop will run independently – enrol for one or as many as you want. See links above to enrol.

Please pass this invitation on to researchers, clinicians and healthcare workers, people with ME/CFS and their carers, or anyone you think who may be interested. We look forward to you joining us, to help push forward the ME/CFS clinical research agenda.

Monica Bolton Research Working Group member