



Diagnosis and Management

Virtual Meeting Minutes

17 November 2020, 9:30 – 10:30 am

Attendees

Parliamentarians

Carol Monaghan MP
Mickey Brady MP
Ben Lake MP
Margaret Ferrier MP
Kerry McCarthy MP
Siobhan Baillie MP
Dr James Davies (representative)
Liz Twist (representative)
Gavin Robinson MP (representative)
Helen Hayes (representative)
Stephen Morgan (representative)
Fiona Bruce (representative)
Jane Hunt
Stephen Metcalfe
Pete Wishart MP
Baroness Scott of Needham Market
Alex Chalk (representative)
Neale Hanvey MP
Emma Lewell-Buck MP
Jason McCartney MP

Speakers

Parent of an adult daughter with ME
Professor Julia Newton
Dr Sue Pemberton

Guests

Charles Shepherd, ME APPG Secretariat, ME Association
Sam Bromiley, Action for ME
Robbie Butler MLA
Paula Bradshaw MLA

Apologies

Parliamentarians

Michelle Gildernew MP
Chris Loder MP

1. Welcome

Carol Monaghan MP, Chair of the ME APPG, welcomed all attendees and provided a summary of the debilitating symptoms associated with ME.

Carol Monaghan MP also introduced the guest speakers and topic: diagnosis and management.

2. Updates

Dr Charles Shepherd, ME APPG Secretariat:

- Overview of draft revised NICE guidelines on ME

Carol Monaghan MP:

- Letters on (a) children with ME and (b) Chronic Pain Abilities Determination (CPAD) assessments

3. Presentations

- The parent of an adult daughter with ME:
 - This presentation focused on the experience of caring for an ME patient. Areas covered include, long waiting times for medical appointments, lack of timely diagnosis, lack of financial support and failure to access appropriate care support.
- Professor Julia Newton, Newcastle University, Medical Director, Academic Health Science Network: North East and North Cumbria:
 - This presentation provided an overview of the current problems facing people with ME who are seeking a diagnosis and appropriate medical care, drawing on the current and draft revised NICE ME guidelines.
- Dr Sue Pemberton, Therapy Director and Specialist Occupational Therapist, Yorkshire Fatigue Clinic:
 - This presentation provided an overview of appropriate and inappropriate management practices with a particular focus on energy management, drawing on the current and draft revised NICE ME guidelines.

4. Further Update

Neale Harvey MP

- Meeting with Professor Russell Viner, President, Royal College of Paediatrics and Child Health

5. Q&A Discussion

The following topics were covered:

- Educating GPs on ME
- Recruiting, training and funding ME specialists
- Barriers faced by ME sufferers
- Updates on the development of an ME diagnostic test

6. AOB and Close

Carol Monaghan MP thanked the speakers for their insightful comments and suggestions and mentioned the provisional date for the next ME APPG meeting: 19 January 2021.