**All-Party Parliamentary Group for Myalgic Encephalomyelitis**

**Minutes of the Inaugural Meeting**

**17 December at 17.00**

**Committee Room 18, Westminster Palace**

***NOTE: THESE MINUTES HAVE BEEN APPROVED BY THE CHAIR BUT REMAIN DRAFT UNTIL APPROVED BY MEMBERS AT THE NEXT APPG MEETING***

**Present**

Jo Platt MP – chaired the meeting

Bradley Thomas MP

Louise Jones MP

Luke Charters MP

Rachel Maskell MP

Paul Waugh MP

Baroness Scott of Needham Market

**In Attendance**

Sonya Chowdhury, Chief Executive, Action for ME

Alexander Harman, Connect (Public Affairs agency working with Action for ME)

Mike Mitchell, Trustee, ME Association

**Apologies**

A large number of apologies were received due to the meeting clashing with other commitments and/or illness.

1. **Introduction from Jo Platt MP**

ME is a profoundly debilitating, chronic illness that affects multiple systems within the body.

There are an estimated 1.3 million people in the UK with ME or ME-like symptoms, including post-exertional malaise: the hallmark symptom of ME/Chronic Fatigue Syndrome (CFS).

Parallels have recently been drawn between ME and Long Covid with some research indicating at least 50% of people with Long Covid have symptoms that directly mirrors ME. Given people with each illness present similar symptoms, finding effective treatments for one could help both groups. JP also now officially chairs the APPG for Long Covid so we will be looking at how we can work together.

Many attending the meeting will know someone with ME or ME-like symptoms but all will have constituents who have ME or ME-like symptoms who will be affected alongside their children and families.

The illness has a significant impact on people’s lives symptoms that include with severe, persistent fatigue that doesn’t improve with rest and often worsened by activity, hypersensitivities to light, sound and even touch, pain, sleep and cognitive issues to name a few. One in four people are so severely affected, they are bed and often housebound. Those most severely affected face major challenges including on their ability to eat and, as with the sad case of Maeve Boothby-O’Neill, malnutrition can lead to death.

The cost to the economy of ME was conservatively calculated in 2017 to be £3.3bn based on the figure of 250,000 people with it. This is a very outdated figure and does not take account of the post-viral impact of Long Covid leaving a large number of people with ME-like symptoms. Action for ME is working to secure funding to commission updated research but an extrapolated figure based on the 2017 calculation would indicate a cost nearer £17bn today.

Health and social care provision is variable and many do not have access to effective support. Despite the announcement of a cross-government delivery plan in May 2022 by the then Secretary of State for Health and Social Care, Sir Sajid Javid, we have yet to receive the report on the consultation and the final Delivery Plan. In response to parliamentary questions, we were told it is due this Winter. We await their publication.

As the cross-government [Interim Delivery Plan](https://www.gov.uk/government/news/government-announces-new-plan-to-help-those-impacted-by-mecfs) identifies, healthcare and other professionals face many challenges in providing care and support but stigma and lack of knowledge and understanding can also be a problem. The impact of such negative attitudes can be profound for people with ME and their families.

There is an urgent need to accelerate research into ME and co-morbid/overlapping illnesses such as Long Covid so that we can better understand and treat people living with these debilitating diseases.

Given the significant burden of ME on people’s lives, our public services and the economy, there is an urgent need for change. This APPG will provide a vehicle for us to work together to secure that change.

The Secretariat will be provided by Action for ME and jointly funded by the ME Association. There is no additional budget, currently, for the work of the APPG but, with the charity’s support, we will develop an ambitious workplan while also ensuring we do not draw too many demands on your already pressured time. Action for ME has ensured that the planning thus far has been easy and this will ensure that MPs time can be used impactfully.

1. **Election of Chair**

Jo Platt was nominated as Chair by Luke Charters and seconded by Louise Jones.

1. **Election of Officers**

Jo Platt nominated the following individuals as officers who were unanimously appointed:

* Tessa Munt
* Lord Offord of Gavel
* Debbie Abrahams.
1. **APPG on ME Purpose**

**Name:** Unanimous approval of the name of the APPG as: APPG on ME.

1. **Purpose:** Unanimous approval of the purpose as:The [All-Party Parliamentary Group on Myalgic Encephalomyelitis (ME)](https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fappgme.co.uk%2F&data=05%7C02%7Csonya.chowdhury%40actionforme.org.uk%7C412e2c2ab9374acc557508dd108a52c0%7Cf809204c48f743b7acc6f0dc6f49b716%7C0%7C0%7C638684908490024602%7CUnknown%7CTWFpbGZsb3d8eyJFbXB0eU1hcGkiOnRydWUsIlYiOiIwLjAuMDAwMCIsIlAiOiJXaW4zMiIsIkFOIjoiTWFpbCIsIldUIjoyfQ%3D%3D%7C0%7C%7C%7C&sdata=UNER1AKPsS8slQ5keHg%2BYkBg7nRZUmyOvj09tZwfY1o%3D&reserved=0) is a cross-party group of Members of Parliament and the House of Lords seeking to improve health, social care, education and employment opportunities for people with ME and accelerate biomedical research into the cause and treatment of ME.
2. **Priorities for the Year Ahead**

A number of different ideas and suggestions were explored which Jo and the Secretariat will consider further before coming back with a proposed strategy and workplan with clear outputs and outcomes:

* Engagement with Health and Social Care Select Committee: The Health and Social Care Select Committee’s call for inquiry topics is open until 17th January. We need to focus on securing an inquiry on ME/CFS. The Secretariat will lead on establishing the submission.
* APPG inquiry into Severe ME: the former APPG commenced this work with a Panel that undertook the first hearing from people with lived experience. We would ideally like to pick this work back up. The aim was to produce an appended chapter to the former APPG’s report [Rethinking ME](https://appgme.co.uk/publications/) with some clear, tangible actions for the APPG to drive forward. This inquiry was started due to the increasing number of concerning cases of people with severe and very severe ME being hospitalised and their needs not being met. Meeting the nutritional needs of people with very severe ME is a growing issue and there are a number of ‘cases’ in the media/social media where people are not getting their needs met. Following Maeve Boothby O’Neill’s Inquest, the Coroner found that the guidelines on ME did not provide any detailed guidance at all on how severe ME should be managed at home or in the community and in particular whether or not there is any necessary adaptation needed to the 2017 guidance on Nutrition support for adults: oral nutrition support , enteral tube feeding and parenteral nutrition.
* Final Delivery Plan for ME: exploring the APPG’s role in supporting and ensuring implementation when launched.
* Securing a Westminster Hall Debate.
* Ensuring appropriate questions and engagement in debates to ensure the impact for people with ME is highlighted.
* Focus on services and support for people with ME alongside addressing stigma that still pervades in some places and the need for education.
* Ensuring implementation of the NICE Guideline as it is clear that it has been patchy and important that support across all disciplines is provided.
* Leveraging research for ME and overlapping illnesses including Long Covid where people have ME-like symptoms. It was also acknowledged that there are other illness areas where there are co-morbidities and the APPG should seek to maximise opportunities to synergise with these.
* Need for the cost to the economy calculation to be updated to include updated numbers of people with ME and those with ME-like symptoms. This is particularly pertinent given the government’s focus on supporting people back to work (while also acknowledging that many people with ME are too ill to work). Action for ME is currently trying to secure funds for this.
* DWP White Paper and ensuring the experience of people with ME is highlighted and considered.
* guidelines on ME did not provide any detailed guidance at all on how severe ME should be managed at home or in the community and in particular whether or not there is any necessary adaptation needed to the 2017 guidance on Nutrition support for adults : oral nutrition support , enteral tube feeding and parenteral nutrition.
1. **Any Other Business**
* Date of next meeting – the APPG will hold quarterly meetings; dates to follow.