



## **Children with ME**

Virtual Meeting Minutes

16 June 2020, 10 – 11 am

## **Attendees**

### **Speakers**

Dr Nigel Speight  
Tony Crouch  
The parents of two children with ME

### **Parliamentarians**

Carol Monaghan MP  
Ben Lake MP  
Debbie Abrahams MP  
Dierdre Brock MP (representative)  
Jane Hunt MP  
Jason McCartney MP  
Liz Twist MP (representative)  
Neale Hanvey MP  
Olivia Blake MP (representative)  
Owen Paterson MP  
Sally-Ann Hart MP  
Scott Mann MP  
Siobhan Bailie MP (representative)

### **Guests**

Countess of Mar  
Dr Charles Shepherd, ME APPG Secretariat  
Debbie Burgess, Tymes Trust  
Sean O'Neill, The Times  
Ruth Richardson, Action for ME

## **1. Welcome**

The meeting began at 1 pm and Carol Monaghan MP, Chair of the ME APPG, welcomed all attendees and introduced the guest speakers.

Carol Monaghan then explained the meeting purpose which was to highlight the condition of ME in children and to use expert contributions to produce a report paper on the key issues impacting ME sufferers.

Dr Charles Shepherd, ME APPG Secretariat, briefly summarised the key issues which stem from lack of education and information going out to professionals working with children with ME. Charles mentioned that the NICE 2007 guidelines barely even mentioned children, citing ME incorrectly as a behavioural problem rather than a neurological disorder.

## **2. Presentations**

- a) Dr Nigel Speight, expert in paediatric ME, charity medical advisor
- b) The parents of two children with ME
- c) Tony Crouch, social worker and NICE ME guideline review panellist

## **3. Q&A Discussion**

Topics included:

- Social security support for families
- Educating social workers and medical professionals on ME in children
- Experience of children with ME in the education system

## **4. AOB and Close**

It was agreed that the ME APPG would follow this meeting with three letters raising the issues discussed:

- a) To local health boards
- b) To the Chief Social Worker for Children and Families
- c) To the education authorities.

Carol Monaghan MP also expressed her intention to apply for a Westminster Hall Debate on Children with ME post-summer recess, and thanked speakers for their insights and suggestions.