

## **Minutes of the Cross Party Group on Medical Research**

**17<sup>th</sup> of May 2023, 11am-12pm.**

### **Attendees**

Russell George MS  
Sioned Williams MS  
Mike Hedges MS  
John Griffiths MS  
Rebecca Hill  
Ben Bleasdale  
Lynne Grundy  
Christopher George  
Andrew Bettridge  
Joanne Ferris  
Nicolas Webb  
Felicity Waters  
Carys Thomas  
Nicola Williams  
Lucy Patten  
Megan Anderson  
Mark Briggs  
Adam Fletcher  
Nigel Rees  
Hugh Adams  
Ryland Doyle  
Jon Oliver  
Richard Clarkson  
Calum Davies  
Corinne Square  
Rhian Thomas Turner

### **ITEM 1 – Welcome and introductions**

The chair, Russell George MS, welcoming speakers and attendees to the meeting.

He gave a short introduction into the agenda of the meeting which was a focus on public perceptions of medical research in Wales.

### **ITEM 2 – Presentation: Results of the Discovery Decade report.**

***Rebecca Hill and Ben Bleasdale, Campaign for Science and Engineering (CaSE).***

The chair invited Rebecca Hill and Ben Bleasdale from CaSE to discuss the recent results of the Discovery Decade project, a project ran by CaSE to determine public perceptions on research and development in the UK.

Ben commented on how the Discovery Decade's aim is to try and understand how we can talk to the general public about why R&D is a social and political priority and how we can talk about investment in R&D in the right terms. The Discovery Decade focuses on public perceptions of R&D and how we can talk about it in a positive way in society that connects with other issues such as the environment, economy and education. Becky discussed the data collected in the Discovery Decade project; 4 nationally represented polls, engaging with over 18,000 people in the public attitudes survey and 14 focus groups. Becky commented on the fact that the project engaged with people across a wide demographic and regional areas. Becky commented that the key findings were that the overall public see R&D as important, it is not considered a politicised issue but more than half of the people interviewed knew little or nothing about R&D. Overall, one of the biggest lessons so far from the Discovery Decade is the issue of tangibility and local visibility; it is important that we can show R&D as a tool for addressing the issues we face in today's society

### **ITEM 3 – Presentation: Elliot's Endeavours.**

#### ***Lucy Pattern, founder of Elliot's Endeavours.***

John Griffiths MS invited Lucy Pattern, founder of Elliot's Endeavours and mother of Elliot, who has a rare condition known as Duchenne Muscular Dystrophy.

Lucy spoke about her son's personal experience of the condition, how and why it can occur to young children, predominantly found in boys. She explained the symptoms for Duchenne, how most patients generally lose the ability to walk when they reach adolescent and the current clinical trials happening to treat and cure the condition. She then commented on her personal experience of clinical trials; in which Elliot is currently undergoing in Newcastle.

Lucy spoke about the importance of raising awareness of such rare conditions and the impact clinical trials can have for the patients and families. Lucy said that clinical research in Duchenne is constantly changing and improving. There is research around tackling the root cause of Duchenne, gene therapy and tackling side effects of Duchenne. Clinical trials for Duchenne are increasing and are currently happening around the UK but there is currently none in Wales. Lucy hopes to leverage skills and resources of trials happening in Cardiff to have Duchenne clinical trials in Wales.

### **ITEM 4 – Q&A and final remarks**

The chair thanked all the speakers and invited questions from the attendees.

One attendee asked a question around perceptions on using public data for research and the finding the right skills for conducting research. Ben from CaSE responded that understanding patient data is a challenge and that it is key people understand how their data is being used and what the benefits are of using such data. He also commented that there is a lot of work to be done to raise the profile of the R&D workforce.

An attendee asked Lucy what she would like to see from politicians in Wales in terms of improving the clinical trials environment. Lucy responded that it is important to get the R&D workforce into Wales so such trials can be conducted.

The chair thanked everyone for attending and brought the meeting to a close.

The meeting finished at 12.05pm.