

## MINUTES OF THE MEETING HELD MONDAY 15<sup>TH</sup> JANUARY 2024

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TIME: 11.30AM – 1PM, LOCATION: ZOOM

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PRESENT: Jenny Rathbone MS (Chair)

IN ATTENDANCE: Sioned Williams MS, Ioan Bellin – Office of Delyth Jewell MS, Bronwen Davies – Abortion Rights Cardiff, Alison Scouller – Socialist Health Association Cymru, Amanda Davies – Swansea Bay UHB, Andrew McMullan – BPAS, Tessa Marshall – Breast Cancer Now, Kayleigh Williams – Community Pharmacy Wales, Helen Perry – NYAS, Pauline Brelsford – Abortion Rights Cardiff, Georgia Walby – Long Covid Wales, Jan Russell – WAMES, Louise Morgan – Long Covid Wales, Ruth William – Long Covid Wales, Dee Montague-Coast – FTWW, Rebecca Davies – Action for M.E, Julie Richards – RCM, Sarah Hatherly – Welsh Senedd, Debbie Schaffer – FTWW, Lucy Grieve - BPAS

APOLOGIES: Sarah Murphy MS, Delyth Jewell MS, Joyce Watson MS, Llyr Gruffydd MS, Rhun ap Iorwerth MS, John Griffiths MS, Dr Jane Dickson – FSRH, Michelle Moseley – RCN, Tina Foster – TGP Cymru

### 1. WELCOME, MINUTES, MATTERS ARISING, AND AGM

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**Minutes:** Minutes accepted.

**AGM:** AGM report circulated to attendees. Confirmed officers going forward as nominated by Sioned Williams MS:

- Elected chair: Jenny Rathbone MS
- Secretariat: BPAS and FTWW

**Matters arising:** Bronwen Davies asked if we had received a response from the Minister about abortion progress in Wales following the letter written in November. Lucy Grieve is to chase at report back.

### 2. POST-VIRAL CONDITIONS IN WALES: AN OVERVIEW

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#### Jan Russell, Welsh Association of M.E & CFS Support (WAMES)

- WAMES was set up in 2001 to support, inform, and advocate for those suffering with M.E and CFS across Wales.
- It is estimated that 13,000 people in Wales suffered from M.E/CFS pre-pandemic, but it is notoriously difficult to get a diagnosis. WAMES estimates that in addition to the 13,000 people, there are between 11,000 and 18,000 people who are living with Long Covid/M.E and that there has been much overlap between the conditions.
- Currently in Wales, there are no medical specialists or clinical champions for M.E or CFS, and as a result, there is no funding, There has been some effort undertaken by the Welsh

Government to create a strategy for those with M.E, as well as a chronic conditions inquiry which is ongoing.

### 3. M.E AND THE GENDER DIVIDE

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#### Rebecca Davies, Action for M.E

- Notes that M.E is a neurological illness that affects at least 1.3 people in the UK alone. It is a long-term (chronic), fluctuating disease that causes symptoms affecting much of the body and in particular the nervous and immune systems. Long Covid has become an overlapping illness.
- Very few people recover from M.E, some may see improvement in symptoms over time but 1 in 4 remain severely affected and are often house and/or bedbound. Even the mildest form of M.E impacts severely with quality of life often very poor.
- Research has shown that females are affected significantly more at a rate of 5:1, and often experience more severe symptoms that increase with age than men.

### 4. LONG COVID AMONGST WELSH WOMEN

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#### Georgina Walby, Ruth William, and Louise Morgan, Long Covid Wales

- Georgina Walby who runs Long Covid Wales spoke about her experience with Long Covid after first contracting Covid in 2020. Georgina had trouble with her GP, who would not diagnose her with M.E or CFS because she already had a Long Covid diagnosis and nothing else could be done – this has affected the financial support that has been available. Georgina is now travelling 100 miles a week for oxygen therapy which helps but means that she cannot work full time and the condition continues to have a huge impact on everyday life.
- Louise Morgan started suffering after spending time in hospital with glandular fever. She went from a marathon runner and corporate business woman to being bed bound in a matter of months. The result of her Long Covid has meant that she has lost her career, she has also had to sell her home and move back in with her parents due to this. She spoke about the lack of resources available on the NHS, which made her seek private treatment.
- Ruth Williams has Long Covid and is a College Lecturer. 4 years down the line with Long Covid, she has applied for an ill health retirement meaning that she has essentially lost her career. She has spoken about struggling to find a treatment that works, and stated that she was referred for exercise classes which had a terrible effect on the condition and were counterintuitive.

### 5. DISCUSSION OF ISSUES RAISED BY SPEAKERS

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Discussion focused on support needed for frontline workers that may suffer from one of these conditions, as well as the length of time taken to be diagnosed in many instances. Points were also raised about the work being done by the Welsh Government, as well as recent advances in the field of women's health that may help us tackle the issues in the future.

#### Support for frontline workers:

- Discussion focused on the predominantly female population of front-line workers in Wales (estimated to have an 80% female prevalence) and the implications of them suffering from Long Covid or CFS/M.E.
- Increase in Health Boards having to hire agency staff on short-term, high-cost contracts to cover absences. This has serious impacts upon budgets.
- Spoke about the possibility of getting in touch with Health Boards to ask what support they're providing specifically in relation to this. Sioned Williams MS also stated this could be an opportunity to ask if masking in healthcare settings would make a difference.

#### Length of diagnostic journey:

- A number of CPG members spoke about their own diagnostic journeys – some of them taking up to 20 years to get a solid diagnosis on their medical record.
- Points raised about the degrading treatment by the DWP, as well as policing from health care practitioners which can have a negative impact on symptoms.
- Spoke about the issues with doctors prescribing exercise, and the implications this can have for chronic illnesses (in many cases causing a flare).

#### Work being undertaken by Welsh Government:

- Welsh Government has committed to implementing the Social Model of Disability.
- The move to a rights-based model will mean that lived experience will be embedded in the services.
- Points raised about the need for women-centric research and initiatives to be undertaken – the work of Caroline Criado-Perez in advocating for medical advances was discussed.

#### 6. AOB

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#### NEXT MEETING: TBA

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