

## CPG on Muscular Dystrophy Meeting Minutes

<b>Cross Party Group Title</b>	Wales Cross Party Group on Muscular Dystrophy and Neuromuscular Conditions
<b>Date of Meeting</b>	17 <sup>th</sup> May 2023
<b>Location</b>	MS Teams - Virtual

### In attendance:

<b>Name:</b>	<b>Title</b>
Rhun Ap Iorwerth MS (RAI)	Chair of the CPG on Muscular Dystrophy and Neuromuscular Conditions
Rhys Hughes (RH)	Office of Rhun Ap Iorwerth
Citta Widagdo (CW)	Health Policy Officer, Muscular Dystrophy UK
Rob Burley (RB)	Director of Care, Campaigns, and Support, Muscular Dystrophy UK
Lucia Gillespie (LG)	Advocacy & Information Officer – Wales, Muscular Dystrophy UK
David Heyburn (DH)	Chair of the Wales Neuromuscular Network
Veronica Roberts (VR)	Neuromuscular Care Advisor, North Wales Neuromuscular
Rhiannon Edwards (RE)	Neurological and Rare Diseases Implementation Groups Coordinator, NHS Executive
Heledd Tomos	Neuromuscular Specialist Physiotherapist, South Wales Adults Neuromuscular Service
PM	Members of the Public
MR	Members of the Public
JR	Members of the Public
KL	Members of the Public
LB	Members of the Public
MD	Members of the Public
WS	Members of the Public
HL	Members of the Public
RE	Members of the Public

### Abbreviations:

WG	Welsh Government
PHW	Public Health Wales
WNMN	Welsh Neuromuscular Network
HB	Health Boards
MDUK	Muscular Dystrophy UK

### Full notes:

## **MDUK's Response on the Rare Disease Action Plans**

- RB presented an overview of the Wales Rare Disease Action Plan and relevant areas to muscle-wasting and weakening conditions.
- On Priority 1, RB highlighted the emphasis on the importance of genomic screening, but noted that newborn screening via the UK Newborn Screening Programme is key to some rare conditions, including SMA; but that screening is not the only intervention needed to help improve the diagnosis of muscle-wasting conditions, since it is important to improve access to health and social care services.
- On Priority 2, RB highlighted that MDUK has been managing educational platforms and shared learning to upskill professionals in understanding neuromuscular conditions, and that these will continue.
- On Priority 3, RB highlighted the emphasis in the action plan on care pathways, and using digital tools to improve consistencies in the coordination of care. However, the muscle-wasting community has highlighted the importance of a neuromuscular care advisor role.
- On Priority 4, RB has noted that some neuromuscular conditions now have access to newly developed treatment that is essential. It is important to communicate this, as well as to ensure access to a wide range of specialist care for the community in Wales.

## **MDUK: Launch of the Newborn Screening Report**

- MDUK is Secretariat to the Westminster APPG on Muscular Dystrophy, which last year launched an inquiry into newborn screening.
- The APPG will launch the inquiry report, *Newborn Screening for Rare Diseases*, next week. The report is currently still embargoed.
- The report will focus on highlighting the importance of robust, yet pragmatic, approach to assessing conditions for newborn screening, and making recommendations for effective changes to the newborn screening programme in the UK, including adopting a clear and transparent approach and engaging further with the stakeholders.
- RB is to update the CPG about the report at the next CPG meeting.

## **WNMN: Updates on Business Cases**

- DH mentioned that it has been challenging for the WNMN to get the business cases into the radar of stakeholders.
- The WNMN met two weeks ago to advance the business cases and discuss some key challenges.
- The funding of £1.5 million requested is an important investment to support the improvement of neuromuscular care in Wales, especially in creating core specialist teams across Wales, both in the region and locally, supporting better neurorehabilitation process, upskilling general services, which are critically needed by the community of people living with neurological conditions and their families.

## **Any Other Business**

### ***Neurological and Rare Diseases Implementation Groups***

- RE provided a brief update on the work of the Neurological and Rare Diseases Implementation Groups.
- Some of the work that has been implemented is a Virtual Health Hub as a one-stop platform to support people, including those with neuromuscular conditions and those with Duchenne MD, and other works such as improving access to neurorehabilitation.
- The Group is also holding training sessions for primary care practitioners in Wales to understand more about managing patients more effectively and learning more about rare conditions.
- There are challenges due to lack of funding for rare diseases to support some of the work.
- Besides access to treatment, some key priorities are improving access to research, which hopefully will be improved by the implementation of Virtual Health Hub.

### ***Inclusive exercise***

- MR, who is living with a muscle-wasting condition, provided stories about her health journey. She is now qualified as a fitness instructor for people with disabilities and runs 2 inclusive dance classes, as well as running a channel Move with Morvenna.
- DH mentioned the importance of sharing such stories, especially from the perspectives of patient empowerment, ensuring that NHS strategies are patient-centred to drive better mental health and wellbeing.
- RB and LG will contact MR separately to discuss peer-support volunteering and other ways MR can contribute.
- RE will be in touch with MR to discuss whether the Group can develop some support, online trainings, and MR will provide good insights for the community.
- RAI complimented MR's progress and that RH is in the meeting too – inclusive exercise is an important cause, including in RAI's constituency.

### ***Access to diagnosis and specialist support***

- LB, who is a parent to a young person with neuromuscular conditions, waited for over a decade for a diagnosis and for support, have to travel to Alder Hey due to lack of neurological services locally.
- LB is based in Harlech and works with VR. VR works on her own in North Wales.
- As Chair of the CPG, RAI will be in touch with the MS in Harlech constituency to discuss LB's case. RAI also encouraged LB to contact the MS to raise her case. His email is Mabon.ap.gwynfor@senedd.cymru.
- DH states that this is unfortunately not uncommon – and an important story and case study on why the business cases are important to advance. DH will be in touch with LB too.
- LG will be in touch with LB too to discuss her case and provide support.
- VR shares that it has been difficult to coordinate services as there is a significant lack of specialist support in North Wales, so people have to travel far. It has also not been easy to coordinate with schools, and there is critical lack of psychological support for patients and their families.
- VR highlights that while newborn screening is important – there needs to be improvement for support post-diagnosis as this is lacking in North Wales.