



## Betsi Cadwaladr University Health Board Motor Neurone Disease (MND) Disease Specific Advisory Group (DSAG)

### **CARER REPRESENTITIVES**

**Would you like to play a key part in making decisions about services for people living with MND in North Wales?**

**Do you care for someone with Motor Neurone Disease?**

The MND DSAG was formed in 2012 to report on and guide development of services for patients living with MND in North Wales. The group comprises of health and social care professionals and representatives from organisations involved in supporting patients and those important to them living with MND in North Wales. The group reports to the Neurosciences board of Betsi Cadwaladr University health Board.

It is important for such a group to hear the views and perspective from service users and their carers to ensure we direct services to meet patient need.

We are looking to recruit 2 carer representatives to join the DSAG from Autumn 2023 to work with members of the DSAG to offer views, perspectives and ideas on how services are delivered.

#### **What's Involved?**

- Attending DSAG meetings quarterly. Meetings are done remotely at the moment using a virtual meeting platform and last around 2 hours.
- Reading papers and undertaking any preparatory work ahead of the meetings
- Working within the Terms of Reference (ToR) for the group
- Participating in discussions, providing feedback and expressing ideas on MND services
- Working with other members of DSAG on specific working groups or projects where appropriate
- Contributing, where appropriate to future education events



### **This would suit me if I:**

- Would like to make a meaningful contribution to help shape MND services
- Am currently caring for someone with Motor Neurone Disease
- Have cared for someone with Motor Neurone Disease
- Have good listening skills and am a good communicator
- Understand the need for confidentiality and the importance of data protection
- Am able to feedback the views of other carers as well as my own views if appropriate
- Am confident in using virtual meeting platforms such as Microsoft teams or zoom or willing to learn

### **How will I be supported?**

- Ongoing support including regular reviews, and a buddy system
- At the moment meetings are held using a virtual meeting platform. This platform can support non verbal communication via an online chat facility and a buddy will be assigned to support you with this
- Reimbursement of out of pocket expenses if appropriate

### **How flexible is the role?**

- The role will generally be for a maximum of 2 years. However, this will be reviewed quarterly to see how the role is working for you

### **What's the next step?**

- If you are interested in finding out more about the role please contact Dr Liz Williams, Chair of DSAG on 03000 851667 or Jo Cunnah, Area Support Coordinator MND Association [jo.cunnah@mndassociation.org](mailto:jo.cunnah@mndassociation.org) on 01604 800628
- Complete the expression of interest form and return no later than 11<sup>th</sup> August 2023
- An informal discussion with the chair and another member of the DSAG to appoint the representatives will take place on 28<sup>th</sup> September