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**Bwrdd Iechyd**
**Addysgu Powys**

**Powys Teaching**
**Health Board**

Ref: AL/SL/HJ/sj                                          7th April 2017

Mike Hedges AC/AM
Chair
National Assembly for Wales Petitions Committee
Cardiff Bay
Cardiff
CF99 1NA

Dear Mr Hedges

**Re: P-04-532 Correspondence from the Chair of the Petitions Committee**

I refer to your letter of 20th March 2017 seeking the views of Powys Teaching Health Board (PTHB) on the issues raised by the recent Petition, both generally and specifically on the Petitioner's most recent correspondence which was enclosed.

Based on data collected from GP practices across Powys there are 19 adults living with a neuromuscular condition in Powys.

From a local perspective, we include ongoing development of services for people with neuromuscular conditions into our Neurological Conditions Delivery Plan (NCDP). This is overseen by a Neurological Conditions Steering Group and the actions are incorporated into our Integrated Medium Term Plans.

Avoidance of unplanned admissions is a key outcome measure for the implementation of out NCDP.

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Rydym yn croesawu gohebiaeth Gymraeg
Bwrdd Iechyd Addysgu Powys yw enw gweithredol Bwrdd Iechyd Lleol
Addysgu Powys

We welcome correspondence in Welsh
Powys Teaching Health Board is the operational name of
Powys Teaching Local Health Board

## 1. Increase in Family Care Advisors and Support

It is important that people living with a neuromuscular condition, and their families, have access to an appropriate level of advice and support. To ensure equity of access to this service opportunities for providing this support via telephone and skype should be explored.

These advisors also need to link in with local services to ensure they are aware of any local services that these people may benefit from. An example of this in Powys would be the Neuro Café's, the Neuro Emotional Intervention Programme, Activate your Life Courses, Community Neuro Clinics and Neuro Out-Patient Services.

In Powys we have a Community Neuro Service Coordinator who is able to signpost to relevant Health and social Care sources of support and coordinates regular multidisciplinary reviews for people living with neurological conditions.

The Integrated Disability Service in Powys provides care and support for children and young adults and facilitates transition into adult services where appropriate. Health and social care professionals plan and deliver client specific care plans with service users through Team Around the Family (TAF) and Care Around the Family (CAF) processes. Any Family Care Advisors and support would need to link in with the CAF and TAF.

## 2. Specialist adult neuromuscular physiotherapists

In Powys we have Clinical Specialist Physiotherapists in neurorehabilitation. It would be valuable were these specialist physiotherapists to have access to highly specialist advice in managing complex cases, either by e-mail, telephone or through video conferencing. Any specialist Adult Neuromuscular Physiotherapists would need to put in place appropriate training and support for Neurorehabilitation Physiotherapists working across Wales.

## 3. Appointment of consultant in adult neuromuscular disease.

This would be welcomed by PTHB. Timely access to a Consultant in adult neuromuscular disease is important for diagnosis and ongoing management. Neurology is a commissioned service of which neuromuscular conditions is a sub speciality. We have a

service level agreement in place and are invoiced on a per contact basis.

## 4. Increase in clinical psychology

In Powys we are working to improve support for emotional, behavioural and cognitive problems for people with stroke and neurological conditions. We have recently piloted a Neuro Emotional Intervention Programme, based on Acceptance and Commitment Therapy. This is in the process of being evaluated as part of the development of a more robust and sustainable neuropsychology services for stroke and all neurological and neuromuscular conditions.

Psychological support for children and young people is provided by Children's Mental Health Service (CAMHS) and Educational Psychologists.

## 5. An equipment budget to enable minor purchases and lease arrangements.

In Powys all equipment is managed through the joint equipment stores or purchased though Individual Patient funding Requests (IPFR). It would be difficult to manage a budget like this on an all Wales basis and ensure equity of access and cost effectiveness.

## 6. a national decision-making forum with resources that is sufficiently aware of service risks and thereby assign an informed priority to the situation.

There is already a national group looking at the implementation of the neurological conditions delivery plan. The Welsh Neuromuscular Network is represented this group. There is more value to be gained in looking at commonalities between the service needs of people with all neurological and neuromuscular conditions in the first instance, and making sure these are met in a cost and clinically effective way. It is not clear if there is a critical mass of service users to warrant a separate national decision-making forum. All services should developed and delivered based on national guidelines and evidence based practice in a model that suits the health needs of local communities.

**7. Neuromuscular services are included within the scope of the national review of neurosciences in Wales being led by WHSSC.**

It would be helpful to have some guidance from WHSSC about what level of service is considered highly specialist and should be commissioned through them and what is considered core and should be commissioned or provided by local health boards in line with other neurological conditions.

In Powys many complex care packages are jointly funded through Health and Social care. This would complicate having health care funded through WHSSC.

I hope that the above answers your queries but if you have any further questions please do not hesitate to contact me.

Yours sincerely

Alan Lawrie
Deputy CEO/Director of Primary Community Care and Mental Health