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GIG  
CYMRU  
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WALES

Bwrdd Iechyd  
Addysgu Powys  
Powys Teaching  
Health Board

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26th May 2015

Mr William Powell AM  
Chair  
Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

Dear William,

P-04-532 – Improving specialised neuromuscular services in Wales.

Thank you for your letter of April 2015 regarding the above and seeking the views of Powys Teaching Health Board on the petition from the Muscular Dystrophy Campaign:-

*We call on the National Assembly of Wales to urge the Welsh Government to ensure that Health Boards implement the investment proposed by the Welsh Neuromuscular Network Vision Document for improving specialised neuromuscular services in Wales.*

In Powys teaching Health Board we have approximately four children/young people with muscular dystrophy and a further three with muscle wasting type conditions. Powys teaching Health Board has no District General Hospital and these people will have to travel some distance to specialist centres for specialist tests for diagnosis, specialist clinics, respiratory care, cardiac care, insertion of pegs for feeding and wheelchair appointments.

In Powys children and young people are supported locally as early as possible, often from babies, in order to fulfil their potential. Local services support families and carers once they have been given the diagnosis; local therapists will be assessing the physical health of the child or young person prior to clinic appointments, sharing assessments, arranging support of equipment for 24 hour postural management including sleep systems, seating, bathing, standing frames, advising and supporting on appropriate wheelchair provision, orthotic management with footwear, preventative chest care, provision of slings and advice on manual handling. Powys is able to deliver on equipment and support in a timely way. This is something we do well. (5)

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



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

There is work going on through the Respiratory and Cardiac Delivery Plans that can be drawn on to improve these services for this service user group in Powys. Up-skilling local healthcare professionals and improving pathways for interventions such as genetic counselling, non invasive ventilation and cough assists devices have the potential to improve services for people with MND, SCI and MS as well as people with a neuromuscular conditions. We would support the development of the use of telemedicine to enable our local population access centralised specialist services more efficiently.

I hope this letter goes some way to clarifying the situation regarding the provision of neuromuscular services in Powys but should you have any further queries please do not hesitate to contact me,

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Carol Shillabeer', with a long, sweeping horizontal stroke at the end.

Carol Shillabeer  
Chief Executive