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Bwrdd Iechyd Prifysgol
Aneurin Bevan
University Health Board

Our Ref: JP/RB/jr
Your Ref: P-04-532

Direct Line: 01633 435905

17 June 2015

William Powell AC/AM
Chair, Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

Dear Mr Powell

Re **Improving Specialised Neuromuscular Services in Wales P-04-532**

Thank you for your letter to the above received by the Health Board on 27 April. As you will be aware, my office contacted the Petitions Committee Office to ask for the deadline for this response and it was indicated that there was no fixed deadline. Therefore, I am pleased to provide the Health Board's response below to the petition being considered by the Committee from the Muscular Dystrophy Campaign.

Petition Statement: We call on the National Assembly for 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.

As you will be aware, Neuromuscular disorders comprise an array of conditions – many will be rare, but others are common such as Charcot Marie Tooth Disease.

Patients with complex needs and requiring highly expert multi-disciplinary input, and those entering a transition period between paediatric and adult services are best supported in Tertiary Clinics in Regional Neurosciences Centres such as the Peripheral Nerve Clinic in Cardiff run by one of our Consultants Dr Gareth Llewelyn.

For individuals with less complex needs, patients are seen at a more local level and this is a service provided by Consultant Neurologists in their General Neurology Clinics within Aneurin Bevan University Health Board.

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Bwrdd Iechyd Prifysgol Aneurin Bevan yw enw gweithredol Bwrdd Iechyd Lleol Prifysgol Aneurin Bevan
Aneurin Bevan University Health Board is the operational name of Aneurin Bevan University Local Health Board

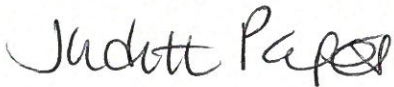
The new acute neurology service within the Health Board will see neuromuscular patients admitted to hospital within 24 hours. The aim however is to prevent unnecessary admissions and the roles of the Family Care Advisors, therapists, consultants and GPs are crucial in this regard.

The Health Board meets the Welsh Government Referral to Treatment times target for routine referrals. Urgent referrals are seen in 2-6 weeks

Currently there is no separate commissioning process for neuromuscular services in Wales. However, as part of the Neurological Conditions Implementation Group, £700,000 has been allocated to Neuro-rehabilitation across Wales and this includes Neuropsychology and specific funding has been approved to make the part time Family Care Advisor posts in South Wales full time appointments. Further work is being undertaken to clarify how this funding will be distributed but this additional funding will ease some of the burden on the workload of the Family Care Advisors to ensure that they can further support patients. This approach will be closely monitored. We will ensure that monitoring takes place of these services for patients with Neuromuscular Disorders as part of our neurological conditions Local Delivery Plan.

I hope this information is helpful to you. Should you require any additional information or clarification, please do not hesitate to contact me

Yours sincerely



Judith Paget
Chief Executive/Prif Weithredwr