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Wales

Bwrdd Iechyd Prifysgol  
Abertawe Bro Morgannwg  
University Health Board

Our Ref: PR/TH/cw  
Date: 14th December 2015

ABMU Health Board  
Headquarters  
One Talbot Gateway, Seaway Parade,  
Port Talbot  
SA12 7BR

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WHTN: 1787 3302

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

Dear Mr Powell,

I am writing in response to your letter dated 16<sup>th</sup> November 2015 and following our response to your original letter dated 1st June 2015.

There are currently approximately 200 patients on the muscle database, each of whom needs to be seen annually. Because of the challenge we have with consultant capacity we are unable to meet this review requirement in a consistent way.

The number of patients above does not include the much larger number of patients who have Charcot-Marie Tooth disease and the considerable numbers with myasthenia and acquired inflammatory neuropathies.

Charcot-Marie Tooth is relatively common with a prevalence of approximately 1:2500 and although many affected people will have very mild disease there are others with very significant disability. With the appointment of a Neuromuscular Care Advisor we have been in a position to run a Charcot Marie Tooth pilot clinic. We are currently in the process of filling the Neuromuscular Care Advisor role which is currently vacant due to secondment. When we fill the post we will be in a position to build on the excellent work that has already started. This pilot clinic has been established from existing resources.

The myasthenic and inflammatory neuropathy cases are seen by two of our consultants who specialise in this field, Dr Marguerite Hill and Dr Nigel Hinds.

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Chairman/Cadeirydd: **Professor Andrew Davies**

Chief Executive/ Prif Weithredydd: **Mr Paul Roberts**

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www.abm.wales.nhs.uk

During 16/17 one of our key priorities across all our service areas is to look at how we can deliver improved care and access to our patients within our existing resources. We have already demonstrated successfully that by reconfiguring existing resources differently, we can provide a more focussed service to specific patient groups. Managing demand into our services is another priority for us, so that we can direct our specialists towards providing the right support for those patients who only they can manage.

Whilst expanding our consultant workforce would clearly provide us with a great opportunity to broaden the service we can provide to neuromuscular patients, doing so as part of a successful programme of service improvement and change gives us even more opportunity to have a positive impact on the patients we care for.

Yours sincerely,



**PAUL ROBERTS**  
**CHEIF EXECUTIVE**

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• Chairman/Cadeirydd: **Professor Andrew Davies**

• Chief Executive/ Prif Weithredydd: **Mr Paul Roberts**

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