

Our Ref:

PR/cw

Date:

1st June 2015

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

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

Dear Mr Powell

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

Thank you for your letter dated 23rd April 2015 requesting an update from ABMU Health Board on progress against the priorities identified.

An Increase in Family Care Advisors

Within South West Wales (ABMU and Hywel Dda Health Board) we have one Neuromuscular Care Advisor, Sarah Harris, who works 30 hours per week, 5 hours of which are funded by the previous Chair of the Neuromuscular Care Group in recognition of the need for increased availability of the advisor.

Specialist Adult Neuromuscular Physiotherapists

ABMU have redesigned existing specialist adult physiotherapy expertise to support the Adult Muscle Clinic, which was established in 2013, there has been no new specialist physiotherapy appointment in South West Wales. Advice for the more complex patients is an area which remains to be resolved.

An Increase in Clinical Psychology

There is currently no service provision for clinical psychology for patients with Muscular Dystrophy in South West Wales. There are meetings within the Health Board to look at the

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provision of Psychology services across a range of neurological conditions and this has been highlighted in the Neurological Conditions Delivery Plan as a priority area to address.

Additional Consultant

Additional Neuromuscular consultant time to provide additional support would be beneficial.

Equipment

2014/2015 also saw the allocation of significant non recurrent investment for the provision of equipment for patients with a neuromuscular condition. Deploying this resource during the year posed a challenge but was successfully delivered by the Neuromuscular Care Advisor for South West Wales, and has resulted in significant benefit for patients.

I would also like to provide some additional information regarding Adult Neuromuscular Care.

The Adult Muscle Clinic has now been running successfully for 2 years and is held every 6 weeks in the Specialist Rehabilitation Centre at Morriston Hospital. This is a Consultant Neurologist led clinic, co-ordinated and supported by the Neuromuscular Care Advisor with input from Specialist Physiotherapist, ECG and Lung Function services. The aim of the clinic is to provide a 'one stop' service for patients, with an MDT after each clinic to discuss each patient and decide individual action plans. The clinic was set up by innovatively using existing resources. Patients and families have welcomed this service.

A Transition Muscle Clinic has also been running successfully for 2 years and is held approximately 4 times a year. Patients transfer from Paediatric Neurology Muscle Clinic into this clinic. The Clinic is run jointly with a Consultant in Neuro Rehabilitation and the Transition Palliative Physiotherapist.

I hope you will see from the above that progress has been made, particularly around redesigning existing resources to improve care for patients with neuromuscular conditions.

We recognise however, that there is still much work to be done. The Integrated Medium Term Planning (IMTP) process is the mechanism the Health Board has for reviewing and prioritising its service development requirements and the outstanding issues outlined in this response will need to be considered alongside other priorities during 15/16.

If you require any further information or clarification please do not hesitate to contact me.

Yours sincerely

PAUL ROBERTS CHIEF EXECUTIVE

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Chief Executive/ Prif Weithredydd: Mr Paul Roberts

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