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Bwrdd Iechyd Prifysgol
Abertawe Bro Morgannwg
University Health Board

Our Ref: SIJ/JT/JN
Date: 14th April 2014

ABMU Health Board
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Private and Confidential

William Powell
Chair
Petitions Committee
National Assembly for Wales
Cardiff Bay
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Dear Mr Powell,

I am writing in response to your letter to the Health Board dated 17th March 2014 about the recommendation commended by the Welsh Neuromuscular Network (WNMN) in their vision document published in late 2013.

Before responding to the specific recommendations outlined in the vision document, I thought it would be helpful to provide you with an overview of the significant progress that we have made in improving care for this patient group over the last 12 months.

Last year we established an Adult Muscle Clinic within the Health Board. This clinic is held every 6 weeks in the specialist rehabilitation centre at Morriston Hospital, is led by a consultant neurologist, co-ordinated and supported by the neuromuscular care advisor with input provided from a specialist physiotherapist, ECG and lung function services. The aim of the clinic is to provide a 'one stop' service for patients, with a multi-disciplinary meeting after each clinic to discuss every patient and agree individual care plans.

The clinic was created by redesigning existing resources to provide a more patient focused service: patients and their families tell us that they welcome it. We have noticed that a high

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number of patients being seen are residents of Hywel Dda Health Board and so we are working with colleagues in Hywel Dda for options to develop a similar specialist clinical locally.

We also started a Transition Muscle Clinic in May 2013. Held four times a year, the clinic supports patients transferring from the paediatric neurology muscle Clinic to adult services. This Clinic is run jointly with a consultant in neuro-rehabilitation and the transition palliative physiotherapist.

We are also planning to commence a therapy-led Charcot Marie Tooth (CMT) clinic in ABM to provide one stop physiotherapy, occupational therapy and orthotic input for CMT patients on an annual review basis. The first pilot clinic is due to take place in June 2014 and will take place quarterly thereafter if it proves successful. We are co-designing this clinic with service users.

During 2013 the south west neuromuscular care advisor organised a multi-disciplinary neuromuscular training day for ABMU and Hywel Dda staff as well as an annual Welsh patient support day, organised in conjunction with the Muscular Dystrophy campaign. Which was attended by over 60 patients.

The following section focuses specifically on the recommendations within the vision document.

a. Family care advisors

In ABMU Health Board we have one neuromuscular care advisor, Sarah Harris, who works 30 hours per week. Funding for five of these hours has recently been provided by the chair of the Neuromuscular Care Group to improve advisor availability. Sarah supports the south west Wales region which includes Hywel Dda Health Board. We are aware that the vision document recommends a full time advisor post for the South West patient population along with administrative support.

As a first step we are looking at options for administrative support to the care advisor so that she can make best use of her 30 hours of work each week.

b. Specialist adult neuromuscular physiotherapists

We have redesigned access to existing specialist adult physiotherapy expertise to provide focused support to the adult muscle clinic, which was established during 2013. However, there has been no new specialist physiotherapy appointment in ABMU.

Providing specialist advice for more complex patients from an expert remains to be resolved.

c. Appointment of a consultant in adult neuromuscular disease

Within ABMU Dr Jon Walters, Consultant Neurologist is the lead neuromuscular patients, supported by other consultant neurologists who will also see adult muscle patients as part

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of their service for example, Dr M Hill has a special interest in Myasthenia Gravis. The Neurology team also have weekly multi-disciplinary meetings in place, to allow for case discussion/review with colleagues about individual patients.

d. An increase in clinical psychology

There is currently no service provision for clinical psychology for patients with Muscular Dystrophy in ABMU or within Wales. There are meetings within the Health Board to look at the provision of psychology services across a range of neurological conditions and we have examples in some services of other members of the MDT being supported to develop their skills and experience, to provide basic support for patients through a cascade model.

e. An Equipment Budget

ABMU recognise that there are issues about equipment for patients with a neuromuscular conditions, for example cough-assist machines. We are pleased that a bid by members of the Neuromuscular Network to Welsh Government was successful and that funding has been made available for 2014/15 for various necessary items of equipment.

We recognise that as a Health Board there is more for us to do to deliver all the recommendations outlined in the vision document. I hope that in sharing with you the progress we have made over the last 12 months that you will see that much of our initial focus has been on redesigning and utilising existing resources and expertise to allow us to provide more targeted access for neuromuscular patients.

The next few months will see ABMU and all other Health Boards in Wales completing its Neurological Delivery Plan. We will be working closely with Hywel Dda Health Board to develop an integrated delivery plan for neurological conditions and the recommendations included in the vision document will form a key part of that plan.

In 2014-5 our focus is on developments such as the CMT clinic, purchasing of essential equipment in line with the agreed WG funding and identifying administrative support for the care advisor. We will be using resources developed through The Muscular Dystrophy Campaign 'Invest to Save 2011' to identify the opportunities we have within south west Wales to release local resources for reinvestment into our local services.

Yours sincerely



Paul Roberts
Chief Executive

