



**GIG**  
CYMRU

Bwrdd Iechyd Prifysgol  
Caerdydd a'r Fro

Ysbyty Athrofaol Cymru  
University Hospital of Wales  
UHB Headquarters

WALLES

University Health Board

Cardiff, CF14 4XW

Caerdydd, CF14 4XW

Eich cyf/Your ref: P-04-532  
Ein cyf/Our ref: SH-ns-04-6134  
Welsh Health Telephone Network:  
Direct Line/Llinell unffonogchol: 02920 745681

**Dr Sharon Hopkins**  
**Interim Chief Executive**

20 April 2017

**Mike Hedges AC/AM**  
Chair, Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

Dear Mr Hedges

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

Thank you for your letter dated 20 March 2017 asking for Cardiff and Vale UHB to provide comments on the above petition.

Cardiff and Vale University Health Board has been making good progress in relation to improving the services provided to patients with neuromuscular conditions, but recognise there is more work to be done over next few years.

In general terms, by way of progress I am pleased to report that:

- All our consultants contribute to the Wales Neuromuscular Network and are supported in attending the Neuromuscular network meetings.
- We are working closely with MDUK and have an Advocacy and Information Officer who holds an honorary contract with the UHB and she attends the neuromuscular clinics providing patients with social support and support with advocacy issues.
- We have developed a transitional clinic to enable the smooth transfer of patients from paediatric care to adult care.

In relation to the specific points you raise in your letter, I am also pleased to report that we have already taken forward a number of actions in these key areas.

**1. Increase in Family Care Advisers**

Cardiff and Vale UHB is in the process of increasing the establishment of Family Care Advisers taking forward the recruitment of 3 new part-time Advisers. The additional staff will be employed by Cardiff and Vale UHB but will deliver services

across South East, South West and North Wales. It is envisaged that these additional staff will be in post by early summer.

## **2. Specialist Neuromuscular Physiotherapist**

Similarly, there is a recruitment process underway to appoint a Specialist Neuromuscular Physiotherapist who will work closely with the Family Care Advisers.

## **3. Appointment of a Consultant in Adult Neuromuscular Disease**

In 2006 the UHB appointed Dr Ellie Marsh, Consultant Neurologist and Specialist in Adult Neuromuscular Disease. Dr Marsh works closely with the Family Care Advisers and with the Paediatric Neuromuscular Team to ensure a smooth transition from paediatric to adult care. It should be noted that there are several other specialist consultants who provide a service for the management of neuromuscular disease in adults.

## **4. Increase in Clinical Psychology**

The UHB provides a limited psychology service for patients with neuromuscular conditions but recognises that this is insufficient to meet the needs of all patients and their families. In 2015 the UHB submitted a bid for funding from the Neurological Conditions and Stroke Rehabilitation Delivery Plan for increased resources to support the appointment of a Psychologist to work with both adult and paediatric patients. Unfortunately, given the number of bids received and the limited funds available the bid was unsuccessful. We are therefore unable to progress this appointment at the current time.

## **5. An equipment budget to enable minor purchases, lease arrangements**

Whilst there is no allocated equipment budget in order to purchase minor pieces of equipment or to provide lease arrangements, we have taken advantage of one off opportunities to access funding where possible. For example, at the end of last year a sum of money was provided to the UHB from Welsh Government to purchase equipment for patients. This money was invested wisely and large pieces of equipment were purchased in order for these to be provided on a loan basis to patients. The service also purchased a number of individual items for patients where required.

In summary, the UHB has been progressing improving the care and treatment for patients with neuromuscular conditions but recognises there is more work to be undertaken. In discussions with the clinical team a number of priorities have been identified and we will work closely with the clinical team in addressing these issues.

- Increasing the capacity in the adult Neuromuscular service to enable a weekly clinic to be undertaken at the University Hospital Llandough where the clinic can be held alongside other respiratory clinics. The timescale for this is likely to coincide with the transfer of Rookwood Hospital to UHL.
- Development of a Neuromuscular “hub” in Cardiff with physical space enabling all professionals to work closely together.

- Establishing an improved integrated nerve and muscle biopsy service to aid diagnostics.
- Improving psychology input for paediatric and adult patients.

Should you require any further information on this matter, please do not hesitate to contact me.

Yours sincerely



**Dr Sharon Hopkins**  
**Interim Chief Executive**

