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Bwrdd Iechyd Prifysgol
Hywel Dda
University Health Board

Ein cyf/Our ref: CEO.535.0417
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Dyddiad/Date: 21 April 2017

Swyddfeydd Corfforaethol, Adeilad Ystwyth
Hafan Derwen, Parc Dewi Sant, Heol Ffynnon Job
Caerfyrddin, Sir Gaerfyrddin, SA31 3BB

Corporate Offices, Ystwyth Building
Hafan Derwen, St Davids Park, Job's Well Road,
Carmarthen, Carmarthenshire, SA31 3BB

Mike Hedges AM
Chair
Petitions Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

Dear Mike

Thank you for your letter of 20 March 2017, seeking Hywel Dda University Health Board's view regarding the petition received by the Petition's Committee from the Muscular Dystrophy campaign.

The petition calls for ongoing development of local services for people with neuromuscular conditions, including:

- additional physiotherapy support
- psychology support
- dedicated neuromuscular consultant time

Currently Hywel Dda accesses a specialist neuromuscular service hosted by Abertawe Bro Morgannwg University Health Board. The Neuromuscular Family Care Advisor is working in partnership with the local professionals providing hands on intervention and support. Of the one hundred and eighty seven (187) people who are projected to have a neuromuscular disorder in this area, sixty (60) adults and eighteen (18) children currently access this specialist service.

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Cadeirydd / Chair
Mrs Bernardine Rees OBE

Prif Weithredwr/Chief Executive
Mr Steve Moore

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

Mae Bwrdd Iechyd Prifysgol Hywel Dda yn amgylchedd di-fwg Hywel Dda University Health Board operates a smoke free environment

The service is supported by Dr Walters, a Neurologist specialising in neuromuscular disorders. All neuromuscular patients known to Dr Walters attend an annual review at the Adult Multi Disciplinary Team Muscle Clinic in Morriston hospital. People with neuromuscular disorders may also be managed by Dr Hirst at her general Neurology Clinic in Glangwili Hospital based on local agreement. Paediatric Muscle Clinics are held in Singleton and Withybush Hospitals by Dr White, Paediatric Neurologist.

One of the recent local service developments relating to neurology is the establishment of a Specialist Community Neurology Team. This comprised a Neuropsychologist, Advanced Scope Physiotherapist and Occupational Therapist and also a Specialist Speech and Language Therapist. Local experience of a regional approach to condition specific rehabilitation services indicates that the local therapists continue to deliver the on-going hands on neuro rehabilitation. The team members are newly appointed and their role will include working closely with the Neuromuscular Family Care Advisor. This team will establish core specialist community neuro rehabilitation multidisciplinary working for a range of neurological conditions, including muscular dystrophy. This model is believed to match the needs of a rural population.

Children with neuromuscular disorders access local therapists for ongoing support through childhood and also have access to local paediatricians as needed. Physiotherapists and occupational therapists that deliver a community paediatric service are supported to develop highly specialist skills in supporting children with neurological conditions as this makes up the bulk of their clinical practice. Paediatric Physiotherapists exchange knowledge and information with the regional Specialist Neuromuscular Physiotherapist.

In addition, access to Neurologists has been reviewed and there is acknowledgement that the service should be more responsive. Hywel Dda University Health Board is working in partnership with Abertawe Bro Morgannwg University Health Board to increase local access to neurologists.

There are some concerns that the further investment of regional or national specialist posts advocated to support people with neuromuscular disorders may not best meet the needs of people living in a rural area. These specialist posts often don't provide the best access for more distant populations such as ours.

I hope you find this information helpful and that it addresses your recent query.

Yours sincerely

A handwritten signature in black ink that reads "Steve Moore". The signature is written in a cursive, flowing style with a large initial "S" and "M".

Steve Moore
Chief Executive