Ysbyty Athrofaol Cymru University Hospital of Wales UHB Headquarters

Heath Park Cardiff, CF14 4XW Parc Y Mynydd Bychan Caerdydd, CF14 4XW

Eich cyf/Your ref; P-04-532 Ein cyf/Our ref; AC-ns-02-5356 Weish Health Telephone Network: Direct Line/Ellnell uniongychol; 02920 745681

Professor Adam Cairns Chief Executive

12 February 2016

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

Dear Mr Powell

Re: Improving Specialist Neuromuscular Services in Wales

I write in response to your request via email dated 4 February 2016 to provide information on the current provision of Neuromuscular Services within the South East Wales area which are hosted by Cardiff and Vale University Health Board. Unfortunately, it seems that Cardiff and Vale UHB was not included in the original request for this information sent to Health Boards in November 2015 and therefore please accept my apologies that we are unable to provide a more comprehensive response given the limited timeframe available.

Provision of Family Care Advisors

Cardiff and Vale UHB currently employs one Family Care Advisor who works 30 hours per week, 5 hours of which were funded by the Chair of the Neuromuscular Care Group. The post holder provides a service to both adults and children in South East Wales. Recent reviews of the service have deemed this unsustainable both for the individual and the service in general. However, Cardiff and Vale has recently received an additional £60,000 via the Neurological Conditions Delivery Plan funding to support the appointment of additional Family Care Advisors for the region and the Neurosciences Directorate is in the process of taking this forward.

Provision of Adult Specialist Neuromuscular Physiotherapy Services

The involvement of neuromuscular physiotherapists in clinics where adult patients are regularly seen is essential. There are currently no specialist adult neuromuscular physiotherapists for South East Wales but as part of the Neurological Conditions Delivery Plan, 1 WTE physiotherapist has been funded to be split between ABMU and Cardiff and Vale UHB to cover South and Mid Wales. Such roles are considered to be important in surveillance, early intervention and avoidance of admissions particularly linked to respiratory health and maintenance of independence. We also have a transition/palliative physiotherapist who works across AMBU and Cardiff and

Vale UHB who supports transition of neuromuscular patients from paediatric service to adult services and attends consultant clinics.

Provision of Psychology Services

There is currently no service provision for psychology for South East Wales. This has been highlighted in our Neurological Conditions Delivery Plan and a bid was put forward for funding, however this was not prioritised as an area to invest in. This will need to be taken forward via the Health Board's Integrated Medium Term Planning process and will be considered alongside our other priorities.

Medical Staff

There is a part time consultant providing a neuromuscular service in Cardiff. The consultant provides a neuromuscular outpatient clinic and also provides support for patients within the inpatient service.

Equipment

In 2014/15 we received significant one off investment to purchase equipment for neuromuscular patients. This was well received by patients and their families and significantly improved their quality of life.

I trust my response provides you with the information you require but should you need anything further, please do not hesitate to contact me.

Yours sincerely

Professor Adam Cairns

Chief Executive

