



Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

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Mr Jack Sargeant MS
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Welsh Parliament
Cardiff Bay
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Ein cyf / Our ref: JW/AM/DL/CE22-1039/31176

Eich cyf / Your ref:

☎: [REDACTED]

Gofynnwch am / Ask for: [REDACTED]

E-bost / Email: [REDACTED]

Dyddiad / Date: 16th June 2022

Dear Jack

Re: Petition P-06-1240 Improve health services for people with epilepsy living in Wales

Adult Epilepsy services

The adult Epilepsy service in North Wales is provided by the Walton Centre NHS Foundation Trust. There are two Consultant Neurologists working in North Wales with a specialist interest in Epilepsy. The Walton Centre also employs one highly experienced Epilepsy Nurse Specialist to support our North Wales patient population who are under the care of the Walton Centre Neurological service. The post holder covers the service extremely well.

We have access to MRI and also to EEG investigations through our Neurophysiology service within the Health Board, with more specialised investigations available through the Walton Centre.

We work closely with the Walton Centre team regarding the best models of care for our patients to deliver agreed pathways of care within the resources available to us, and these discussions are ongoing. The average waiting time for first appointment with a Consultant Neurologist is currently 26 weeks unless the patient is marked to be seen sooner.

Epilepsy service provision for children and young people

With respect to services for children and young people with Epilepsy living in North Wales, we have Consultant Paediatricians with an interest in childhood Epilepsy in each of our 3 areas (Centre, East and West) and they provide Epilepsy clinics in each of the areas. Each of the 3 areas has a specialist Children's Epilepsy Nurse who works seamlessly with our acute and community paediatricians with an interest in childhood Epilepsy, supporting families and the delivery of best quality clinical care. We have tertiary specialist children's Consultant Neurologists who deliver outreach clinics in all three of our hospitals in North Wales and these are joint clinics, held in partnership with our local consultants with an interest in children's Epilepsy, in a hub and spoke model, which is well established.



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Children's and young people's Epilepsy services are part of the EPIC (Epilepsy in Children) regional network, with Alder Hey Children's Hospital being our Tertiary hub and centre. In addition to the visiting children's neurology clinics, we have access to specialist services for children and young people with Epilepsy, including the NorCESS (The Northern Children's Epilepsy Surgery) service and Ketogenic Diet Service. We have access to MRIs and also to EEG investigations through our Neurophysiology services within the Health Board, with more specialised investigations, for example high resolution MRI (3T) and video-telemetry available through Alder Hey children's hospital.

The next available appointment with a Consultant Paediatric Neurologist at Alder Hey is 7 weeks.

Transition services

Joint transition clinics are held between our local paediatric consultants with an interest in Epilepsy and adult Neurologists in each area, however, over the last 2-3 years, due to staff changes and retirements in adult neurology, these have been variable in 2 of our 3 areas. We are working with our local adult tertiary centre to address this and are making progress towards these being re-established. In the meantime we continue to have good communication and pathways with our adult Consultant Neurologists and adult Specialist Epilepsy Nurse from the Walton Centre to ensure that young people entering adult services receive appropriate support and follow up.

Partnership working with the Third Sector

We have extremely strong partnership arrangements with the Third Sector and work very closely with both Epilepsy Wales and Epilepsy Action Cymru to meet the needs of people with Epilepsy living in our Health Board area.

- **Epilepsy Wales**

We have an agreed contract with Epilepsy Wales to deliver services to our patients with Epilepsy.

Epilepsy Wales help people with Epilepsy in North Wales to live as full, independent and active lives as is possible in the community. Helping them gain a better understanding and control of their condition limits the impact of the condition, with the aim of improving job opportunities, improving health and wellbeing, supporting people to stay in their own homes, maintaining independence and avoiding hospital admissions. Epilepsy Wales provide 1:1 support to people with Epilepsy who have complex needs supporting their families and carers. They also provide support to children with Epilepsy and their carers.

- **Support for Epilepsy Clinics**

Epilepsy Wales provide support and take referrals from Consultant led, GP and Specialist Nurse clinics in North Wales. Clinics are held at Ysbyty Gwynedd Bangor, Ysbyty Glan Clwyd, Colwyn Bay Community Hospital and Wrexham, and where necessary Epilepsy Wales visit people in their own home. They also attend Multidisciplinary meetings when required to support people with Epilepsy and liaise



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with various agencies to address needs identified within the clinic- this includes first aid advice and training for families, safety issues, benefits advice, emotional support and advocacy. They undertake home visits, visit schools and care homes visits, and maintain contact both online and over the phone. They offer training for families and carers with Midazolam care plans, and work alongside practitioners to deliver a person centred service, either in an individuals home or within Epilepsy Wales' own training facility for those unable to access online training.

- Stakeholder Involvement

Epilepsy Wales hold family events for our individual patients with Epilepsy and for the children and parents of children with Epilepsy. In addition, they hold regular “walk and talk” meetings in local parks and support group meetings in Wrexham, Conwy and Bangor, including evening events.

They also offer an online support service via a closed Facebook page. During lockdown they arranged both educational and social opportunities at a local level online. They shared activities that promoted wellbeing, capturing people’s lockdown experiences, volunteering activities, crafting, garden and environmental projects. They produced a permanent record book, “Lockdown Creations,” which highlights the achievements, volunteering endeavours and promotion of the mental and physical health and wellbeing of the support group members.

- Education and Training

BCU work in close partnership with Epilepsy Wales on education and training, and as an organisation Epilepsy Wales support education initiatives across BCUHB. Epilepsy Wales also support us to raise awareness of Epilepsy, its causes, treatment and ways to control the condition to the public and to Health and Social Care Organisations and Care Agencies, providing training and promoting cooperation and contact with, and between, Statutory agencies (Health and Social Care), voluntary and private sector groups. They offer free online training to adults supporting them with their well-being, and they also have a course that parents who have children with epilepsy can access too, which is free. They offer a free service called ‘Epilepsy Space’ which is aimed at young people aged 16-24. This was created by young people themselves to help manage their epilepsy.

- Befriending service

Epilepsy Wales have also started the process of setting up a befriending service for our patients.



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- **Epilepsy Action Cymru**

Epilepsy Action Cymru also support our patients with Epilepsy in North Wales:

- A new course has been established which is aimed at parents called 'Your Child and Epilepsy' which is free to access.
- A new tool kit for employers has been produced which includes specified information that employers need when they recruit or anyone who has a newly diagnosis of Epilepsy.
- They also offer 'Epilepsy Space' to our young people aged 16-24
- Local and general support groups are running virtually
- New Parents and Carers support groups are running weekly. These enable parents to share their experiences worries and concerns in a safe environment.
- A new bespoke Epilepsy awareness training for Schools and employers is being delivered virtually.
- Counselling service for people with Epilepsy - Epilepsy Action Cymru are looking to create a counselling service for anyone over 18. This could be adults caring for someone with Epilepsy, or a parent of someone affected by Epilepsy. This will provide emotional support for our patients at various stages of their condition. This could be at point of diagnosis, a change in condition, or coping with living with a long-term condition.

Yours sincerely

A handwritten signature in cursive script that reads 'Jo Whitehead', written in black ink on a light-colored background.

Jo Whitehead, PSM
Prif Weithredwr/Chief Executive