

Epilepsy Aware Event 3rd July 2018, Senedd, Cardiff Bay.

It was a beautiful day in Cardiff Bay and the organisers Epilepsy Wales were delighted at the large turnout gathered for our awareness event and to meet the sponsor Mark Isherwood AM and the assembly members who kindly gave up their lunch to attend.

Mark gave a thought provoking talk that included reference to the plight of both Billy Caldwell and Alfie Dingley's families as they attempted to get a Cannabis based medication unlicensed in the UK to treat their children who had life threatening epilepsy. We were delighted to hear that Billy has been given a life time exemption certificate allowing him to access his vital medication.

There were information stalls available during the day and we had presentations giving information and statistics that highlighted the impact of living with epilepsy. We had stories and experiences of those living with epilepsy and the opportunity to share issues with local assembly members.

A common theme emerged from our contributors on the day- Epilepsy Wales, Liva Nova, Glut1D, Matthews Friends and the families and individuals with epilepsy who attended.

All individuals with epilepsy need access to healthcare professionals who can diagnose and treat their condition appropriately.

Unfortunately in Wales there are groups within the epilepsy population who are disadvantaged.

Those with rare and complex epilepsies experience difficulties in gaining access to appropriate investigations, treatment, health and social care support.

An example of this was given in the presentation of My Glut1 child. The Ketogenic diet is the only treatment for this condition but there are no specialised dieticians in Wales to support this treatment.

There are individuals whose epilepsies are not controlled by standard medications.

A patient story of a young man who found that having a Vagal Nerve Stimulator transformed his life after years of uncontrolled seizures.

Contributions from people attending the event.

We had statements from families expressing the difficulties they had in accessing support and appointments in a timely manner from their epilepsy teams and the impact this had on their wellbeing.

We had families who had difficulties securing education and social care support for their children with complex needs.

We also heard how having access to genetic testing had supported diagnosis and enabled individuals with rare genetic disorders to access the most appropriate treatment. This is an exciting area for research and development.

Many also commented on the support they had received from the contributing charities and organisations present "they were a lifeline in times of crisis", "their information and support were invaluable" but also "we need you to do more", "there needs to be more awareness and more resources for epilepsy".