My name is , I live in a regional town in northern NSW in Australia, I'm a mother and carer of a young person who is living with Epilepsy and have been for 21 years with 2 children who have epilepsy and I want to tell our story.

I want to focus on my youngest and introduce my daughter she is now 15 years old and all her life she has been dealing with Epilepsy.

has formally been diagnosed in with an ultra rear *CSNK2B*-related neurodevelopmental disorder (*CSNK2B*-NDD) only in March 2025, it's reported in more than 80 individuals to date, and is characterized in most individuals by developmental delay (DD) / intellectual disability (ID) and seizures.

Most young children have delays in speech and motor development. The majority of individuals older than age five years at the time of evaluation have ID ranging from borderline/mild to severe/profound. Seizures, present in most individuals, range in type and severity. While many individuals have pharmaco-responsive epilepsy, others have severe epilepsy with recurrent episodes of refractory status epilepticus.

And in case she hits the Jack Pot with a wide number of medical and disabilities diagnoses

CSNK2B – related Neurodevelopment Syndrome (Poirier-Bienvenu Syndrome) genetic, Developmental and Epileptic Encephalopathy – Drug resistant / uncontrolled, Functional Neurological Disorder with functional Seizures, Psychosocial Disability – Anxiety and depression as well, Autism Spectrum Disorder (ASD) level 2- 3, Intellectual disability, Abdominal migraines, PDA pathological demand avoidance, ARFID (eating disorder -weight loss and constipation, Incontinence and that just the start but today were her to focus on her Epilepsy.

For 20 years with 2 children, I have bounce between states seeking support, diagnoses and access to appropriate treatment options, honestly in looking for answers as to why has epilepsy and to seek better supports in caring for her. I moved our family from the Northern Territory as there was simply nothing in the area to help her with the on-going care and services she needed, support systems and education programs were closed down and Paediatric services for consistency were appalling, I think we seen every Nuro in Australia back then and when we thought we had found someone in the NT they the left too.

So we moved closer to the QLD Hospital thinking it would be in the best interest of care, again seeking clinical trails and research programs linking in to Melbourne and overseas services, modified diets and so many different medications, pushing and advocating to be heard and really fighting to be linking in with services and on-going support and basic access to finding an appropriate treatment plan to keep her alive.

But it’s funny you think you live in Australia and are and Australian citizen you can get help anywhere right, sadly nope locked in with boarder control and restrictions it crazy.

The daily barriers your faced are unbelievable, we live in Australia you honestly wouldn’t think that a young person would be told your declined services because of where you live right, well sadly that dose happen all to often.

Specialist in Mel and Brisbane and local providers in Northern NSW, emergency departments to afraid to cross the medical borders to make a simple call when your child in in epileptic status, fighting with them just to call the on call Nuro who has your child’s records, fly in fly out doctors wanting to change medications without consultation with the Nuro you have been involved with for year this is what happens. Family’s give up of medical systems who won’t listen or put appropriate procedures in place is sadly our normal.

Lengthy waiting times and even access to specialist care, 18 months and constant nagging from calling and asking for appointments becomes your life, recording seizures and documenting and reporting and never really being a parent, you actually learn really fast and get educated with complex care, medication management, airway management and I could continue on with the list. Because at the end of the day your child’s life is dependent on you.

Education systems refusing to acknowledge to complex situation you’re living in or potential supports your child would benefit from.

Government agency’s and transitional to adulthood is a joke as well, as a parent were locked out of medical records at 14, at 16 they are and adult right can make decision on their own and honestly decline medical treatment if they want, correct? God help when is 16. Applying for NCATS is overwhelming. I'm terrified the day a doctor actually refuses treatment because she is verbally abusive, postictal and high as a kite on Midaz after being epileptic status because that's already happening, living in hospitals has bought trauma to her and then to think 18 but hay on the other hand parental responsibility till she's 21 with other areas.

I can't work full time because the reality is I'm on call 24 hrs a day, sometimes I even do 72 hrs straight when is backing up back-to-back seizures, so when we talk about cost of supporting some one with epilepsy it's, expensive. Were lucky some meds are on pbs but the reality is, without supporting in financial areas life would always be at risk. We can't not by her medications she's on 19 pills a day at the moment and I lose count how much Midaz is used. She's had over 30 ambulance calls in the last 12 months and yep only the last min calls, self-transported to ed's and lost count how many admissions to hospitals and extensive testings done on her. We are a tax payers night mare and the reality is someone living with epilepsy is a finical burden.

has a drug-resistant epilepsy and its finally taken a psychosocial toll on her at such a young age. In 2024 had increasing concerns with anxiety and depression so much so she was also diagnosed with functional neurological disorder with functional seizures. With the help of my own reporting and recording she was given a label and put out the door. No help no support nothing, I learnt really fast what a 6 hr seizure looked like and Still to this day I'm trying my hardest to educate and support on my own. But honestly how do you help a young person overcome her fears of dying from epilepsy. Systems were made to help people like but when you become to complex and too hard it feels like everyone gives up and your again fighting broken systems.

Epilepsy imposes a significant economic impact on patients, their family and the community. The stigma that's still around, Epilepsy is not even seen as a disability still to this day, it's a medical condition. No one wants to accept the reality of how disabling epilepsy truly can be and how it affects a person functional ability every day.

Being bounced between broken systems failing families like ours, being stripped of basic human right, placing people at risk, declined from services of supports, funding cuts to packages and rising cost of services are being met with failures and the needs of people living with Epilepsy not being met. Families are broken and have nowhere else to turn, Parents are tired of having to do battle on a daily basis along with caring for their loved one as well as a feeling of going around in circles time after time again. We live in Australia and systems are broken and no one knows how to navigate the broken systems anymore.

Complaints and cries for help fall on deaf ears, families are falling apart and broken by systems that are meant to support them. Segregation and isolation are real, not only for the person with epilepsy but the whole family, and judgment from out siders or the labels that get attached to carers who advocate are unbelievable sometimes as you seek clinical, medical, mainstream services just to keep them alive, the wider community really have their eyes closed when it comes to epilepsy. It’s not till someone you know is living with epilepsy that your truly understand how it affects not only them but informal supports as well.

As for the NDIS what a joke that in its self needs a whole over hall. Epilepsy is not a disability need I say more… Under section 24 of the NDIS Act good luck ever proving the complex diagnoses especially when you have multiple reports with detailed and well documented evidence by Australian’s best of the best in the Ped’s Nuro world it means nothing to the NDIS, until people in a position to make change actually help make the changes needed.

NDIS is currently failing my daughter even with epilepsy as an accepted disability diagnoses on her file.

under Section 34 of the NDIS Act, Part 1,2,3,5 of the NDIS (Supports for Participants) Rules, and the NDIS (Plan Management) Rules. Rule 5.1(b): Support is not related to the participant’s disability. Rule 5.1(c): Support duplicates other supports.

I have to prove value for money for supports and equipment, or that its effective and beneficial oh and I love this one what is reasonable to expect families, carers, informal networks and the community to provide.

My child uncontrolled Epilepsy has a price tag that has little cost to her true value of what is truly needed to support her whole functional needs and the risk NDIS places her at with 1:2 and 1:3 supports is not reasonable.

And I ask the question at what point is it parental reasonable reviewed and acknowledged that I'm actually going well and above reasonable parental responsibility to provided life saving supports to daily needs.

It's ok for me to do 72 hrs straight, live on 3 hrs sleep a day, manage complex airway management, medication management, seizure management, till further help arrives, and do it on my own as its parental responsibility, right?

You don't send first responders in to an emergency on their own so why is the NDIS failing families like ours to keep doing it on our own.

No parent asks for a child with epilepsy or a disability let alone to keep doing it on their own.

They say one in fifty people are affected by Epilepsy at some point in their life, but yet it still feels like the least talked about, funded, supported and acknowledged medical condition that should be reviewed as a disability with in Australia.

People living with Epilepsy and their informal supports are in crises, and those in a position of power to make change keep sweeping it under the carpet. Not a you issue till it is a you issue right. We need to be heard.

Sincerely