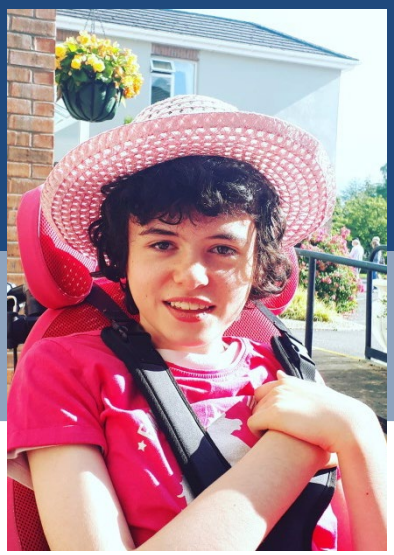

PROFILE

Caoimhe

LIVING WITH severe intellectual disability, dysphagia, incontinence, epilepsy, osteopenia and sensory issues

One word used a lot was RARE! At that time there was no Facebook or any support groups. How I wish there was….

"Caoimhe is a very happy and smiley girl and melts the hearts of everyone she meets. She is certainly rare!!"

Caoimhe was born a healthy 6lbs 15 ozs. Everything was just perfect. She came home after 3 days and we loved having our new baby in our lives. At 5 and half weeks she started smiling. She passed her three month developmental check with flying colours! We knew what primary school she would be going to and were looking forward to all the normal milestones and special events in her life.

At 5 months I began to worry that she wasn't holding her head up the way she should. She also started to do little "scrunches" in my arms. I brought her to a few different medical professionals who all believed it to be colic. Her public health nurse at the time reassured me "all kids do things in their own time". I also brought her to a baby chiropractor due to her throwing back her head and the "colic". He said she had a bone out of place in her neck and he fixed it.

As Caoimhe turned 7 months she developed a chest infection. Our GP sent her to our local A&E where she did one of these 'scrunches". A student doctor quickly realised this was not colic. She was admitted and we were told the next day these scrunches were a very rare form of epilepsy called infantile spasms, often misdiagnosed as colic. Infantile spasms really need a lot more awareness.
We were transferred to Temple St Children's Hospital where we spent the next 3 months. Caoimhe's seizures went from 1 to 2 a day to over 100 per day. On her worst day she had 352 seizures despite numerous medications including steroids. We were then told her future wasn't looking bright. Caoimhe's medical team carried out numerous tests looking for a cause, a syndrome, a gene mutation but everything was clear. Caoimhe underwent 3 lumbar punctures, MRIs, metabolic and genetic testing. All testing was clear.

During Caoimhe's 3 month stay she developed aspiration pneumonia (due to poor swallow) and was admitted to the Paediatric ICU. Our new world now consisted of paediatricians, neurologists, dieticians, occupational, physical and speech and language therapists. Our vocabulary was broadened too with words like hypsarrhythmia, aspiration, nasal gastric tube, video fluoroscopy, Epilim, Keppra, ACTH, Topomax, EEG waves, polyspikes, the list goes on.....

One word used a lot was RARE! At that time there was no Facebook or any support groups. How I wish there was....

After three months Caoimhe was discharged to our local hospital. We were told it would be best if staff got to know Caoimhe as she would be spending a lot of time there. We had a meeting with Caoimhe's doctors who said she was always going to need 24 hour care and our aim now was to keep her comfortable.

We finally got her home but her infantile spasms were not any better, still averaging 80 a day. We decided to look into other options and on the 10th March 2008 we flew out to Children's Memorial Hospital, Chicago. We had planned to stay 6 weeks. We were there for 9 and half months! We met a wonderful epileptologist. It is here Caoimhe had her first telemetry video EEG (48 hours). Caoimhe also attended physio, speech and occupational therapy every week. A MEG scan was carried out to see if Caoimhe was a suitable candidate for brain surgery but unfortunately it showed her seizures were originating in all parts of her brain so this was ruled out. Caoimhe also developed Tonic, myoclonic and atonic seizures. Her cognitive and physical development was put at 4 months of age despite Caoimhe being almost 2. Caoimhe was started on the ketogenic diet which reduced her infantile spasms to 6 or 7 a day but she was still getting other seizure types daily.

We came home for a few months and went back to Chicago in April 2009. Different medications were added and taken away. Caoimhe got very sick with aspiration pneumonia again. She spent 5 days in PICU and a further 6 in the respiratory ward. It was after this we decided to come back home.

4 weeks after Caoimhe turned 3 her seizures stopped completely. However she was still unable to sit, had limited use of her hands and was non-verbal. Due to aspiration and low weight Caoimhe had a gastronomy tube inserted. During the next 3 years we saw no physical signs of any seizures however Caoimhe's EEG was still very abnormal.

Caoimhe started to walk a little at age 6, although she was quite unsteady. At 8 years of age her cognitive age was put at 12 months of age.
In July 2018 Caoimhe was diagnosed with brittle bones in her knees. Caoimhe got an appointment for a full bone assessment in Temple St. hospital for the 7th January this year. Unfortunately due to COVID-19 this was cancelled.

Caoimhe is now 14. She has very mild seizures daily upon waking. She also takes some tonic-clonic seizures but thankfully they are very short duration. Her EEG is still quite abnormal with constant seizure activity showing. Her neurologist is currently doing more genetic and metabolic testing in the hope of finding a diagnosis for Caoimhe. He is confident with the new research that is being carried out every day we will receive a diagnosis for Caoimhe.

Caoimhe needs 24 hour care and is totally dependent on her Dad Matt and me to look after all her daily needs. Caoimhe has a severe intellectual disability, dysphagia, incontinence, epilepsy, osteopenia and sensory issues. She is on 3 medications in the morning and 5 medications at night which have recently been increased in the hope of gaining back seizure control. She also requires a feed over-night through her PEG. She is non-verbal and has no understanding of receptive language but recognises faces and is very determined to do as she wishes!!

As Caoimhe can take a seizure at any moment she requires constant supervision. Due to Caoimhe's complex needs she cannot be left with a regular childminder. She requires nursing care. Lockdown has been extremely difficult on us all but especially on Caoimhe. She has no understanding of COVID or why she is at home. She gets very frustrated in the mornings she is not in school.

We are blessed to get respite and this makes a huge difference to us as a family. Caoimhe also loves it! Caoimhe has a younger brother Evan who is 10 and a younger sister Saoirse who is 9.

Caoimhe has mastered many milestones despite her poor prognosis as a baby. She is now eating pureed food orally, can walk around the house, understands some gestures and is generally very healthy.

Caoimhe is a very happy and smiley girl and melts the hearts of everyone she meets. She is certainly rare!!