Brave battle Jessica continues to live life to the full

Compiling data The youngster is pictured wearing her overnight electroencephalogram (EEG) used to monitor her brain activity

Jessica

43, and big sister Jennifer, 15, and mum Claire shared how difficult it was when doctors first told them about Jessica's diagnosis.

She told the Advertiser: "Six months before Jessica was diagnosed we knew something wasn't right. We got to the summer and then she was first diagnosed with epilepsy and then Ring Chromosome 20.

"There was lots of grief at first and it became clear this was going to be a very hard condition to control.

"The next few months were extremely challenging; the reality of frequent and aggressive seizures, anti-epileptic drug (AED) side effects and an abnormal sleeping pattern all contributed to the rapid decline in Jessica's behaviour.

"Then we attended a conference in Liverpool, where families of people with the condition came from all over the world, as well as a few neurologists.

"After speaking with everyone it became clear that we weren't alone.

"We've had two years now and you learn to cope and find the best way of dealing with things. It is a progressive illness and you just don't know how it's going to develop which, as a parent, is one of the hardest things to cope with; Ring Chromosome 20 isn't the same for every child affected."

Despite the daily challenges she faces, courageous Jessica refuses to let her condition stop her from living life to the full, with the keen footballer recently signing up for a fifth season with Gartcairn Football Academy in Airdrie.

Claire added: "Jessica is a wee trouper. She does remarkably well with the challenge of Ring Chromosome 20. She still goes to school most days, but time will tell how things go when it comes time for her to move to high school.

"She loves playing football and the neurologists have said that her diet and exercising combined can only help control her seizures."

Selfless Jessica and her family are looking to lead the fight to uncover greater knowledge about Ring Chromosome 20 Syndrome and treating the disease by organising a series of fundraising events over the next 12 months in aid of charity Ring20 Research and Support UK.

Claire explained: "Neurologists told us about the charity and we were fortunate as a lot of families can go years without learning much about Ring Chromosome 20.

"The charity has formed a stable platform and receives the support of medical professionals from across Europe and the United States, but it needs financial support to further research in the hope the condition can be medically controlled. To help make a difference, we decided to plan out a year's worth of fundraising events, with the help of our family and friends.

"We came up with the idea of family, kids and adults-themed events and they will kick off on October 28 with a kids' Hallowe'en disco. We're also thinking about doing a Santa Dash. We've already received a donation from the kind folks at the Round Table.

"I have set up a BT MyDonate page. We're looking to finish the calendar of events with a gala ball."

Giving backing to drive

Councillor Michael Coyle has given his backing to the Sullivan family's fundraising campaign – and called on the NHS to devote more resources into researching Ring Chromosome 20 Syndrome.

The Airdrie South representative told the Advertiser: "I am amazed by the bravery and dedication shown by Jessica and her family in raising funds and awareness of her condition.

"The daily battle Jessica and her family have to go through is extremely difficult, but they have shown remarkable courage and determination to help other families in the same scenario.

"Not a lot is known about the disease and the Sullivan family's fundraising campaign will help to raise awareness.

"It would also be of huge benefit to the families affected by Ring Chromosome 20 Syndrome if the NHS leads the way in terms of doing all it can to further research the condition."

Check out the packed diary of fundraisers by her family

Jessica and her family and friends have a packed calendar of fun-filled fundraisers planned as they target a healthy final total for the Ring20 Research and Support UK charity.

A spooky spectacular gets things underway later this month with a kids' Hallowe'en disco.

Next month it's on to festive-themed activities during a Santa's Sleigh event, before creative types across Monklands are invited to get involved in a Christmas card donation initiative in December.

Jessica's birthday on January 19 will act as a double party-fundraising celebration and there may be a few struggling to keep their feet in a pub crawl later that month.

A bag-packing day is planned for February and all bets with be off as the Sullivan family get in the saddle to host a race night in March.

April will see a prize raffle being run and then it's an event aimed at those with a head for heights as a group climb of the 4411-foot tall Ben Nevis takes place in May.

A "Gung Ho" family fun day is pencilled in for June and the next couple of months will be spent preparing for a planned gala ball spectacular in September to bring the curtain down on the year's worth of fundraising.

Donations to the Sullivan family's campaign can be made at https://mydonate.bt.com/fundraisers/clairesullivan1?View+your+page=View+your+page, and for further details on the calendar of events, including announced dates, visit www.facebook.com/jessicasring20journey/?modal=media_composer

To find out more about the support Ring20 Research and Support UK has to offer, visit https://ring20researchsupport.co.uk/

Factfile

Ring Chromosome 20 Syndrome

- The disease causes epilepsy in children and is due to an abnormality in chromosome number 20.
- There are only 100 known cases that have been reported globally in medical literature.
- In R20, a little piece of genetic material is missing from each end of one of the number 20 chromosomes, and the ends fuse or join together to form a ring.
- This happens very early in pregnancy and sporadically by chance, so, therefore, doesn't usually affect more than one child in the family.
- The long-term outlook for people with R20 is variable and depends on the person, the severity of the epilepsy and associated learning and behavioural problems.