



HOW TO BE A SUPERHERO

Be a Hero is LauraLynn's fun campaign for Children's Hospice Week. Ciara Leahy visits the Duffy family in Co Monaghan, where she meets a superhero mum

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It's Liam Duffy's communion this Sunday. And like many eight year olds, Liam is hoping to celebrate the day with his mum, dad and family.

This may seem like a simple request, but the reality is that for the Duffy family organising a day out can be a near-impossible task.

That's because Liam's older sister, Lucia, suffers from a rare genetic condition called Aicardi-Goutières Syndrome. Needing 24-hour care, Lucia must have someone with her all the time. As her condition worsens, it is impossible for her to leave her home as she is at risk of picking up even a common cold, which for her could be life-threatening.

BE A SUPERHERO

However, this weekend, Liam's wish will be granted and mum Sonya and dad Padraig will both be sitting in the church for their son's celebration.

"The reality is if it wasn't for LauraLynn@HOME, either myself or Padraig would miss the Communion. But this Sunday, our LauraLynn nurse Terry will be with Lucia and we can be there for Liam and our other children Matthew (10), Oliver (seven) and Violet (three)," Sonya says.

You really want the Duffy's to have a great day out because life has certainly been tough.

"I'd love to have the spontaneity of being able to bring my kids down to the shop for an ice-cream or even go to the park on a sunny

day, but everything has to be planned, weeks in advance."

Certainly the toughest element is caring for Lucia. Diagnosed at the age of one, Aicardi-Goutières affects every part of the brain, but Sonya says they knew from early on something wasn't right.

"Lucia lost control of her swallow at six-weeks-old, so we had to mix her bottle with baby rice to thicken it, but she couldn't keep it down, it was a constant battle."

When Lucia's cousin, Mirrin, was born a few months later, she had similar problems.

"All our bloodwork was sent to Leeds University and both Lucia and Mirrin were diagnosed with the same condition. It's genetic and there was a one in four chance that other children would be affected. I was pregnant with Matthew at that stage, so you can imagine the worry."

Thankfully, Matthew was born fine and healthy. And these three children were part of revolutionising the diagnosis of Aicardi-Goutières across the world.

"My sister is married to Padraig's brother. Because of this connection, the girls condition and Matthew being healthy, the doctors were able to pinpoint the gene affected by Aicardi-Goutières. As a result, they were able to develop prenatal tests which are now used across the world. They were run on all the rest of our children and, thankfully, they are all healthy," says Sonya.

While there have been devel-

opments in regards to diagnosing the condition, there has unfortunately been no progression on treating the condition.

"Mirrin died at the age of two. We were told Lucia wouldn't live much longer, but then she turned three and then four, five. When she got to seven we stopped listening to the doctors."

Now 12, Sonya says her condition is really starting to deteriorate, especially since Christmas.

"It's been like having a newborn baby for 12 years. She aspirates, which means she inhales vomit or fluid and then she has to be suctioned. This could happen at any time, so we always have an ear out and a camera on her at night. There are too many nights to count that we went without sleep. Her condition has definitely worsened and now she needs a nebuliser and chest physio."

Getting away for a few days is just not an option anymore for Sonya or Padraig.

"We've only left her a few times, once was to visit my mom in England for the weekend, but when we got off the plane we had a call from the nurse to say she was in an ambulance on the way to hospital. Lucia ended up on life-support that time, she has been on life-support a total of three times now, so leaving her is just not an option."

GETTING CARE

When Lucia was on life-support earlier this year, the hospital was

astonished that the family were doing it all on their own. It was only then that the health board signed off on night nurses.

"So many mornings, I woke up not knowing how I would find Lucia in the bed. At least now with the nurses, there is a little more peace of mind. However, it does take a long time for nurses to really know her, to suction her and care for her specific needs."

Terry, the **Lauralynn@HOME** nurse has been working with Lucia since last year and Sonya says she is one of the few people who she can leave her with.

"Terry comes once a week for one morning and she is really great with Lucia. She gives her a shower, a hand and foot massage and does music and light therapy with her. She has even created a canvas with a tree and the leaves all have fingerprints of the family. We have Lucia's footprint on it as her hands are quite tight, but it will be nice to get it framed."

While Terry is with Lucia, Sonya gets a few hours to get out of the house.

"It's not like it's me time. It's chores time. I do the shopping, pay the bills and go to the post

office. I also bring the rest of the kids to school. One day during Easter we were able to get a few hours to bring the rest of the kids to the beach. It's important that they get time to be kids as well."

So what does the future hold for the Duffy family?

"Lucia is sick, she is really sick and getting worse. I'm worried about her all the time. I never want to turn off a life-support machine on my child. I hope that it is peaceful. As for me, I sometimes feel like it is too much. I'm just exhausted."

About **Lauralynn**

Children's Hospice Week takes place on 11-15 May and focuses on the incredible little heroes, the seriously ill children, and their families cared for by **Lauralynn**, Ireland's only **children's hospice**.

There are 3,840 children living with a life-limiting condition in Ireland, and each year about 320 of these children die. **Lauralynn** provides **paediatric palliative care** and cares for **children** with life-limiting conditions by providing high-quality **transitional** care, home support, respite, crisis and end-of-life care.

Lauralynn's approach is holistic, ensuring that the whole family is supported, allowing parents to be mums and dads rather than full-time carers. With no direct Government funding, they need to raise in excess of €3m every year. It is fundraising events such as **Children's Hospice** Week that enable **Lauralynn** to keep the doors of the **hospice** open.

For more information on how you can be a hero for **Children's Hospice** Week, log on to www.lauralynn.ie or text 50300 SUPERHERO to donate €4.



The Duffy kids: Matthew, Oliver, Liam, Lucia and Violet.