

A lifeline for the Ferguson family.

The Ferguson family, live together in their specially adapted home in Shoreham-by-sea. Their home has been adapted for the youngest member of the family, Emma, who has an undiagnosed neurological condition which she has had since shortly after she was born. Emma needs round the clock care. Mum Jan, tells the family's story.

"Soon after Emma was born, I knew things weren't quite right. She lacked interaction or acknowledgment with me. I was told not to compare her to her sister, Lucy, as at such a young age all babies develop at different rates, but I knew something wasn't quite right.

"Every type of test Emma underwent couldn't prove anything. Emma's condition has no diagnosis! She regularly suffers from seizures. For a period of time, she would have around 60 seizures a day. She has lost skills she once had and goes through different stages of development, regressing frequently. Emma cannot weight bear, cannot

communicate and is dependent on someone to look after and watch her 24 hours a day.

"Around four years ago, Chestnut Tree House children's hospice and Leo House at Home came into our lives and have been what I can only describe as a lifeline. Their support helps relieve the chronic feelings of sorrow for the whole family. The Care Team are there at any time of the day to offer us support and help us deal with the different paths of Emma's condition. At home, we are cared for by Laura, one of the Community Nurses funded by Leo House at Home.

Laura has helped make it easier for me to care for Emma at home and provides respite for me to do the little things that we all take for granted but that are so difficult for me to do when I'm looking after Emma.

"I always feel comfortable leaving Emma with the nurses because they have such specialist skills and know her and her condition really well. They can deal with anything that might happen and know



Emma with Mum, Jan, and Sister, Lucy.

exactly what to do if things take a turn for the worse.

"Chestnut Tree House and Leo House at Home have helped my family and I enormously. The knowledge that they are there for us is more than reassuring."

George says farewell

George Bowles has been a wonderful supporter for Leo House since its inception. He and his loyal congregation from St. Richard's Church in Hollingdean, Brighton have so far raised over £8,500 to support the nurses.

Now nearly 86, George has finally called it a day and handed over the reins to Hazel, the group's treasurer. George and his wife Mary first got involved with Leo House when the Church was looking for a local charity to support. Over the years they have organised successful concerts and sales in aid of the families needing the Leo Nurses.



Sadly, St. Richard's church was closed in 2011, but the small group continues to fill collecting boxes and raise money. We are very grateful to George and the congregation from St. Richard's and we look forward to continuing the relationship in the future.

Looking ahead

Don't forget to let us know of any forthcoming fundraising events in aid of Leo House at Home.

Contact us

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Emma in 40th birthday blitz

Emma Godden decided to celebrate her birthday with some tough challenges. A week before her birthday she climbed Ben Nevis and then it was the triathlon! Although a regular runner she had never tried anything beyond a simple running event.

The Seaford triathlon was aimed at 'first timers' and it was the first time Emma had tried swimming, cycling and running all in one day. She launched herself into the sea (wearing a wetsuit) and the 200m swim was easier than she anticipated. Pulling herself up the beach,

it was off with the wetsuit and on with her trainers and shorts for the 10 kilometre bike ride. This time she was confident and found herself overtaking people, only to realise she had started too quickly and her legs became like jelly. The last section was her favourite, a run for 2.5 kilometres. Things went well and Emma surprised herself by coming 6th, a great result from a field of 42 women.

Emma raised money for Leo House at Home through the website, JustGiving; our grateful thanks and congratulations on your birthday!



Who are we?

Leo House was established by Brighton Lions Club to help life-limited children, young people and their families living in East and mid Sussex as well as in Brighton & Hove. Leo House supports children and young people with a life-limiting condition from birth to 25 years of age and their families. We know we cannot cure them but we can help to give them the best quality of life for as long as that might be.

What's new for Leo House at Home?

- Generous golfers at East Brighton Golf Club raised over £1,000 for Leo House at Home as part of a charity golf day.
- Leo Nurse, Laura, is back from maternity leave and looking after a full caseload of families.
- We still have 2 places in the 2014 Brighton Marathon, let us know if you want to run for us.
- If you would like to join our monthly lottery, download a form from www.leohouse.org.uk or leave a message on 01273 556834.

Dancers step out for Leo House at Home



Students from the Redhurst School of Dancing raised money for Leo House at Home at an event in July. The school is based in East Grinstead and has been

a supporter of Leo House for many years. The students are able to learn many types of dance including ballet, tap and Greek. Thank you to all involved.

Thank you!

Thank you to everyone for your generous donations to Leo House including:

J Bygrave
East Brighton Golf Club
Newhaven Marching Band
Steven George Danahar
Memorial Golf Day
Michael Davids
Rottingdean Lions
G Eves
Hassocks Townwomen's Guild
R White
G Carver
P Howard

Don't forget, Leo House at Home spends almost all this money to fund our nurses, less than 2p in the £ goes to pay expenses.