

Aimee's story

Fifteen years ago, Marie and Martin welcomed their beautiful new baby girl, Aimee, to their family. After an easy pregnancy and normal birth, they were over the moon to bring their perfect, healthy little girl back to their family home in Eastbourne.

Their world was turned upside down, however, when Aimee had a seizure at just four months old. By nine months old Aimee was diagnosed with Dravet Syndrome, a rare form of epilepsy that affects every area of her life.

A happy little girl, Aimee "lives in her own little bubble" according to mum Marie. "She is so cuddly, loves school and playing with her car and train toys." But her condition means that Aimee suffers seizures on a weekly basis, often having six to eight fits in the space of a few hours. Aimee is mobile, but unsteady on her feet, she can communicate but is unable to speak and has a severe learning disability. She is also tube-fed and has a strict medicine routine to control her condition.

For the first four years Aimee would have a seizure every seven to ten days. It would last up to an hour and result in her being hospitalised for four to five days at a time, putting a massive strain on family life.

Looking for some respite from the demands of caring for a child with such an unpredictable condition, the family were referred to Leo House at Home. They started receiving regular visits from one of the Community Nurses, who takes care of all of Aimee's needs whilst the rest of the family enjoy activities that are usually out of bounds for them.

Marie explains, "I would never usually go to the cinema because I would be

terrified to turn my phone off for two hours and focus on anything other than Aimee. But with Kirstie, our Community Nurse, I can do just that. She knows Aimee and us so well, I know she will look after her with the same care and attention that I would."

Due to Aimee's complex medical needs, the family were shielding at home for months when the COVID-19 pandemic struck. "It was really hard for us. We have been working from home, trying to take care of Aimee and her medical needs, it has been really intense. But we have had regular contact from Leo House at Home and they really have been a lifeline for us. We know that there is always someone at the end of the phone if we need them."

When the family came out of shielding, they began having visits from their Community Nurse, Kirstie, again, "recently, Kirstie has been taking Aimee out and about for the day when she visits. This is because my husband and I have been working from home, so it gives us a little bit of time to get our heads down and work."

"It really is fantastic knowing that we have the support of Leo House. We have been given the opportunity to build a really strong relationship with our Community Nurse, something that doesn't often happen with other care providers."



Contact us

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If you'd like to make a donation directly into our bank:
Sort code: 40-14-01
Account no: 51335979
Name: Leo House

Registered charity no. 1091541. A company limited by guarantee, number 3803928.

David braves the elements for Leo House

David Harris took part in the Beachy Head Marathon on 25 October in really tough conditions. The winds of 25mph were gusting to 40mph and the elevated route made it all the more challenging. He finished the course in just over 5 hours, despite feeling unwell with 6 miles to go.

We are very grateful to David and all his sponsors, including Barwells Solicitors, who together raised a good sum for Leo House at Home. Our pictures show David part way through and celebrating at home afterwards. As he put it "a fabulous day all round despite the battle at the end".



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.



The 'Sussex Peasant' mobile farm shop will be visiting the Pepper Pot at Queens Park and collecting for Leo House.

St Christopher's spooks raise funds

A fun Halloween dress-up day at Howe House, part of St Christopher's School in Hove, saw plenty of witches and ghouls do their scary things!

Many thanks to them and their families and teachers for their support.



Thank you!

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

- Hassocks Townswomen
- Mr J Schofield
- Miss A H Allard
- Steven George Danahar Memorial
- Ms P Easton
- Farrington Property Developments Ltd
- Mr M Twine
- Miss J F Norris
- Sussex Masonic Charities
- Adur East Lions Club

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

Mayor's Charity Events

As announced in our last newsletter, Leo House at Home is delighted to have been chosen as one of the Mayor of Brighton and Hove's Charities for 2020/2022 (yes two years!) Representatives of the charities have met several times, mostly online via 'Zoom', and are planning a series of fundraising events.

