

Caleb's Story

Ten year-old Caleb has always been a little bit in his own world, according to his mum, Michelle. Like many young boys, he likes to listen to music, sing and go swimming, but he is not able to do these things independently like other children his age. Caleb has lost his sight, requires the use of a wheelchair and remains under the care and review of multiple medical disciplines, professionals and hospitals, and will need lifelong medication.

At four months old, Caleb was diagnosed with Osteopetrosis – a rare disorder whereby bones harden – which caused him to lose his sight completely and to develop Hydrocephalus, causing significant brain damage. Just five months later he underwent a bone marrow transplant, his older sister being a donor match.

The transplant was eventually successful, but Caleb was left with profound and multiple learning difficulties,

severe development delay, physical limitations, a gastrostomy and blindness. Aged four, he was also diagnosed with Autism and minor problems with his ears and digestion.

The family started receiving support from the Leo House community care team when they moved to Brighton a few years ago, and they quickly found that it made a massive difference to their lives.

When Caleb receives visits at home from a nurse, it allows his parents, Michelle and Matt, to spend some quality time with his older sister, Scarlett, and together as a couple. Mostly, this is something simple like going out for a meal, walking the dog, or going to the cinema or beach, but these are all things that are difficult or impossible when Caleb is with them.

"I honestly don't know what we'd do without our community nurse," says Michelle. "The support we receive enables us to take a breather, and relax in the knowledge that Caleb is safe and well cared for."

Michelle sums it up by saying, "The



support we receive makes such a huge difference to our lives – it makes us feel less alone and more able to cope with whatever life throws at us."

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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• www.leohouse.org.uk
• email info@leohouse.org.uk

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Sussex Hospices Trail Challenge

Regular readers of the Leo Newsletter will have heard about the Hospices Trail which was established to celebrate 21 years of Friends of Sussex Hospices.

There will be a special event on Saturday 23 September to highlight the work of the hospices. It will be a relay walk of the whole route, with 26 simultaneous starting points, each section being walked by three teams of eight people. If you or someone you know would be interested in taking part, sponsoring or acting as a marshal, please email info@leohouse.org.uk or leave a message on 01273 556834.





Make your bid on these

We are holding a silent auction for these two generous gifts, all in aid of Leo House. The first item is a hand-made patchwork quilt kindly sewn by Miss Easton of Hove. It would make a perfect present for a new baby or as a Christening gift.

The second item is a framed, signed

Philip Dunn print from his well known Brighton series.

If you would like to make a bid, please email info@leohouse.org.uk or leave a message with your telephone number on 01273 556834, stating which item and the amount of your bid.

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.

Masons do it two ways

We were very grateful to receive two donations from the Masons. The Sussex Masonic Charities, via John Hornblow, gave Leo House at Home a cheque for £1,500 (see picture below with John and his wife Deborah with three of the Leo Trustees).

The Masons have launched the 'Masonic Charitable Foundation' as a focus for their centralised charitable giving. In future, hospices will be one of the community causes which will benefit from this fund. They kindly donated £500 following an application from Leo House at Home.



Thank you!

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

Brighton Railway Club
 Hassocks Townswomen's Guild
 Mrs M Knowles
 Woodingdean Methodist Ladies
 Brighton Lions
 Rottingdean Smugglers Night
 Mrs B Cheesman
 Evelyn Glennie Bingo Players
 Mrs J D Tuppen
 Mr & Mrs J Miller

More questions than answers!

Over £820 was raised by participants in four pub quizzes during March. All in the context of the Friends of Sussex Hospices 'Mad March Pub Quiz' season, there were quizzes at Horns Lodge Chailey, Brighton Marina Yacht Club, Ovingdean Village Hall and East Brighton Golf Club. Pictures show some of the quizzers in deep thought.



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.