

Meet Tiger-Lily

At one month old, Tiger-Lily was diagnosed with Congenital Central Hypoventilation Syndrome (CCHS) which means she stops breathing as soon as she falls asleep. The condition is so rare that it's thought to only affect 100 families in the UK. For mum, Vicky, and dad, Ricky, the last four years have been a journey they never expected to go on. Vicky tells their story:

Minutes after Tiger-Lily was born, she turned blue and was whisked away. Her dad and I were in complete shock - it was our first baby together, and the pregnancy and birth had all gone smoothly. The next time we saw our baby she was in intensive care with wires everywhere and a tube to help her breathe. I had no idea that it would be seven months before we'd go home again.

It wasn't until Tiger-Lily was a month old that she was diagnosed with Congenital Central Hypoventilation syndrome (CCHS). Her brain wasn't telling her body to breathe when she was asleep, and at six weeks old she was fitted with a tracheostomy and fully ventilated.

When we did eventually get home, I was fearful of everything. Suddenly, we were on our own with a baby who was on a ventilator every second of the day and needed loads of equipment and constant monitoring to keep her alive. I'd barely left her side when we had a visit from Ruth, a lovely Leo House community nurse. She told us about the support that was available to us at home, but I turned down her offer. I was determined that I would be able to look after Tiger-Lily on my own.

In the weeks that followed, my world shrank. I'd gone from being a busy hairdresser with loads of clients to feeling

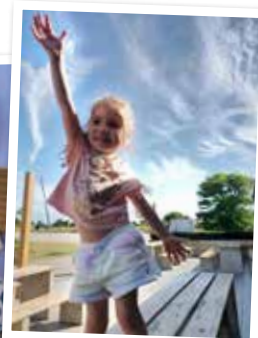
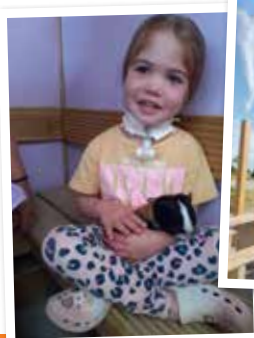
like I had a new career as a nurse. I realised I hadn't left the house for a whole month. That's when I picked up the phone to Ruth.

Visits from the community team became a lifeline. I could step out the door knowing Tiger-Lily was safe and happy. One day I drove into town to get my nails done and I'll never forget just walking around, breathing in the air, and thinking - so this is what the world is like!

Four years on and Tiger-Lily now has a nurse called Laurie who she adores. Before Laurie steps through the door, Tiger-Lily will be looking in her bag as she knows it's full of games, arts and crafts and other fun stuff. And while they play and Laurie looks after all her medical needs, Ricky and I might go out for dinner. Just being able to have a long shower, listen to music and take my time getting ready is such a treat.

Now Tiger-Lily is a bit older, she enjoys going out for the day with Laurie. There's always a lot of medical equipment to pack, but just like any four-year-old, Tiger-Lily loves to cuddle the guinea pigs at Blackberry Farm, run through the fountains at Princes Park or say hello to all the animals at Knockhatch.

Seeing Tiger-Lily so happy after the crazy journey we've been on is amazing. Every year she gets a bit stronger, but there's no way we'd be where we are today without the support and expertise of Leo House.



Contact us

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If you'd like to make a donation directly into our bank:

Sort code: 23-05-80

Account no: 46081021

Name: Leo House

Reference: 'your surname or organisation'

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

Queen Elizabeth II Platinum Jubilee Street Party Raised £160

The Platinum Jubilee of Queen Elizabeth II celebrations in June included a fundraising street party in Freshfield Street, Brighton. Supporter, Margot Freeman, and her friends held a party including Morris Men and a marching band, with a traditional tea party in the road. They raised £160 and Leo House is very grateful.



East Brighton Golf Club Members Raise over £5,000 for Leo House Nurses

Our grateful thanks go to the members of East Brighton Golf Club who have raised money throughout the year for their Captain's charity. Neil Lancaster, this year's Club Captain, was happy to support a local charity which is well known to the members.

The biggest money spinner was the Charity Day, when entrants to the competition bought 'charity bundles', these included a putting competition, raffle, beat the Pro on the 10th and a sweep for vouchers to rounds of golf at other clubs. Thank you so much for your generosity.



Changes to our Bank

The Trustees of Leo House have decided to change our bank as we have become subject to bank charges on all our transactions. From now onwards we shall be using the Metro Bank, the new bank account details are shown in the 'Contact Us' section. This will save about £200 per year in charges. All standing order arrangements will be transferred to the new account.

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.

Thank you!

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

- Mr & Mrs J Millar
- Mr J Ayling
- Miss A H Allard
- St Christophers School
- Stirling Arms Hove
- Farrington Property Development
- Mr & Mrs T D Baker
- Mrs B Corke
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