

Jo and Saul's story

Jo Balmer describes her 14 year old son Saul as a gregarious, outgoing, sociable and happy boy, who loves Formula One motorsport, football and Thomas the Tank Engine. To hear this you would think Saul was a healthy, able-bodied child but Saul has been very sick since just after his birth and needs 24 hour care.

During Jo's pregnancy, a scan showed up some irregularities and she was sent to Kings Hospital in London for a scan and assessment by several different doctors. They told her there was a 50/50 chance as to whether the baby would have any problems and that they could do a termination there and then, but of course Jo refused. After that, her obstetrician in Brighton scanned her regularly to keep an eye on the baby. At the last scan before Saul was born he told Jo everything was fine and, following a difficult labour and emergency caesarean in May 2002, that seemed to be the case.

However, Saul was continually screaming and Jo realised there was

something wrong. An ultrasound on his head showed that his ventricles were enlarged. He was eventually diagnosed with Ventriculomegaly and Jo received the devastating news that Saul would require round-the-clock care for the rest of his life. Saul then started having seizures – sometimes up to 50 times a day, which were extremely frightening, and was diagnosed with epilepsy.

When he was one year old, Saul had a nasogastric (ng) tube placed. The procedure for the PEG tube into his stomach didn't go according to plan and resulted in a very long stay and Saul having his second birthday in hospital. Saul ended up needing to be fed intravenously. He required Total Parental Nutrition (TPN) though a feeding pump and his PEG was eventually re-sited.

Jo then heard about Leo House and now receives support from our community nurse, Paula Charnley, which allows Jo to have a break so that she can complete the weekly shop or meet a friend for coffee. Little things like this have



made such a difference to Jo's life and well-being - she was even able to learn to drive so that she and Saul can live an independent life.

Jo said, "I don't feel so isolated - like I'm the only one. The support from our Leo House nurse has been like a lifeline. I don't know where I would be without it."

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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SPC Wildlife links with Leo House at Home

Do you feed the birds in your garden? When you shop at spcwildlife.co.uk, 5% of your total transaction value can be donated to us at no extra cost to you! SPC Wildlife supplies top quality wild bird food, wildlife food, gardening products, luxury gifts and more.

Remembering Max Miller

Max Miller, Britain's top comedian in the 1930's, 1940's and 1950's, was born in Brighton. He excelled as a stand-up comic, playing in large variety theatres where his skill allowed him to hold an audience in the 'palm of his hand'.

The Max Miller Appreciation Society was founded here in Brighton in 1999. The objectives of the society are to keep his memory alive with social evenings and special events, a regular newsletter, the collection and exhibition of memorabilia

and the erection of blue plaques on places where Max lived. If you are interested, their website is www.maxmiller.org and see the MMAS page.

This summer, the society held a fundraising event at the Pavilion Gardens in Brighton, with the support of David Sewell from the Pavilion Gardens Café.

In our picture are David Sewell, Richard Lintott, Chairman of Leo House at Home, with Averil Older and Terry Hardy from the Max Miller Appreciation Society.



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.

Donation from ASDA Hollingbury.

Customers at ASDA in the north of Brighton voted for Leo House at Home to receive a £200 donation. The picture shows Maria Carpenter, their Community Life Colleague, with Angie Lintott, Trustee of Leo House.



Festival 21



In September, Friends of Sussex Hospices celebrated 21 years of fundraising. All 12 of the Sussex hospices came together to create a family fun day at Danny House in Hurstpierpoint. Our photos show John Culley, Alistair Harvey and Val Randall helping in the 'Hospicetality tent' providing drinks and cakes to the visitors.

Thank you!

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

Scallywags Toddler Group
D Scott
Mr A Kewell
Ovingdean WI
Brighton and District Nursing Association
Ms N Salmon
Mr & Mrs Awcock
Miss J Bygrave
Uckfield and District Lions Club
Ryle House, Brighton College

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.

Hassocks Coffee Morning

Despite torrential rain, the annual Coffee Morning in aid of Leo House at Home went ahead in the Congregational Hall in Keymer Road. There were a number of stalls with hand-made items as well as a tombola and donated bric-a-brac. Our thanks go to stalwart, Shirley Adsett, and her supporters from Hassocks WI who raised £252. Shirley is shown right in the green Leo polo shirt.

