

Caring for life-limited children and young people in their own homes

Winter 2012/13

# There's no stopping Talitha!

Little Talitha loves riding her bike but she can't operate the brakes. She has Worster-Drought Syndrome which means she has very poor fine motor skills. Talitha lives with sister Rebekah, her mother and grandparents in Burgess Hill and attends the lovely new special needs school, Woodlands Meed.

Talitha is 5 years old but has no speech. She suffered heart failure when she was 5 weeks old, but it wasn't until she was 4 years old that her unusual condition was diagnosed. She communicates with sign language and using an iPad but her development is significantly delayed.

She enjoys her school and the facilities it provides, including swimming, music and speech therapy and she has recently joined

Riding for the Disabled, which is a great opportunity. Talitha and her sister have the usual upand-down sibling relationship, but having a disabled sister is hard and Rebekah needs some special time of her own. Recently, she was able to benefit from Brighton and Hove Albion football tickets secured by Leo House at Home. Talitha and her family have made their first visit to Chestnut Tree House and will soon be receiving visits from the Leo House Nurses. Thank you for making this possible.



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

## Thanks John!

John Rees, an audio-visual designer from Forest Row, collected change for Leo House at Home and presented us with a huge bag weighing over 28 kilos.

After lots of counting, we were able to bank £191!

### **Ouse Valley Quilters put on a Show!**



The lovely quilters put on a magnificent exhibition of their work at the Community Centre in Ringmer. Apart from demonstrating their skills, they also raised £1,600 for Leo House at Home from a sale of work and a raffle. Well done and thank you to all involved.

### **Contact us**

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# Leo House is 10 Years Old

We recruited our first nurses in 2002. Since then, hundreds of children have benefited from their support. Your help has meant thousands of visits have been made possible. The lives of the children and their families have been changed with an extra shoulder to lean on. Thank you to all our supporters, both now and in the future.



with trips to Cornwall and spending time with her family, friends, cats and rabbits.

She is proud to be part of a team which makes such a difference to people's lives. She has a case-load which is spread widely and a typical month can include visiting children in specialist London hospitals. These visits provide parents with a much-needed break from the bedside and continuity of care when they return to Sussex. Some of the most challenging cases are neo-natal babies, born with a short life expectancy. Karen helps parents by supporting their decisions and helping with end of life care.

Karen is a real rock to families in tough circumstances. She is able to direct families to sources of help, as well as regular respite support and end-of life care if required. Bereavement care is also part of her role, which is tough when she has known the young person for a long time. She thanks you for your financial support, without which her work could not continue.

### 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 to everyone for your generous donations to Leo House including:

| Shepperd

P Cheesman

Society of Friends Lewes

St Richard's Church Hollingdean

M Gobey

N Ansell

Friends of Sussex Hospices

A Bryan

Adur East Lions

E Smith

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.

Mum of two, Karen, loves being part of the Leo House funded Community Team. She first qualified as a Registered Nurse in 1993 and worked in Cardiology at the Royal Sussex County Hospital before specialising in paediatrics at the Royal Alexandra Hospital. After 16 happy years there she moved to Chestnut Tree House to shorten her commute from Horsham. Last year she jumped at the chance to become a Leo House Nurse, helping lifelimited and life-threatened children in their own homes.

Karen has two daughters of her own, aged five and thirteen and has a busy life

On a breezy day in the summer, David Sewell, proprietor of the Pavilion Café, kindly sponsored a fun day in aid of Leo House at Home. At least one man-size lion was seen entertaining the children. There were plenty of stalls and refreshments to keep all the visitors happy.

