

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

Spring/Summer 2010

# A Life with Hope



I met Hope Jeffcoat at her home, two weeks after her fifth birthday. She has been attending Aldrington School in Hove since September and really enjoys it. As you can see from her photograph, she has a cute smile and looks like any happy girl. However her life has not been easy and early problems have led to her being 'selectively mute', which means she can only speak directly to certain people.

Hope suffers from two conditions, Vasculitis and Juvenile Systemic Arthritis. It is not known if there is a link between the two. The symptoms include fever, pain, welts on the skin and general debilitation. At age three, she was the youngest sufferer of Vasculitis in the world. A year ago she was unable to stand and needed to spend time at Great Ormond Street Hospital (GOSH); they have helped her with medication to ease her symptoms.

Hope has undergone various types of chemotherapy, and has also tested trial drugs for GOSH. She has weakness in her arms and legs and is unable to run and climb with her classmates.

Hope lives with her two year old brother Jeremiah and her parents, Karen and Neil. Leo House came into their lives during one of Hope's more challenging times and her family needed some respite. Due to Hope's problems, they are unable to go out as a family, and to add to their difficulties, Hope's Mum suffers from M.E. Hope gets very tired easily, and in fact her bed time is 5pm. One special outing she did enjoy was a trip to Lego Land with the Leo House Nurses. The family really appreciate the help Leo House at Home can give and thanks you for your support in making it possible.



Thank you to those who helped buy this special bed, being modelled by Sam Barclay.

### **Looking ahead**

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

## **Contact us**

Leo House, Lions Dene, The Deneway, Brighton, BNI 5AZ

Telephone: 01273 556834 www.leohouse.org.uk

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# **Brighton Marathon Stars**

Well done to all the runners in the inaugural Brighton Marathon held on April 18th. Over 7,000 finished including several raising money for Leo House at Home. Pictured are Naomi Clark (with medal),

Gina Lane (running) and Alistair Harvey (one of our Trustees). Others were Barry Blackwell, Anja Brandt and Cathy Davies. Congratulations and thank you so much.





# ClyndebournelitsallighNote

On Sunday 18th April, Glyndebourne Opera gave an afternoon concert to support two local charities, the Lewes Railway Land Project and Leo House at Home. The proceeds of the concert – final figure not yet confirmed but more than  $\pounds 20,000$  – will be split between the two charities. The concert, the Mozart Requiem (in D minor, K.626) was performed by the Orchestra of the Age of Enlightenment and the Glyndebourne Chorus.

The sun was shining, the warmest day of the year so far, and a great opportunity to enjoy the idyllic setting of Glyndebourne opera house. Many of the audience arrived early, either to have Sunday lunch in the fabulous restaurant – reminiscent of Alice through the Looking Glass - or to simply enjoy a springtime walk around the lake and gardens nestled in the Sussex Downs. As everyone took their seats in the modern 1200-seat theatre, they saw a slide presentation of images from the charities and the concert was opened by Lord Dennis Healey. The Glyndebourne Chorus sounded sublime, the soloists and the orchestra were magnificent and it was conducted brilliantly by James Gaffigan. As the Requiem finished there was a momentary stunned silence and some

audible sniffing from people moved to tears before the rapturous applause.

Leo House would like to thank Gus Christie and Glyndebourne management who so kindly arranged the concert and especially the conductor, soloists and front of house staff who so generously gave their time without pay to help local charities.





#### S Brighton Marathon

# 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.

# Viv Walks 'The Way'



Novice walker Viv Steinhardt has completed the Southdowns Way in aid of Leo House at Home. Despite "hating the hilly bits", Viv finished the 100 mile journey in 10 segments over a 3 week period. She raised £520 and built up some fine muscles! She is pictured (left) with organiser Shirley Ross and others from the 7-strong group.