



## Friends of Landau Kleffner Syndrome

3 Stone Buildings, Lincoln's Inn, London, WC2A 3XL

Tel: 0870 8470707

Internet: [www.friendsoflks.com](http://www.friendsoflks.com)

E-mail: [info@friendsoflks.com](mailto:info@friendsoflks.com)

Friends of Landau Kleffner Syndrome  
(Regd. Charity No. 1059499)

### Trustee Report 2007 - 2008

It is very pleasing that once again the Trustees of our charity can advise its members that the charity continues to improve on the support it provides, is in its strongest ever financial position and has now approved funding to a research programme. The Trustees who are also active committee members continues to be made up of parents with children who have been diagnosed with LKS. The Trustees actively seeks to attract new blood to the committee but even though our membership continues to increase no new trustees/committee members have been appointed.

It is the dedicated voluntary support of parents that makes FOLKS what it is today and without this would not exist. It is worth reminding ourselves what the primary aims of FOLKS are:

- The relief of persons affected by Landau Kleffner Syndrome ("LKS") and related disorders
- To advance the education of the medical profession and the general public on the subject of LKS and its implications for the family
- To promote research into LKS, to publish the useful results thereof, and to support organisations providing research into LKS

The year has been relatively quiet with the family day having to be cancelled due to a lack of confirmed attendance. We again issued two newsletters, one in April and one in November and we thank all those that contributed articles. Our help-line continues to answer questions from parents and carers and provide general support when most needed. However the rarity of the condition and the depth of information on the new website means that call numbers are very low.

As stated above we continue to improve our financial position following another successful year of fund raising. Fundraising accounted for just over 82% of our total income of £18831.99. Our claim on Gift Aid (£818.63) together with Building Society Interest (£1641.38) accounted for a further 13% of income. The balance of income coming from membership receipts, donations and the sale of Christmas cards which were disappointingly low for the year. We still hold significant stock of Christmas cards however future sales will create further income as all production costs have now been covered. On the expenditure side we continue to reduce our costs with the

**Executive Committee:** Angie Conlon (**Chairperson**), Richard Budnyj (**Secretary**), Steve King (**Treasurer**), Cathy Cowie, Martin Cowie, John Conlon, Robert Duncombe, Patrick Magee and Marie Magee.

greatest savings on printing and postage. We now send out more than half our newsletters and other communications by e-mail.

Our priorities are now to maintain what we have achieved in terms of information and support and to now focus on research. We have now approved funding (£30,000) for a specific research programme with Professor Brian Neville and his team at Great Ormond Street Hospital (GOSH). The programme will focus on basic scientific research into LKS and the money donated by FOLKS will fund the addition of one member to the GOSH team to assist in this work. GOSH are currently sourcing a suitable candidate. We will keep our membership updated with progress.

Finally we have agreed to hold a Charity Gala Dinner later in the year to help raise further funds for research.

An excellent year again for FOLKS with 2008-09 looking very promising.

For and on behalf of FOLKS

Secretary  
Richard Budnyj

1<sup>st</sup> November 2008

**Executive Committee:** Angie Conlon (**Chairperson**), Richard Budnyj (**Secretary**), Steve King (**Treasurer**), Cathy Cowie, Martin Cowie, John Conlon, Robert Duncombe, Patrick Magee and Marie Magee.