

# Newsletter

## November 2005



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### Introduction

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Wow, where did this year go? I can't believe Christmas is just around the corner.

Christmas is one of the happiest family times. For a parent of a child with LKS, however, it can be a time of heartache and anxiety. The sadness and pain that is felt by a parent, when there is no understanding about the excitement and anticipation that the Festive Season brings, is devastating.

Stress levels race out of control when presents have had to be re-wrapped countless times, tree decorations re-hung and lights removed from the tree through fear of an accident. Let alone trying to cope with getting the shopping done????

Several of you reading this will, perhaps, be facing your first Christmas following your child's diagnosis of LKS. At FOLKS, we want to help you have the best Christmas possible. Many of us have experienced exactly what you are feeling and going through. Help and support are only a phone call away.

This issue of the newsletter contains several

articles describing the activities of FOLKS over the past year and how FOLKS is developing.

There is a report and members articles on the family fun day held at Scallywags in September, as well as an update on research, fundraising and the development of the new website. To help you prepare this Yuletide, FOLKS Christmas cards are now available, so please place your order as soon as possible if you haven't done so already (order form enclosed).

Please remember that this Newsletter is for YOU, so if you would like something included in it which hasn't been covered, please contact either myself or Richard, and we will endeavour to make it part of the next newsletter in April.

May I take this opportunity to wish you and yours a very Merry Christmas and a Happy, healthy New Year.

**Yours sincerely**  
**Angie Conlon**  
**Chairperson**

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## Family Day - 10<sup>th</sup> September 2005 at Scallywags

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On a very wet day in Birmingham friends and families met for the FOLKS Annual Family Day. Feedback from those members who came suggested the day was a great success. Below are two articles from two of those; the Malans from Denmark and Wendy from London. Thank you to Lars Malan who took pictures some of which are shown throughout this newsletter. We look forward to next year and hope that more of you can attend and share the experience. Details of which will follow in the next newsletter.



### From Friends in Denmark

It was lovely to meet you all at the family day. We had a great day and are happy to be able to put some faces to the names of some of the people we have read about on the Folks list. We are back in Denmark now. We came home Monday, the 19<sup>th</sup> September – one week after Martin's operation, which went very well and without complications. Martin went down to the operation theatre at 8.30am and at 12.30pm Mr Harkness returned to tell us that everything had gone well. He showed us a picture on the MEG-scan, what part of the brain they had operated on, which was quite a big area of the brain. When we first saw Martin in the recovery room, he wasn't feeling too good. He was sick and in pain, and there was no doubt that both his arms and legs were working just fine. After some medication and some water to drink, he fell asleep for several hours, and when he woke up, he was much better.

The first day (Monday) he had something to drink and eat, and around noon the next day (Tuesday) he was up playing for about 15 minutes. After some hours of sleep, he just got better and better, and in the afternoon he was moved out of intensive care. He was walking around the ward and the staff were so impressed to see his fast recovery. In the evening the drain in his head was removed, and we were so lucky that two clowns visited the ward at that time, so they entertained him during the

procedure. He was so impressed, that he didn't even notice that the drain was taken out. The third day (Wednesday) we were moved from the ward to the patients' hotel, just across the street. We just couldn't believe that everything had gone so easy – it was wonderful! The following days, we merely waited for time to pass, so we could go back home, and so we did last Monday.

Last Tuesday was an off-day, though. Martin had a major seizure lasting for 2-3 minutes in the morning, and he was feeling sick for several hours afterwards. But later in the afternoon he was all right again, and he has been just wonderful since. I know, that we are very much aware of any possible change in his behaviour, and maybe are seeing and hearing things because of wishful thinking, but I really experience that he is more present than before – babbling all the time, and repeating sounds and words (or at least trying to), more willingly than before. So all in all, this has been a very good experience for us. Now we just have to wait to see if it will change things and make Martin better in the long run.

We were made very welcome at the family day and it was very beneficial to share experiences with other parents. Our best regards to all. I enclose some pictures from the family day to put in your newsletter.

### Malan, Lars and Martin Denmark



### And from a newer member

I read with interest the March newsletter, as I am trying to learn as much as I can about LKS. A family day at Scallywags sounded like a jolly good idea, as there is nothing so useful, I believe, as meeting other parents who are going through the same things as you are. Just meeting people and chatting will always bring about some useful snippet of information that you might otherwise not

have discovered. The last time I met others with epilepsy was when I climbed Ben Nevis for Epilepsy Action, so this certainly seemed like an easier way!

I felt slightly apprehensive about going, as Francesca has not in fact been diagnosed specifically with LKS, but I feel strongly that this is her syndrome.

Francesca had her first tonic clonic seizure in October 1999 at the age of two and a half, and although the second didn't come for another four months, they soon became more and more frequent - every couple of days or so. We started medication, initially Tegretol, which it seems almost immediately brought with it the myoclonic jerks which remain with Francesca today. Gradually cocktails of drugs were suggested in various combinations, all of which we tried, trusting of course totally in our doctor's advice. At the suggestion of steroids, we said 'no more' and asked for a referral to Great Ormond Street Hospital to try the ketogenic diet.

In 2002, after a number of people had suggested it, we asked our then neurologist whether Francesca might be autistic. "Let's spare her that label" he replied. "Way over-diagnosed, no I'm sure not". Over the next months, I gave examples of when I asked her if she'd had a good day at school and her reply would be "can we buy a golden casket". Not once did he suggest that many children with epilepsy suffer with language difficulties and looking back, it is quite clear that Francesca did. Having had endless blood tests, waking EEGs, eye tests, a hearing test and two MRIs, what was never suggested was that she might have a sleep EEG.

Finally, through Great Ormond Street, in January this year, Francesca had a sleep deprived EEG "to rule it out", as I have been 'banging on' about Landau Kleffner Syndrome ever since early 2003 when the syndrome was mentioned to me by a speech and language therapist during her statementing process. And sure enough, although, she does not quite formally meet the criteria for ESES, it's still about 70%. Steroids were immediately suggested - which in fact are not a sensible combination with the Ketogenic diet, so we began Clobazam, which didn't work and Francesca is now taking Keppra. We're waiting for an overnight EEG to see whether Keppra is doing its bit, or whether steroids will be the next step and discontinue the diet.

So, I felt that we would be justifiable members of a LKS group at Scallyways and set off on our

horrendous journey up the M40 in driving rain. We arrived, late, as I always underestimate the time it takes to get two kids prepared for a day out - particularly with the pre-planning and weighing that the diet entails and we finally arrived at the noisy, fun-filled Scallyways. My younger daughter, Anya ran straight in - absolutely her kind of thing. Francesca, however, dug her heels in at the door. She **absolutely hated it!** It was so unlike her, although I have had an inkling recently, that she may have a sensitivity to noise. I couldn't get her to move. I could see the group seated further down and was completely torn between wanting Francesca to be happy and wanting to join the group and talk about LKS.

As it is obviously a safe environment, and I could keep an eye on Francesca from a distance, I joined the group and immediately felt very welcome. Someone asked Scallyways to turn the music down and I managed to talk to a number of people. Interestingly, two other parents told me their children had had problems with noise, which improved over time. It was just lovely to talk, to see the kids playing (well every one else's!) and to be in a situation where others understand.

I think that the Scallyways Family Day was a big success - even though Francesca might have thought otherwise and thank everyone who was involved in organising it - well done. I will definitely join you again next year - how about a zoo or safari park where there is indoor space for the inevitable British weather and outdoor play areas if the sun shines...

**Wendy Meteyard-Winful, London**



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## **London Marathon 2006 - 'One more time' again**

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Yes, it's true, I have decided NOT to retire after all and "subject to getting an entry" will be lining up

with Paula Radcliffe in April 2006!

My 2005 performance had a high and a low point. First of all, let's talk about the high point, I raised £5813. A huge thank you to all my supporters who made a donation, some of whom had already been very generous when we raised £6395 in 2002.

Now for the embarrassing bit, the low point. I confess, I passed out at 18 ½ miles and did NOT finish. Don't laugh! I suffered from a combination of running too fast and over-hydrating by drinking too much. I have now made a full recovery but was

rather startled when I came around in hospital only to see a 6ft rabbit lying in the bed next to me saying "what's up doc?"

On a final positive note, I will read the story of the hare and the tortoise before next years event and hopefully learn a lesson.

**John Conlon**

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## Fund raising events

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This year has been a particularly successful year for fund raising. In addition to John Conlon's tremendous efforts we also acknowledge below the superb efforts of other members, their families and friends.

In June Miriam Curtis from Manchester organised and played to a sell out concert raising a total of £721 for FOLKS. Miriam, an ex sufferer of LKS, also celebrated her 21<sup>st</sup> Birthday. Miriam having gained Grade 8 at violin and a performing diploma on the piano is now studying for a degree at Manchester University.

In July 2005 20 pupils from tutor group 8kf and 8mf at Thornden School, Chandlers Ford ran to raise money for FOLKS. The children ran around the Astroturf pitch at the school continuously for 1 hour in temperature of over 30 degrees C. The children raised over £400. Cameron Budnyj and Nick Harding were responsible for organising the event. Cameron has a younger brother who suffers from Landau-Kleffner syndrome. On Thursday 20<sup>th</sup> October the year group held an assembly at which point they presented a cheque to Angie our Chairperson.



Brett Owen, a friend of Cathy and Martin Cowie, from Alderstone in Surrey raised £600 running in the London Marathon.

And lastly Lucia Magee, 17 years old and oldest sibling of Tosh who has LKS persuaded her House of 70 girls aged 14 -18 years old, at Prior Park College, in Bath, to support FOLKS as their charity of the year. Fielding House last year raised money for RICE and Babe Appeal. They were unanimous in their vote, despite stiff opposition. The girls plan to have a house concert where they will perform a variety of solo, group and instrumental performances to friends and family. They will also have cake sales. The house is divided into vertical groups, and each team has to come up with imaginative ways of raising money throughout the year. They have also asked for a FOLKS representative to visit and talk to the girls and staff about LKS and the work of FOLKS. Marie-Suzanne (one of our committee members), Lucia's mother will be visiting this term with Tosh to enable them to see how valued their hard work will be.

We will keep you informed in subsequent newsletters as to how they get on. Good luck girls.

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## Research

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In our last newsletter we advised that we had been in consultation with some of the leading experts in LKS to determine where best to concentrate efforts. As a result we have decided to support Great Ormond Street Hospital in a research programme. The aim of this study is to use a comprehensive

database to explore in detail the characteristics, time course and outcome of LKS. It is hoped that this investigation will increase our understanding of the behavioural and cognitive impact of LKS and how this may be related to various disease factors (e.g. type of seizures, characteristics of the EEG,

medication, age of onset etc). The outcome is to answer the following questions:

What is the time course of LKS and how does this vary across individuals?

What are the best predictors of long-term outcome?

It is hoped that this database will form the springboard for a broader LKS research program in the longer term, to include more detailed experimental investigations of particular subgroups of children (identified through the database). These might include, for example, studies using neuroimaging techniques that could shed light on the causes of cognitive, language and behavior difficulties in LKS.

How will this be done?

The data will be drawn from children with LKS currently attending the Developmental Epilepsy Clinic (DEC) at GOSH, including a retrospective analysis of case notes from those who have visited the clinic over the past ten years. The clinic has specialist expertise in diagnosing LKS, which has resulted in a high rate of referrals of these children.

Preliminary estimates suggest that this could yield as many as 100 possible cases for inclusion in the database. The current world literature contains a total of only 350 cases to date. An Access database template has been developed in conjunction with the IT department and relevant information will be easily transferable to SPSS for statistical analysis. The database will be kept on a password-locked drive on a GOSH computer,

accessible only to the named investigators taking part in the study. There will be no additional paper files stored as all information will be drawn from standard medical notes. It is anticipated that the database will be implemented over a period of five years in the first instance, in order to provide important longitudinal data on the progress and outcome of children with LKS.

The project has been granted approval by the Institute of Child Health/Great Ormond Street Hospital Research Ethics Committee, (REC reference number: 04/Q0508/113).

In the first instance, it is necessary to obtain funding for a medical research worker for the period of one year, in order to allow completion of retrospective data entry to the database. The costs of this are in the region of £40,000.

It is then anticipated that this one-year 'pilot' study would form the basis of an application for further funding from external bodies, to extend implementation of the database for a further two years, and to include 'add-on' studies as described above. It is hoped that this larger body of work would constitute a PhD thesis for the research worker involved. The cost of this extension would be approximately £50,000 per year for two years.

So our first hurdle is to raise £40,000. We are probably just over half way there and would hope to be in a position to reach this first hurdle by June 2006. So we still have some way to go just to reach the first hurdle but with more fundraising, concerted effort and support we are confident we will achieve our goal.

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## Website

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As many of you will be aware, there has been much debate over the past year regarding the FOLKS website and the desire to update it. We are pleased to announce that the new website is in the final stages of construction and is due for launch very soon. There will be a new, easier to remember, website and e-mail contact address.

Designed by Alistair Curson, the new FOLKS website draws upon the content of both the old site and of the recently published booklet 'Landau Kleffner Syndrome: Information for Families'. Its aim is to guide both experienced LKS families and those recently diagnosed, as well as interested professionals, to the information and support they require in a quick, easy and intuitive way.

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## And Finally.....

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At the family day some parents asked me about the prognosis of children with LKS. Unfortunately it is a difficult one to answer. Our understanding from what the experts believe is that the earlier the onset combined with a longer periods of regression the worse the prognosis. The later the onset combined with shorter periods of regression the better the prognosis. But there is so little evidence to prove this. What we do know is that every single child suffering from LKS is different. Parents

understandably ask because they are unsure of the future. All they hear about is children who are currently suffering. They want to hear about children who are now in their teens or adulthood and what life is like for them. Well I don't want to mislead people but I do believe we should hear some good news stories. Since I became Secretary I have spoken to many parents whose children have now grown up. What is encouraging is that there are ex sufferers out there leading near normal

lives (if there is such a thing). You have read about one earlier in this newsletter and a very talented young lady she is. I also recently received a thank you card from a mother in Belfast called Gail. Gail enclosed what she described as a small donation (I hope all small donations are like this). In the card she describes how her daughter recently obtained 1 A\*, 4 A's, 1B and 3C grades in her GCSE's and has gone back to school to sit her AS Levels in four subjects. I rang to thank her and learnt that her daughter at the age of 3, having developed normally, regressed over a very short period of time to a level of no speech and little comprehension. Gail very kindly allowed me to share this with you in the hope that some positive news will help you deal with the difficult times and stay positive about the future.

All of this leads me onto fundraising and research. Due to the support of many members, their families and friends we are having one of our best financial years in a long time. We have acknowledged some of those achievements in this newsletter. But that's not good enough. We as a committee are determined to support research in a significant way. We may then get the answer to many of the questions we get asked. We can only do that if we

raise money. So I will keep asking you for your help. There are many ways are highlighted in this newsletter. One easy way is to buy or even better sell our Christmas cards. So please get your orders in. If you would like to help by selling cards please contact the helpline 0870 8470707 or drop me an e-mail and we will happily discuss arrangements.

And finally a reminder of another request. We also need people to help. As I stated in the last newsletter some of our committee members have been so for many years and are looking to hang up their boots. This means we need new committee members. We meet up every other month for a couple of hours. If you don't feel you can join the committee but still wish to help you can. If you are interested and can spare some time or you just wish to help in some way please call us on 0870 8470707 or e-mail me at [richard@budnyj.freeseve.co.uk](mailto:richard@budnyj.freeseve.co.uk).

Best wishes for the festive season and a prosperous new year

**Richard Budnyj**  
**Secretary**

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F.O.L.K.S.NEWS welcomes all contributions, articles, letters and comments for publication. If you have any item suitable for publication it should be sent to Richard Budnyj 8, Malibres Road, Chandlers Ford, Hants, SO53 5DT alternatively e-mail to [richard@budnyj.freeseve.co.uk](mailto:richard@budnyj.freeseve.co.uk). F.O.L.K.S. does however reserve the right to omit or edit items where necessary. F.O.L.K.S. NEWS is published to provide general information to parents and carers of children with Landau Kleffner Syndrome and to interested professionals. The contents are not and are not intended to be, a substitute for advice from a qualified medical practitioner, preferably one experienced in the management of this complex disorder.

**Executive Committee:**

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