

# Newsletter

## November 2006



Syndrome

Friends of Landau Kleffner

(Regd. Charity No. 1059499)

*\*\*\*\*\*Celebrating 10 years of supporting parents, carers and professionals\*\*\*\*\**

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### Introduction

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After a sweltering summer and some monsoon-like rains of recent, let us hope that the build-up to Christmas is not marred by any extreme weather phenomena. Of course, if you are an LKS parent, the weather is the least of your problems and days of 90° heat and unforgiving rain can pass unnoticed amid the traumas at home.

It's at times like these, that it's my pleasure to remind you that this year FOLKS is celebrating its 10th anniversary. Since Vicki Horwell first laid the foundations for the charity that is now FOLKS, we have gone from strength to strength.

Building upon the successes of our previous family days, FOLKS held its first Parents' Day in Leicester, in September. Many parents & carers of LKS children attended the event, and benefited from meeting each other and learning more from medical professionals who had travelled from across Europe.

2006 will also be remembered for the outstanding achievements of dedicated FOLKS supporters who themselves had gone beyond the call of duty to raise money for their charity. Read more about their efforts in this newsletter.

In addition, we have seen the launch of our new website, [www.friendsofks.com](http://www.friendsofks.com). The stories of our gallant fundraisers, our Parents' Day, and invaluable information about LKS can be found there. We are also selling our Christmas card collection for the first time on-line. Using PayPal you can now purchase FOLKS Christmas cards, as well as make a donation on the internet.

I would like to emphasise our oft sung message that help is only a phone call away. The experience gained by LKS parents through adversity is invaluable and the kind of help they can offer for everyday mundane issues is best passed on with a simple chat. Coping with a child suffering from LKS is heartbreaking, as you well know, **but**, as an LKS parent too, I honestly believe that by being positive, pro-active and at times bloody-minded you can make headway.

So, from the words of the song, "When times get rough, you can depend on us, don't give up, please don't give up!"

Merry Christmas & a Happy New Year. Let's make it happen for 2007!

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## Parents' day - Saturday 23<sup>rd</sup> September 2006

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Marriot Hotel, Leicester. What a successful day. The day started by organising all the kids into the playroom with the carers so the parents could grab a coffee, relax and sit back and listen to the speakers. Angie Conlon opened the day with a big thank you to Wednesday's Child for making a donation to make the day possible. Dr Jayaprakash A Gosalakkal (aka Dr Jay), Consultant Paediatric Neurologist at the University Hospitals of Leicester was the first speaker. His subject was 'LKS an Enigma' where he shared his extensive knowledge and experience of LKS. The parents had lots of questions but the time was limited so Dr Jay kindly stayed on until after lunch to answer further questions.

Well if we thought we were learning lots from Dr Jay we were all in for a surprise when Dr Ritva Paetau from Helsinki followed. With her excellent command of the English language she engaged the audience with her presentation on MEG scans, the objectives and benefits. Then it was time for lunch. Hold on a minute we had all forgotten about the kids. Not to worry they were having a great time. After feasting on the buffet and finding out what the kids had been up to all morning it was back to the meeting room for the most exciting part of the day.



Yes, the AGM. There were no new nominations so all the existing officers and committee members were re-elected. Richard Budnyj gave a review of the charity's success over the last few years, how it had achieved its objectives set by the new committee and how it was now focusing on fundraising and research. Steve King explained the accounts for the last financial year. Richard went on to say that the running costs for FOLKS were in the region of about £1500 per annum excluding events like the parents day. Income over the last few years had significantly outstripped expenditure which in the main was down to the excellent efforts of fundraisers. The Charity had also received one significant donation with a condition that it was used solely for research. FOLKS had also been

speaking with GOSH about supporting the proposed research into LKS (as covered in previous newsletters). Richard asked the members if they supported the committee to push ahead with this course of action and using surplus funds to support GOSH. The general consensus was to fully support this important and urgently needed research. Richard pointed out that although FOLKS could make a significant contribution it was still some way of the £150,000 needed. The only way to achieve this was more fundraising and Richard asked the members to think how they could all help with this. He also asked for members to e-mail their ideas on what should be considered in constructing the information database for research i.e. possible common factors. The AGM closed.

Next up was Katherine Delargy who spoke about "Our story- with regard to pharmacotherapy". Katherine and her husband Robert are both Pharmacists and have a son, Anthony, who was diagnosed with LKS and has now been well and free of clinical seizures for over 2 years. Katherine spoke about Anthony's history and details of all the Anti Epileptic Drugs (AED's) that had been tried. Katherine's conclusion was that Monotherapy is often best option and should be tried before 2 or more AEDs are prescribed.

Last but not least were Maria Clark and Nicola Jolleff from Great Ormond Street Hospital (GOSH). Their Session was on Learning, Language & Behaviour and included an interactive session with the parents. This session looked at approaches and strategies that could be used in education and how to apply the theory. It was clear from the feedback that we could have spent a whole day covering this subject. This is something we will certainly look at for the future. The output from this session together with all the presentations on the day can be found on our website.



The meeting closed and time to find out what the kids had been up to. Happy smiling painted faces and a tired bunch of carers said it all. The day was a great success and can best be summed up by an

e-mail received from one of the families attending the day.

*"The day was amazing! We all (kids included) enjoyed it; thank you so much for the child care it was first class. Dave and I have not learnt so much in 1 day! The information was brilliant, and we have passed it on to our school. James' teacher is keen to see the completed copy of the education sheets that we got at the end".*

Finally a big thank you to all the guest speakers who gave up their time to attend, Cathy Cowie for sorting all the child care arrangements, the girls that looked after and entertained the children all day, committee members for helping with all the other things on the day, Matthew for managing the laptop all day and finally but not least to all the parents and children for attending. See you all next year.

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## Case histories from members

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We received an interesting e-mail from an American lady earlier this year. As a result we asked if she would write an article for our newsletter. Colleen's story follows. We very much appreciate, as we believe you will, Colleen sharing her story with us and also offering to share her contact details: Thank you Colleen.

### Colleen's Story

My name is Colleen (Mason) Bedard. The following is my story. During the summer of 1963, at the age of 3, my mother noticed something wrong. Up until then, my speech and hearing had been normal. I used to grab the phone when it rang and run to the door when the bell rang. But that all ceased. I stopped talking and was not responding to sound. My parents were told that I wasn't deaf but I couldn't hear. Slowly, improvements were made. Over the next few months, I regained hearing but did not begin to speak again. One day I heard the church bell ringing and ran to my mother covering my ears. At first, it was hard for my parents to notice the silence of one child when there was a busy household (church rectory), which also contained the office. Dad was an Episcopal (Anglican) priest of several small churches and Mom was a stay-at-home parent. Piercing screams and erratic behavior grew out of my frustration. My superhuman parents spent about 2 years searching for answers in Canada (where my family is from) and the U.S. (where we now live). Visits to a local clinic, then a large city hospital and eventually to Boston were made where tests were done. An EEG showed abnormalities. No visible seizures were ever noticed. Drug therapy was mentioned but my mother said no.

Finally in 1965, at the age of 5, I was diagnosed with "aphasia" or a profound auditory verbal agnosia (the closest diagnosis that the doctors could come to). The doctors at Mass General Hospital said that what I had was rare. It wasn't until 1988 just before I got married, when due to circumstances at the time, we went to visit the same doctor who first saw me in 1965. It was then that we (my parents and future husband) found out the new diagnosis. The doctor, a neurologist in

Boston, Massachusetts, USA, had since learned after using my case many times that it was Landau-Kleffner Syndrome and not retardation as some thought.

My father has written a book about me and my parents' search for answers and what followed over the years, as I got "better". The doctors told my parents I probably wouldn't graduate from high school and to forget about college. But not only did I graduate from high school, I earned a B.S. degree in Psychology. It has been my father's dream to have my story published. His book entitled "Search For Tomorrow" is in the hands of a publisher.

My mother was instrumental in getting answers for my loss of speech and "hearing" by reading and writing to various places, making lots of phone calls while my father was busy with work and taking care of the other children. They left their homeland (Canada) and their families behind so that I could get the best care possible for recovery in the United States. At the final consultation, the doctors at Mass General Hospital mentioned Crotched Mountain Rehabilitation Center as the next step for recovery. They asked my parents if they would consider moving to Massachusetts because then the state would pay for my schooling. The decision was made and we moved to Massachusetts where my father was able to find a church that needed a priest. My parents were required to bring me home each weekend and holidays.

From 1965 to 1968, I attended Crotched Mountain School for the Deaf in New Hampshire, living on campus Monday through Friday, using sign language while I regained my ability to speak. The school was just over 100 miles away. My father drove me there every Sunday night and picked me up every Friday afternoon so I could be with my family on the weekends. My mother wrote me letters every week and always drew pictures to go with many of the words in the letters to help me learn to read and write. After three years, the school had done all it could for me. I then continued at Applewild School from 1968 to 1970 (a small private school in Fitchburg, Massachusetts) where the student-teacher ratio was smaller than a public

school. I was pulled out daily for special education services. After finishing third grade there, my mother decided that I was ready to try public school. I had an IEP (individualized educational plan) all through school until I graduated from high school. School was never easy for me. In high school and college, I ran cross-country and track. It helped to build my self-confidence as I won many races and broke records. I still hold many records today. The one I'm most proud of is the 100-yard dash set in 1978 at a state meet with a school record of 11.3.

I had always wanted to be a teacher so I enrolled at Westfield State College, about 2 hours away. But I became very homesick and transferred to Fitchburg State College. When it was time for the student teaching, I fell apart as I realized I couldn't stand in front of a group of children and staff and teach. Words didn't come easily for me. So I quickly changed my major to psychology. After college, I continued to work with children. In 1988, I married

a wonderful man who is very understanding and patient with my challenges and me and was blessed with 4 beautiful, healthy children. For 15 years, I stayed home taking care of the children. I am now in my third year as an inclusion aide (helping children who struggle with math and reading) for a third grade classroom in a public school nearby.

I have started only recently to use the computer and look for information on LKS. That's when I found the FOLKS website. I was so excited to know that there are others like me with LKS. My mother's words of advice today to all parents with "special children" would be to persevere and research. New discoveries emerge when least expected.

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## The Ten Commandments for parents of children with special needs.

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1. Take one day at a time, and take that day positively. You don't have control over the future, over today, or over any other day, and neither does anyone else. Other people just think they do.

2. Never underestimate your child's potential. Allow them, encourage them, expect them to develop to the best of their abilities.

3. Find and allow positive mentors: parents and professionals who can share with you their experience, advice, and support.

4. Provide and be involved with the most appropriate educational and learning environments for your child from infancy on.

5. Keep in mind the feelings and needs of your spouse and your other children. Remind them that this child does not get more of your love just because he gets more of your time.

6. Answer only to your conscience: then you'll be able to answer to your child. You need not justify your actions to your friends or the public.

7. Be honest with your feelings. You can't be a super-parent 24 hours a day. Allow yourself jealousy, anger, pity, frustration, and depression in small amounts whenever necessary.

8. Be kind to yourself. Don't focus continually on what needs to be done. Remember to look at what you have accomplished.

9. Stop and smell the roses. Take advantage of the fact that you have gained a special appreciation for the little miracles in life that others take for granted.

10. Keep and use a sense of humor. Cracking up with laughter can keep you from cracking up from stress.

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## Fundraising

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We stated in the last newsletter that 2005 was a good fundraising year and that 2006 was potentially looking good. Well 2006 has been a great year and it's not over yet. In addition to some kind donations once again we are grateful for the tremendous efforts of our fundraisers.

### Cathy jumps for FOLKS

After a minor hitch on the day Cathy completed a tandem skydive out of a plane raising **£1,600** for FOLKS.

Well done Cathy. That took some courage.

Photographs are on our website.

### Prior Park College

Lucia Magee, oldest sister to Tosh successfully persuaded Fielding, her school house to name FOLKS charity of the year 2005. The girls' raised funds throughout the year with cake stalls and raffles. The climax of their efforts was the variety concert where girls & teachers put together a medley of virtuoso pieces from the classics to the musicals. Every child contributed their time & energy into making an enjoyable evening for

parents & teachers. On Monday 10<sup>th</sup> October 2006, Marie-Suzanne Magee, (Tosh's mum) was invited to attend the girls' house assembly where a cheque for **£657.35** was presented to FOLKS. A huge thank you to Mrs Louise Brierley, Fielding House Mistress, for her enthusiastic encouragement of the girls and of course to Lucia for initiating FOLKS as the chosen charity.

### **Manchester 10 km for FOLKS.**

Patrick & Marie-Suzanne Magee decided to put an end to being couch potatoes and ran the Manchester 10 km last May in aid of FOLKS. They raised **£900**. They were amazed at people's

generous support & hope to run it again next year as a family endeavour. Sadly there are no photographs as Marie-Suzanne said "we looked rather ghastly on the finishing line!". However they have promised to take some next year which suggests it is more than a hope that they run it again next year.

### **Gilhooly's walk Hadrian's Wall**

Jo and Dave Gilhooly walked the length of Hadrian's Wall, celebrating their 10th wedding anniversary in the process. To date they have raised a fantastic £2400 with still more to follow. Well done. Maybe the Great Wall of China next!

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## **And Finally.....**

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Well as you can see from reading this addition FOLKS is continuously making great progress. We have had an excellent year, again achieving all the goals we set ourselves. But we can't be complacent. It's only through the continuous efforts of fundraisers that will allow us to achieve our objectives. As discussed at the AGM our key objective now is to focus our efforts on research whilst maintaining the great progress we have made to date. We can only do this with your support, which means spreading the word and looking for fundraising opportunities. Remember no amount is too small. There are many ways to raise funds so please put your thinking heads on and see how you can help to raise funds for FOLKS. If everyone can do their bit we are more likely to reach our objective. If you do have an idea and need support please contact us to see how we can help. We can provide sponsorship forms, T-shirts, posters etc just let us know how we can help.

As I have stated in previous newsletters we would

gratefully welcome new blood to the committee. We have lost a few committee members over the last two years without replacing them. 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 FOLKS in some other way please contact us 0870 8470707 or e-mail us at [info@friendsofpls.com](mailto:info@friendsofpls.com).

Finally, due to our financial success we are now required to submit fully audited returns to the charity commission. I would therefore like to take this opportunity to thank Geoffrey Hodge, Chartered Accountant for auditing our accounts at no charge. Thank you.

Many thanks and I look forward to your continued support.

**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, Secretary, 8 Malibres Road, Chandlers Ford, Hants SO53 5DT, alternatively e-mail to [info@friendsofpls.com](mailto:info@friendsofpls.com). 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.