

Newsletter

March 2006



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

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Introduction

The grey days of winter can be depressing, but the promise of Spring with its bright prospects and burgeoning colours is unfailingly uplifting and encouraging.

Hopefully when you read this newsletter you will share in my optimism and delight. I am so pleased with what we have already achieved so far and equally excited about our future.

You may recall that in the last newsletter, one of our main objectives was to design a new website. Great News!!! It is now up and running and bursting with the latest information on LKS. (See inside for more details). Alistair Curzon has done a fantastic job creating the website and he fully deserves our grateful thanks.

FOLKS is blessed with an imaginative and hardworking membership, so please continue to support it as actively as you can, particularly by attending the Parents' Day on September 23rd (pencil it in your diary) and by raising money through sponsored events such as Cathy's parachute jump and the Gilhooly's walk along

Hadrian's wall. (See inside for more details). A leap of faith if ever there was one and a gentle stroll in the park, not! Good luck and thank you to our fundraisers.

The Parents' Day will take place in the Midlands. I am currently hunting around for a suitable venue and more details will follow shortly.

The sale of the Christmas cards proved to be a profitable venture; however, my study is still lined with full boxes, so please bear us in mind when buying cards for this Christmas. I shall fill my boot with them and bring them to the parents' day. No pressure!!!

Happy reading and I hope to see you in September.

Yours sincerely

**Angie Conlon
Chairperson**

Our new website – www.friendsoflks.com

We are pleased to announce the launch of our new website. You can now log on at www.friendsoflks.com. This replaces the old website address www.bobjanet.demon.co.uk/lks/folks.html. Anyone using this old address will be redirected to the new site. As you can see, the new address represents FOLKS more closely and is easier to remember. Following feedback from many members we have significantly improved the navigation to make it easier to find the information you are looking for, and also made it easier on the eyes. For those that have already seen it, the feedback has been very positive. Our grateful thanks go to Alistair Curzon who

designed and built the site in his spare time.

You can also send e-mails to us from the site. The address to use is info@friendsoflks.com. Should you need to contact us by e-mail please use this address. The old compuserve address (101361.2530@compuserve.com) will be turned off in due course.

Finally, if you have any comments on the new site, would like something added or changed, please do not hesitate to drop an e-mail to info@friendsoflks.com. We welcome your comments and ideas.

Case histories from members

Continuing our theme of hearing from parents regarding progress of their children with LKS below are two stories from overseas members.

The Tina LaFlure Story

Richard has invited me to write to all of you about our daughter, Tina, who was diagnosed with Landau Kleffner in 1992. Back then things were so different. We were given two sheets of paper explaining what it was, no "cures", or even any recommendations for therapies, drugs, nothing. This was it. Good luck. The internet was relatively new, but still there were no hits when you put in LKS. No one in our upstate New York town had ever heard of it, including doctors and educators. We had no other parents to talk to, nothing. Tina's neurologist in Albany, NY who had diagnosed her had seen one other patient with it, but as you can imagine, you don't get to talk to a man like that real often. He started her on a high dose prednisolone, which at the time was the only course of action being taken. We were fortunate enough to have good contacts at an early intervention educational program, so she started her schooling shortly after her second birthday.

Tina's symptoms were the usual, fading speech until she was down to only one word, social regression, tantrums, eating only one or two foods, very little sleep, little eye contact with people other than Brian and me, no response to pain, sensitivity to certain noises, you all know what I'm talking about.

Tina started the high dose prednisolone treatments in '93. We had to take her off sooner than we wanted to because her blood pressure spiked. But in the short time she was on it we did see improvement. Then it would regress again.

In the beginning of '94 we tried again. This time she showed improvement in speech and behavior. She could even type (the computer was a big help to her) the alphabet backwards in seconds. She stayed on the medication until November of '94. Then miraculously in April of '95 words began coming out again, but this time there seemed to be no regression. We found out that she could read!!! We believe this was from years of reading the "closed captioning" on the TV which we turned on years before to try to help her. (Do this----it works for many). This opened a whole new world for her and us. We now could communicate, (she had never taken to sign language). From that day in April '95, she just kept progressing more and more. Her school scores were going up to her six year age, except for the receptive and cognitive, but that's so much the LKS. She still received intensive speech therapy along with OT and PT.

We dropped the OT & PT when she went into middle school, but kept speech therapy going until 7th grade. We still request consults yearly, but now at 16 they will pretty much be done. TINA TALKS!!! Pretty much non-stop, (many years to catch up on). Since 2nd grade she has been in regular school classes with an aide until 8th grade. We firmly believe that the regular classes helped her immensely, since she was shown proper role models for the different age groups. These kids visually learn, and having her in regular education was one of the biggest and best moves we made for her. Now in 9th grade she is totally independent, has all regular classes, is manager of the field hockey and softball teams, travels independently with them, is on principals list every quarter, and maintains one of the highest averages in SPANISH in the school system. (Maybe we were using the wrong language all these years!!!) The teachers are extremely proud of what she has accomplished

and I know it brings them a lot of happiness to know that they've been part of a true miracle. The doctors in our small town are also amazed at how Tina has recovered.

Tina will go on to have a very normal life. She is looking forward to learning how to drive and going on to college. She has friends now and loves school a big difference from the days of dragging her into places. Now she just blends in with everyone and is asked to constantly be part of teams and projects "because she is so smart" and humorous. People and teachers who meet her now don't realize that she used to be in special education at all. She just blends in.

Personally, we feel that she is quite naive for her age, but that too will change, we're sure. Her eating habits have become fairly normal now, and she's the first to want to go anywhere her friends go. She's been in Girl Scouts for years and really enjoys it. She'll be going for her silver award this year.

So, for everyone just beginning this hard journey, we really want you to know that there can be a successful outcome for our kids. No, we didn't have any of these new drugs they are trying now, and we were in the first bunch of kids that had the high dose prednisolone therapy and early school intervention. We're grateful that she was very healthy, basically, through all this. Maybe it was because of the limited drugs she was on, but we never had any other medical problems. Again, we know how lucky we are. We also believe that this ugly thing does seem to "burn" itself out when they hit puberty. That seemed to be when the huge strides really took place, and once we taught the teachers the teaching methods that worked for her, she just flew. We always keep in touch with her teachers, and have meetings to stay on top of any problems or questions they might have. We've taught them to look for facial expressions which might signify she's having trouble or is very stressed. It's very important to keep that door of communication open with the educators, even when things are going well.

From what seemed like an endless, dark, never-ending nightmare, she has turned into the light of our lives. We are so very proud of all that she has accomplished and how she has blazed so many paths for other kids in the area with similar disabilities. Her diagnosis opened up the eyes of many area paediatricians and educators to keep looking and trying, and not giving up with just a label of "autism". By no means am I saying that the whole trek wasn't hard. But at least now people have others to talk to and information right at their fingertips. We know the value of being able to go on-line and talk to other parents who are facing these many challenges. To be able to talk to educators and finally having them be able to equate a certain behaviour or learning problem

to one they have already encountered is priceless.

Yes, Tina surely is blessed with such a great recovery. But we've too been blessed, not only with her recovery, but we have a super great daughter who has the biggest heart, and is truly a caring person way above her years. And we are blessed too to have met so many wonderful people who have helped us along the way that we never would have known otherwise.

Don't give up. We hope there is a light at the end of this tunnel for you too. We're here if you ever need to talk. BALNCL@aol.com. Thanks for this opportunity to share "Tina's Story" with all of you.

Nancy LaFlure
Queensbury, New York

From down under

Greetings from Down Under!

We received the November 2005 Newsletter editions yesterday - thank you very much. We would like to continue to receive the newsletter via email. Although we do know of other LKS children and parents around Australia we don't get together and it is good to keep up to date with what's happening with LKS.

Our son Wesley (13yrs) was diagnosed with Classic LKS when he was 4 yrs old. He was treated with a cocktail of medications (and steroids) until we found the right combinations and dosage levels. Obviously, these have been monitored and adjusted many times over the years. A few months ago, he was taken off all medications and he has not regressed in any shape or form. It appears as if the epilepsy has burnt itself out. His next check up in February 2006 will hopefully be EXTRA good news! HURRAH! But past experiences have taught us to tread cautiously but hopefully. So we wait. Wesley goes off to Secondary School next year with some Government funding (8 hours per week) for a classroom aide. All through Primary schooling he has had an aide with him 3.5 days a week - a very privileged position in our Victorian Government schools. He still struggles with various aspects of his language skills but wants to learn Japanese! Why not!!! We are amused by this but very proud of him. Because he is a visual learner it might just be the right for him. Wesley is a very independent young man with a flair for drawing and graphics. Much to the dismay of his brothers he is not interested in Aussie Rules or cricket but loves his Tae kwondo. He is also very aware of others' feelings and understands their hurts and disappointments more keenly than other children his age. I attribute this to his experiences with LKS. He has walked the miles so he understands. With that little insight into our boy and us we'll say bye for now.

All the best to all FOLKS in the UK.

Max and Robyn Blythe
OZ

Parents' day - Saturday 23rd September 2006

For the last two years we have held 'Family' days, informal get-togethers, which have been very successful and rewarding to those attending, not forgetting to mention great fun for the kids too. Well this year we want to go a step further and hold a parent and children day. We are currently looking for a suitable venue, probably somewhere in the Midlands. We plan to hire out two rooms, one for the parents and one for the children. For the parents we will invite speakers and have discussion groups. For the children we will provide entertainment and of course carers so you can relax and get the most out of the day.

As I am sure you are aware organising something like this takes a lot of effort. It is important that we have an idea of how many people would likely attend the day. We need to ensure we have sufficient carers and adequate catering. We would also like to know what topics you would like to be covered on the day. Therefore please let us know as soon as possible if you would like to attend and what topics to cover either by e-mailing us at info@friendsoflks.com or by calling the helpline 0870 8470707. We will update you on details of the day early in the Summer. We look forward to hearing from you.

Fundraising

Last year was a particularly successful year for fund raising and 2006 is already looking potentially as good. Regrettably our own marathon man (John Conlon) is taking a break this year but he has promised to make a comeback next year. However we have few other members willing to sacrifice their time and physical well being. Here is what they are doing and how you can support them to help raise money for FOLKS. The choice is yours but both efforts are as equally deserving. If you can't make your mind up then why not split what you are willing to donate between them.

Cathy Cowie taking the Plunge!

"About a year or so ago I dropped into a conversation with my husband Martin that I would love to 'one day' jump out of a plane! Needless to say when he was stuck for ideas on what to get for me for Christmas, he got me my 'longed for' skydive!

Yes, a skydive. After nearly falling off the sofa with shock on Christmas morning I then began to scream with excitement! I then decided that I couldn't just do a skydive for myself; I would also do it for our very own charity FOLKS!

So as you can imagine, I am looking for as much sponsorship as possible to make this one of the most worthwhile things that I have ever done in my entire life! I am taking the plunge in May weather permitting.

If you wish to sponsor me please email me on cathy.cowie@ntlworld.com so I can take your details and also give you my address to post the cheque. If you don't have email, please call me on 01932 889967. So please, please, please dig deep and sponsor me as much as you can!"

Jo and Dave Gilhooly to conquer Hadrian's Wall

"We are celebrating our 10th anniversary this year, and always knew we wanted to do something a bit special, so we decided to walk the length of Hadrian's Wall, which is 84 miles long. It may sound mad, but it will take 6 days, which means we get 6 whole days during the summer alone!! On a more serious note, we really did feel we wanted to try to raise some money for FOLKS. Since James' diagnosis, we have felt so supported. Everyone has been so welcoming and the family days are brilliant. When we heard about the research that had been proposed, we decided to combine a holiday (?!) with a chance to raise some money.

So we are training hard at weekends. Sometimes we take the children with us, and walk up to 5 miles. Other times we drop them off with relatives and walk further. We are also approaching companies and businesses for sponsorship, and have been interviewed by the local paper, which will be doing a feature on us in March.

We would love to hear from anyone who could help us, whether that is sponsorship or advice and tips on raising funds. We will keep you all informed, and let you know how we get on, and look forward to seeing you all at the next family day. Our e-mail address is jodave@ntlworld.com or we can be contacted via FOLKS by calling the helpline."

Remember if you sponsor Cathy or Jo and Dave FOLKS may be able to claim a tax recovery through the gift aid scheme. This means that if you are a UK tax payer and pay tax at least equal to the donation you make FOLKS will be able to

claim 28p on every £1 donated. In our last financial year we were able to claim well over one thousand pounds through the Gift Aid scheme from HM Revenue and Customs. So please support our fundraisers and help us reach our goals.

Fielding House Folks Charity Concert

Finally, in our last newsletter we wrote about Lucia Magee and her school House 'Fielding' at Prior Park College in Bath who had chosen FOLKS as their charity of the year. Lucia's mother Marie-Suzanne tells us below how well the fundraising is going.

Prior Park College, Fielding House Charity Concert in aid of their charity of the year FOLKS took place on Friday 3rd March in the John Wood Chapel. The guests were family and friends of the pupils. On arrival we were greeted with a drink and programme of the evening's entertainment. The concert hall was buzzing with anticipation; girls were running in the outer corridors dressed in all manner of outfits. By 7pm the room was packed and the show began. Mrs Brierley, House Mistress, introduced the evening's events and emphasised that this was a friendly occasion where we all needed to support the performers, many of whom were nervous about singing on their own. Juliet, the charity representative then

talked about FOLKS and Landau Kleffner.

The first ensemble were the upper sixth tutor group who confidently sang 'Lean on Me', this was followed by Mrs Brierley who bravely sang a solo with piano accompaniment of the Sting classic 'Fields of Gold'. The acts that followed included uplifting songs from musicals, the highlight of which was the lower 5th, who dressed as lions sang and danced 'I just can't wait to be King' from Disney's The Lion King. This is one of Tosh's favourites and we all enjoyed singing along. There were also violin, bassoon, saxophone and piano solos. The range of material stretched from Beethoven to Jazz to show stoppers to Irish ballads to pop and ended in us all joining voices to sing happy birthday to the head girl who had given up her evening to be there.

As a mother to four children I have been to many children's concerts in my time. None have been quite as engaging and fun as this concert was. The enthusiasm of the children and the effort that all involved made as well as the time that had been given to put it all together was demonstrated by the success of the evening. The contributions at the door, the money made from the bar and the proceeds from the raffle are still to be added up. Last year £300 was raised; the girls are hoping to do better this year. Watch this space!

Wednesday's child

A big thank you goes to Wednesday's Child who very kindly donated £2000 to FOLKS to help fund our Parent Day later this year. Wednesday's Child, a charitable trust, was founded in 1987 by a group of friends living in North London. Since then Wednesday's Child have raised over £100,000 enabling funds to be given to a wide variety of selected children's charities. Such charities cover illness, disability, poverty and other social issues. Clearly the efforts of Wednesday's Child have helped a great number of support groups and we

appreciate their consideration of and donation to FOLKS. From all at FOLKS a big thank you.

Great Ormond Street Hospital launches consultation on plans

Great Ormond Street Hospital for Children NHS Trust (GOSH) is launching a consultation on new plans to become an NHS Foundation Trust. This will mean that families will be more involved in the improvement of their services and the way in which the hospital is run. The Trust would very much like hear from you, particularly if your family has had to use their services in recent years. In particular, they would like you to help them by commenting on their vision and plans for the hospital, and considering whether you would like to become a member.

As you may know GOSH has the widest range of children's specialists of any UK hospital and is a leader in the care of children with rare and complex conditions. It is the biggest centre for research into childhood illness outside the USA and the largest centre for children with cancer, or needing heart or brain surgery, in the UK. Recently they have also taken on the running of the local children's services based at the North Middlesex University Hospital, and a small team of community doctors in Haringey.

Foundation Trust status means that GOSH remains part of the NHS and committed to the care of children. They will have more flexibility in how they meet national targets, and they hope quicker decision-making. There is more financial flexibility, although there will be no extra money.

As a Foundation Trust GOSH will have a membership, largely drawn from staff, families, patient support groups, and others interested in child health. Membership is free. The membership elects a Members' Council which helps the Trust with strategy and also appoints some directors. They will use the membership as a sounding board to help them improve services. They see active parent and support group involvement as absolutely crucial. Membership information is available from the websites and Louise Bounds, (see her contact details below).

GOSH believes involving children and young people is extremely important and is committed to listening to them regardless of their age. We are proposing that young people should be able to be members from the age of 12, and should be able to stand for the Council from 16. Current rules do not allow children below the age of 16 to become Councillors. We are keen to hear from people, particularly young people of any age, about what they think, and to develop other ways to listen to them.

The consultation runs from 27th February until 26th May. There is information for grown ups on www.gosh.nhs.uk/foundation and for children and young people on www.talk2gosh.nhs.uk If you would prefer you can email or phone Louise on 020 7762 6761 foundation@gosh.nhs.uk to ask for the consultation document.

And Finally.....

Well we have a new website but while we congratulate ourselves on achieving this we should also take this opportunity to thank a few people for their support in the past. Firstly to Bob Warwicker who created the original website and also to Robert Hantusch who has maintained the site in more recent years. Thank you to the both of you for your help and assistance over the years.

On 23rd September we will be holding our annual event as referred to earlier in this newsletter. Although the majority of the day is set aside for members to learn from others experiences and gain further information from each other and guest speakers, I will be looking to set aside a short period of time (approximately 15 to 30 minutes) to conduct some formal business. The purpose of this is to hold an Annual General Meeting (AGM) to enable the election of a new committee, present Officers' reports and discuss any other matters you put forward as members. For a few years now we have not been able to hold a formal AGM due to an insufficient number of members attending. I hope that this year we can deal with this matter. I am pleased to advise that all the Officers of the current committee are prepared to stand for re-election. However should anyone wish to stand for election to the committee then please forward your nomination in writing to myself. In addition, if there are any matters you wish to add to the agenda for

the AGM please again advise me in writing. Both your nominations and agenda items should reach me by no later than 31st August 2006. We will be writing to you all later on in the year with further details of the day, at which point I will also remind you all about the AGM. As I have stated in previous newsletters we would gratefully welcome new blood to the committee. 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@friendsoflks.com.

Finally, many people have e-mail these days and keeping people informed and issuing newsletters by e-mail can significantly reduce costs. Therefore, if you do have e-mail I would be grateful if you let us know your current e-mail address so that in future we can send our newsletter and other information this way. If you are happy to do so, please e-mail your name and post code to info@friendsoflks.com. If you received this newsletter by e-mail please ignore this request.

Many thanks and I look forward to your continued support.

Richard Budnyj
Secretary

Remember Parents' day' is 23rd September. If you are intending to come please let us know as soon as possible so that we can make the necessary arrangements. Please send an e-mail, detailing attendees (names and ages) to info@friendsoflks.com or call us on the help line 0870 8470707.

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@friendsoflks.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 and Janet Pain.