

# Newsletter

## May 2008



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

---

### Contents

---

Introduction  
Case Histories from Members  
Gala Fundraising Dinner  
Fundraising  
And Finally .....

---

### Introduction

---

As we settle into a sweltering May, I feel as though I have worn my entire wardrobe to tackle the elements of April. You, too, may have seen snow, rain and hailstones, heard thunder and been blown about by the wind and, oh yes, seen the occasional ray of sunshine! Like the weather our lives can indeed be changeable. Sometimes, full of doom and gloom and only intermittently being blessed with a little bit of light at the end of the tunnel. So on that note, I would like to welcome you to our first newsletter of 2008!!!

A great deal of activity has been taking place behind the scenes, since my last communication and I would like to personally thank all the members of the Committee for their continued hard work and commitment.

I am hoping you will find this newsletter of great interest and value to you. All our efforts are focused on developing a better understanding of LKS, so that parents, carers, teachers and the medical world can help to provide children suffering with this condition maximise their potential and minimise the impact that it can have.

Have a read through the members stories, a snippet may relate to you in some way that perhaps could lead you down a different road. Familiarise yourself with the fundraising activities including our **Gala Charity Ball on Saturday 27 September, 2008 at the Heathrow Marriott Hotel**. We will be devoting a large proportion of our next newsletter to the GOSH research that we are helping to fund which is why your support, and that of family, friends and work colleagues, is SO critical to the success of our

Gala Charity Ball.

This is promising to be a truly wonderful evening and, definitely, not one to miss out on. It is a fantastic opportunity to raise awareness of our Charity, but at the same time help to provide much needed funds to continue the work on researching LKS. We already have some fantastic lots to auction, but, if you are in a position to be able to offer that extra-special donation, please email FOLKS so we can add it to the list. Please don't forget to keep this date free, enter the event into your diary, as tickets are now available to purchase either individually as a couple or if you prefer in tables of ten.

Finally, as always, in those darkest days of despair, do try to remain positive and recognise even the smallest good thing. See every problem and obstacle as an opportunity and keep in the forefront of your mind, or your frontal lobe what you ultimately are aiming for. Be proactive and plough your energy into what you can do and change!! It is so important to be upbeat and focused to be one step ahead of this syndrome.

I look forward to seeing you in September at what will no doubt be a fantastic event.

Happy Reading!

Angie Conlon  
Chairperson for FOLKS

---

## Case Histories from Members

---

### Emily's story:

The week preceding me writing this article my 14 year old daughter got a school detention. It is something I met with secret happiness. I had to pretend to be serious, but inside me I was delighted. You see, when she was a toddler I was told she would never speak, and that her comprehension of the verbal language would be limited. Her future was uncertain. I never imagined that one day she might go to the beach after school and swim with her friends in her school uniform and get caught! The look of happiness and delight on her face when she told me how much fun they had on that hot summers' afternoon is something I will always be grateful for. Teenage daughters can be challenging, that's for sure, but I am so grateful for those challenges.

When I reflect back on the last 14 years I find it hard to recall the details, but I know that there are many of you right in the middle of those details right now. I just know what a tough fight it was for us and how important it is to keep fighting. Never give up. Emily developed normally and apart from sleeping problems, feeding problems and colic, she developed normally - speech included. One day however I remember shouting at her "are you deaf". It dawned on me that day that she didn't seem to be hearing, and not only that but her behaviour was just awful. We went through the usual run of the mill testing - hearing tests all normal, she needed grommets they said - still no improvement. No-one helped or believed me. Eventually I went to a new GP and said I wanted two referrals - one for me to see a psychiatrist and one for Emily to see a Paediatrician. I honestly didn't know if it was me who needed the help or my daughter. Luckily for us all I got an appointment with the Paediatrician first. I never went to the psychiatrist.

This started the path to Emily's recovery. I was so pleased to finally have someone tell me that there was something wrong and this terrible thing had a name. I finally could have a plan of treatment. It

### Scott's story:

I successfully have recovered from having LKS. I have just passed my 46th birthday and I have been fortunate and blessed to be seizure free and medication free for 30 years. The neurologist who treated me, Dr. Isabelle Rapin of Albert Einstein College of Medicine in the Bronx, NY, says that I have had the most remarkable recovery of any of the LKS patients she has worked with. I am not sure if I can be of any help for people who either have LKS or parents of children with LKS, but I am happy to share my story.

took a long time and a lot of work but Emily got better. I remember so clearly that awful feeling of having your daughter go missing. To look at her and see this little body, but the thing that made her Emily was gone. That indescribable thing that made her who she was had disappeared.

The treatment started with big doses of Prednisolone. She got fat and round. We managed to fight hard for a full time teacher's aid at the local primary school. We learnt to sign. We did speech education. We got help with her behavioural problems. I read and researched everything I could on the subject. I joined FOLKS. I went to every talk on anything that was remotely connected to what could help Emily. We got her a dog. Slowly, slowly she started to improve. To begin with, her Paediatrician thought that the Prednisolone did not help, but for me I could see a little light go on in her head. I knew it had triggered whatever it was that she needed to recover, and with all the other support going on, she got better.

Today she is doing so well. To me it is like she has climbed Mount Everest! She plays hockey, she talks to her friends for hours on the phone. She hates school! She hates homework! She is getting good grades. She is able to stand up in class and give a speech. She got As in Japanese and French. Can you believe that - I never thought she could speak English, let alone Japanese and French.

Sometimes there are little reminders of the LKS. Things only a mother would notice. When she gets tired, her words get a little tangled. She has learnt to laugh at these moments and make light of them with her friends, not get upset. She doesn't always "get" things and needs a bit more explanation than her younger sister. She is a dreadful sleeper - still! Nobody, nobody would believe what she went through, where she was and what she is today. It is a miracle. It is a miracle I hope that all of you experience.

Emily's mum Helen Saunders

A little about myself: I am married and have working as a bank teller for nearly 10 years. I have both a Bachelors and Masters degree and feel that I should be teaching and am considering that possibility. I believe in trying to learn something new everyday - big or small. I am involved with my church and enjoy the work I do there as a lay speaker/preacher the most.

I do want to tell you that I have a daughter who is now experiencing benign Rolandic epilepsy. Dr. Rapin informed me that my EEGs showed Rolandic spikes and we are willing to try to help with exploring the genetic link in epilepsy and other seizure related illnesses.

Dr. Rapin did include my case in a paper she collaborated with others on:  
Verbal auditory agnosia in children. Rapin I, Mattis S, Rowan AJ, Golden GG. Dev Med Child Neurol. 1977 Apr;19(2):197-207. (I am written about as Case 1).

I do like your website and have directed a few people there to just get information. However, I do know that I live here in Connecticut and FOLKS is based in London and that might be an inconvenience, but if I can be of help for someone, please let me know!

Scott Welliver

---

## Gala Fundraising Dinner

---

Over the last few years we have held parent and family days that have been very successful. Unfortunately, last year we had to cancel the family day due to the limited interest. So this year, we thought we could do something a little different and at the same time meet some of our objectives. For example, sharing our experiences for the benefit of others and continuing to raise money for FOLKS. Conclusion! Hold a Gala Fundraising Dinner. This will give parents the opportunity to meet with like minded people and have some fun (we all deserve that) and at the same time raise monies for FOLKS to help us with our research goals.

So as Angie states in her introduction, please make a note of **Saturday 27 September, 2008** in your diary. The venue is the **Heathrow Marriott Hotel**. **Tickets** are now on sale at £55 per head, which includes 3 course meal and first class entertainment. To purchase your tickets please complete the tear off slip at the end of this newsletter and send it, together with, your payment (cheque only and payable to FOLKS) to Angie Conlon, Osborn Cottage, Eggington, Nr Leighton Buzzard, Beds, LU7 9PD. Your tickets will be

issued on receipt. If you wish to stay overnight we have obtained concessionary room rates at the hotel. These are £93.00 for a Double Room including breakfast or £81.00 for a Single Room including breakfast. Please book these directly with the hotel quoting 'FOLKS.'

We have some really exciting things lined up for the evening including a spectacular auction, great raffle prizes and first class entertainment. Just as a taster, for those budding 007's you can bid for a weekend's exclusive use of an **Aston Martin** or for the more cultural types **afternoon tea at the House of Commons**. We have managed to obtain some truly exceptional auction items. However, we really need more donations for the auction, so if, you have any contacts please use them. Even if you can't make the evening you can still support FOLKS by helping with obtaining auction items. Maybe you have a sporting contact or a friend who owns a shop.

Hopefully we will get the support required and we will see many of you on the 27<sup>th</sup> for a really enjoyable and successful evening. Don't be disappointed as we expect to sell all the tickets.

---

## Fundraising

---

Once again we are truly grateful to those that raise money for FOLKS. Whether it be a small donation, significant sponsorship or a fund raising event we are very lucky that FOLKS is the chosen charity. Without this support we could not do what we do. Here are just some of the ways we have been supported recently and events planned for this year.

### Gala for a King

In October 2007 - Steve, Tina and George King arranged a Charity Ball to raise awareness and money for FOLKS. The event was a great success and everyone enjoyed the evening. Many of their friends and family attended and their managed to raise £5730.85 which included Barclay's Bank matching proceeds policy which amounted to £2250.00.

They were bombarded with raffle prizes including generous donations from local businesses and restaurants. The stand up bingo was a hoot and pockets were emptied willingly!



The Ball was well supported and the 80 tickets sold out quickly. We certainly raised awareness and understanding of Landau Kleffner Syndrome.

Steve said “despite having very strong friendships we have never really divulged the nightmare of ten years ago. I explained what happened to George, and our family and the importance of the continued work of our group. Unfortunately, with not a dry eye in the house, I quickly explained how fortunate we are and thanked them all for their support”.

Marie-Suzanne and Patrick will be running again this year in the Manchester 10K to raise money for FOLKS.

Miriam Curtis is likely to hold what is now an annual concert in Manchester in the late Summer. Ros Kenny has indicated that the successful Manchester/Ballyshannon fundraising Pool tournament held last year (which raised over £3500) may happen again this year.

Thank you to them all.

---

## And Finally.....

---

Firstly and once again a big thank you to all the contributors of this newsletter and to all those that have raised money for FOLKS over the last year. It is fundraising and donations that allow us to continue as a successful charity. So keep thinking and acting on ways, in which, we can raise more funds to support our goals for the future. Be it £50 or £5000 it all makes a difference so think what you, a relative or a friend could do in 2008.

Secondly, having to cancel the family day last year was a huge disappointment for us as a Charity. We are here to support parents of children diagnosed with LKS. Giving the opportunity to get together once a year is a real benefit to those struggling to deal with this condition. I know as a parent of a child with LKS and also as a trustee of this charity that sharing our experiences is invaluable and we are all more than happy to do it, as we relied on the support we received in the early years. So if you are new to FOLKS and struggling to understand LKS or a seasoned LKS parent then please support us at our Gala Fundraising Dinner in September. We

don't get many chances to meet up so let's take advantage of it and have a great evening at the same time.

And finally as I have stated many times in previous newsletters we would gratefully welcome new blood to the committee. I make no apologies for continually reminding everybody but without new blood we don't move forward. 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@friendsofllks.com](mailto:info@friendsofllks.com).

Many thanks and I look forward to your continued support.

Have a great summer and hopefully we will see you in September.

**Richard Budnyj**  
**Secretary**

---

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@friendsofllks.com](mailto:info@friendsofllks.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.

**FOLKS Charity Gala Dinner**

I require ..... tickets for FOLKS Charity Gala Dinner at The Heathrow Marriott Hotel on Saturday, 27 September at £55 per head.

Payment enclosed of £.....  
(Please make cheques payable to FOLKS)

Full Name .....

Telephone No .....

Address .....

.....

.....

.....

Postcode.....

Please advise if any of your guests are vegetarian.

Send your payment with this form to:

Angie Conlon  
Chairperson for FOLKS  
Osborn Cottage  
Eggington  
Nr Leighton Buzzard  
Beds  
LU7 9PD