

# Newsletter

## November 2007



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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As I write the introduction for this newsletter, there is something very prominent in my mind that I feel I would like to share with you. Today (October 3<sup>rd</sup>) is a very important and memorable day for us as a family. 5 years ago, our little boy, Michael underwent Multiple Subpial Transection (MST) brain surgery at Kings College Hospital in London.

As I put pen to paper I'm very aware that the weather is very similar to that of 5 years ago, both warm and sunny. Thinking back to that day, my husband and I spent the majority of the time sat outside a little bistro just around the corner from the hospital, in shock, deliberating as to whether we had made the right decision putting him through such an ordeal, agonizing, hoping and praying that the operation would be a success. Well the weather may have been the same today, but believe me, our little boy, Michael is now completely different. He is completely unrecognisable to the pathetic, unhappy, frightened and extremely poorly child we handed over to the surgeon. I, honestly, hadn't seen Michael smile for months but he woke up from the operation and gave me the thumbs up and smiled. We could not believe what we were seeing!

Now you may be wondering why I am sharing this with you. It's simply because I want to prove to you that there is hope, and in fact miracles do happen. I don't want to come across as if I am preaching but having spoken to numerous desperate

parents/carers on the helpline, time is of the essence, catch it early and the prognosis can be good, do nothing and the damage can be debilitating for the rest of your child's life. I don't mean to be a scaremonger but be pro-active, keep asking questions and if you do not get the answers you need, don't be discouraged. Find the courage to ask somebody else. I implore you to stay focused, remember what you are aiming for and leave no rock unturned. Anything is possible.

On a slightly less positive note, it was so disappointing to have had to cancel the Family Day due to a lack of interest. If a Family Day is not what you'd like, I have to rely on you to tell us what it is you do want, so that it can be organised. Give us feedback, share your experiences, make suggestions, join the committee, voice your opinion, and fundraise! This is your charity after all! You can either call the helpline or email via the website. I'm sure you'll enjoy reading this newsletter, it's packed with information which I hope will be of benefit in some way. With Christmas fast approaching, FOLKS Christmas Cards can once again be ordered via the website [www.friendsofllks.com](http://www.friendsofllks.com). Please order from us, and encourage your friends and relatives to do so as well to help us raise those extra funds. The more money we can raise the more we can do to help sufferers of LKS. Finally, may I take this opportunity to wish each and everyone of you the very best for 2008.

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## FOLKS donation to GOSH for research

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Over the last few years we have made great progress in achieving our objectives. We have comprehensively updated the information available to parents, carers and the medical profession through our new website and information booklet, issued regular newsletters and held annual events. As we discussed with members at the last AGM we are now in the position to make a donation to research. This is a significant milestone for FOLKS and one we are really proud of achieving.

For some time now we have been in consultation with Great Ormond Street Hospital (GOSH) about how best to support research. As result of these consultations we have finally reached a decision to support a Research Fellow to research specific mechanisms of LKS.

The Research Fellow would work specifically on LKS and its basic mechanisms, studying neurophysiology, using investigative mechanisms such as MRI scans, and research treatment and outcome. A clinical research fellow is a junior

doctor who has been qualified for five or so years, taking time out of clinical work to do research before returning to clinical work and applying for a consultant job. FOLKS will be making a donation of £30,000 to support the salary for the first year for the Research Fellow. The results of that year's research would be used to apply to the Medical Research Council to fund a further three years work. Funding from MRC is extremely competitive and there is no guarantee that further funding could be found. However, the trustees believe that with the support of Professor Brian Neville and his team at GOSH there is a good chance of obtaining further funding. Whatever research we select, our £30,000 donation would only be a 'kickstart' so we are taking a measured risk but one we feel is worth taking.

We will keep you posted on progress on what we believe to be a significant step forward for FOLKS and in finding answers to why children suffer with LKS.

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## Need another opinion

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LKS at Guys and St Thomas Trust (GSTT)

GSTT has hospitals on several sites in central London. It has a large Paediatric Neurosciences department within which several of the Consultant Neurologists specialise in epilepsy. We receive referrals from all over the UK (and sometimes further afield) from local or regional services, either for medical investigations such as video telemetry or for confirmation of diagnosis, specialist advice and assessment.

The initial referral will normally be from the neurologist who originally saw, or diagnose, your child, to one of the neurologists at GSTT, perhaps for a sleep EEG or a repeat EEG looking at the type, amount and focus of abnormal electrical activity in the brain. There may also be a question about appropriate anti-convulsant medication, whether or not an MRI scan would be of value, or indeed, whether surgery is an option. You will of course usually have had some of these discussions with your neurologist locally.

Irrespective of the reason for the referral, the neurologist will always ask for a detailed neuropsychological assessment and speech and language assessment from other team members (the neurosciences department has, as well as neurologists, psychologists, speech and language therapists, occupational therapists, consultant paediatricians, a consultant neurophysiologist and

a neurosurgeon, among others).

These assessments are especially important if the neurologist is contemplating a change in medication (e.g. introducing steroids), or if a surgical procedure is to be undertaken (i.e. multiple sub-pial transection or MST) so that baseline measures of the child's abilities can be obtained for pre- and post-treatment comparison. However, even when such treatment options are not being considered, these assessments are routinely undertaken in order to track progress or change over time.

Once the assessments have been completed the family is given some immediate feedback about the results. Detailed reports are then sent to the family, and these reports will usually contain recommendations about appropriate educational placement and strategies for intervention with regard to communication skills.

Review assessment will usually be scheduled for 6-9 months after the initial assessment, and these reviews continue annually until such time as they are no longer deemed necessary, or until the child is discharged from our service.

Martin Smedley  
Paediatric Principal Speech & Language Therapist  
GSTT

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## Fundraising

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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 this year.

### Charity Pool event in Eire.

On the bank holiday weekend in August, James and Christine Kenny, myself and 12 members of the Manchester Pool League and their partners travelled by mini bus to Ballyshannon, Co Donegal, Ireland. The purpose of the trip was to play in a tournament against various pub Pool teams to raise money for FOLKS.



The lads played 4 matches against the Travellers Rest (Cashellard), Macs Bar (Ballyshannon), Sean Og's (Ballyshannon) and the Black Cat (Belleek). A great time was had by all and the generosity of the Donegal people was outstanding. As the pool tournament was a joint venture a proportion of the monies raised will be donated the Parkinson's Association in Ballyshannon.



The total amount raised so far is £3,666 and there still more sponsor money outstanding. Many thanks to Brendan Gallagher who organised

everything on the Irish side and to the proprietors of the Irish pubs mentioned above who kindly made generous donations. Not forgetting a big thank you to our sponsors in Manchester.

We felt the trip was a great success, not only because of the money we raised but because it raised awareness of Landau Kleffner and FOLKS. Planning has already started for another trip next year.

Ros Kenny

### London Marathon one last time!

You see impossible; I saw the finish line; nothing is impossible.

Whilst this was the sponsor's strap-line for the 2007 London Marathon, I think it is a fantastic vision for all we stand for in FOLKS.

It also had further significance to me given that I didn't see the finish line in the 2005 race, still due to unknown circumstances although a betting syndicate having spiked my Lucozade sports drink does seem to be the mostly likely cause!!!!

Well, here I was, at the start line with things not looking good as the weather decided to provide a summer's day – indeed it got up to circa 90 degrees on the race track. I decided at this point that, the time was irrelevant and I just had to finish.

The gun fired and I was quickly into my stride, my confidence grew as I passed a 10 man chain gang; the army regiment in full battle dress; a chap dressed in a woolly Scooby Doo outfit and another wearing a telephone box (wasn't sure if male or female) in the first 10 miles!!!

I settled down into a pace, which would ensure the gap between the race leaders and myself was kept to 2hrs!!! As always, the crowd was fantastic; cheering all the way around and pushing me on towards the finish line. I saw my family for the first time of the race at 15 miles, which gave me a real lift. That was a heart in the mouth spot for them as in 2005, they had seen me at 15 miles but I never reached the 19 mile marker where they were waiting for me to pass them again. I, unfortunately, collapsed at 18 ½ miles.

This year between 15 and 19 miles, I got cramp which meant I had to slow down and did not arrive at the 19 mile mark at the anticipated time. The water I was pouring over myself had got into my phone so when they had tried calling, there was no answer. They were very anxious that I had met the same fate as in 2005 but as I emerged from the tunnel sprinting past a 76 years old lady, I shouted to them, never fear, JC is here!!!!

By this time not only had my phone broken but my

timer and my running belt had too and as I handed these now useless items to my sister, she kindly remarked that I could do with a handbag. By now, I knew that I was going to finish, it was just a case of not doing anything stupid over the next 7 miles.

I absorbed all, of the atmosphere over those final few miles knowing this was probably going to be my last London Marathon. As I crossed the finishing line, I felt such a great sense of achievement given the disaster in 2005. My time of 4hrs 25 mins was 35 minutes slower than in 2002, but this was the hottest race on record and my aim was to finish no matter what.

Whilst I felt I had run within myself, it soon became apparent that I was very dehydrated and low on body salts as I felt very faint and light-headed, cold and clammy. One look at my grey face from my brother and that was enough to put him off ever running a marathon. Having my family there at the end to greet me was fantastic and my efforts would have been so much harder without their support.

However, the real hero's and heroine's here are all those that sponsored me. The £ raised in 2002, the

£ in 2005 and £ in 2007. This in total gives over £ raised for FOLKS. I really do appreciate your generosity.

As I now sit here; unfit; 10lbs heavier and with the African runners relieved that I have retired from marathon running there is one significant memory – nothing is impossible.

John Conlon (retired marathon runner)

### **An evening of Music and Art**

Two years ago a young lady in Manchester (who suffered with LKS as a child) decided one way to celebrate her 21<sup>st</sup> birthday was to hold a concert and in doing so raise money for FOLKS. On 13<sup>th</sup> September this year and for the third year running Miriam Curtis organized an evening of music and art.

Miriam, who plays both the violin and piano, together with her music and art friends raised £400.

Well done and thank you to you all.

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

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Firstly, 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 charity and I am pleased to advise that even after making our significant contribution to research we still have sufficient funds to keep FOLKS running for the foreseeable future. If we also take into account future fundraising we should also be able to consider future support for research. 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, it was with regret that we had to cancel the family day this year but to put it simply very few people advised us they would come. This is a shame as anyone who has attended previous days will tell you what great benefit they get from meeting other parents. Hopefully next year's event will get the support required. As you know we have varied the events over the years from informal to more formal events with guest speakers. We need you as our members to tell us what you want so please drop us an e-mail with any ideas. We acknowledge that travel can be an obstacle particularly with children which is why we have always sought to have the venue somewhere in the Midlands. Again we are happy to consider other proposals.

I would also like to draw your attention to an article (to which I contributed) about a child with LKS in the November edition of Discover Magazine. To read simply add the following link to the address bar on your internet explorer.

<http://discovermagazine.com/2007/nov/boy-interrupted/>

And finally as I have stated many times 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@friendsofiks.com](mailto:info@friendsofiks.com).

Many thanks and I look forward to your continued support.

Have a great Christmas and 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, Secretary, 8 Malibres Road, Chandlers Ford, Hants SO53 5DT, alternatively e-mail to [info@friendsoflks.com](mailto: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.