

# Newsletter

## March 2005



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#### Executive Committee:

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

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### Introduction

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Spring is upon us and I hope that you are able to share in the air of cheerfulness, anticipation and optimism that it brings.

It has been a good year for FOLKS in that the background organisation and general business have been much improved in its running, and is now far more efficient. For this, I thank all the committee members and in particular Cathy Cowie. Cathy is probably suffering with Repetitive Strain Injury, after all the hours she has spent on the computer updating the database.

As you are probably aware, the FOLKS website is not very "user-friendly" and it has been one of the committee's aims to have it reviewed and updated. We are currently looking at ways as to how this can be achieved.

A date for your diary, **Saturday 10<sup>th</sup> September 2005**, FOLKS will be hosting another 'Family Day'. This year, it has been booked at **Skallywags, Brierly Hill, near Birmingham**. They are fairly centrally located, so hopefully, we will see lots of you there. It was a huge success last year, and Joanna and Dave Gilhooly have written an article of their experience from the day. At the back of the newsletter is a return slip for you to complete if you are planning to attend. We look forward to seeing you.

FOLKS is your support group and I hope that when you have contacted any of the committee members or the Helpline, the experience was positive and that you have been assisted in some way. We endeavour to provide as much knowledge and guidance as possible on all aspects of LKS. The Helpline will also be able to provide you with further sources of information and contacts.

The aim of the FOLKS newsletter is to update you and to reassure you during your most desperate times. Support is only a phone-call away.

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

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### Family Day 2004 at Snakes and Ladders

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Last September we travelled to Snakes and Ladders near Oxford for a day of family fun. We were a little apprehensive, yet very excited as well. We didn't know anyone going, and were unsure even of the arrangements for the day! But we were desperate to talk to someone about our son without the inevitable question.... "Landau what?"

James, our eldest child, is 7 years old. He was first diagnosed with Benign Rolandic Epilepsy just before his 5th birthday and with LKS the following year. We did not know anyone else with this condition, and felt very alone, and so were excited when the opportunity came to go to a fun day and meet other families. We thought it was important also for James to see other children with the same difficulties he had, and for Jessica, our 6 year old, to see other siblings of LKS.

On arrival we quickly saw a group of families and sure enough were directed towards them. At once I (Jo) felt shy and nervous and wondered how I would cope, as it appeared everyone else knew each other! But I really needn't have been concerned; everyone was friendly and we were soon chatting about all sorts! It was great to discuss education, drugs and behaviour issues with other parents without having to first explain what Landau Kleffner is!

The children played happily, running around like maniacs and thoroughly tiring themselves out! James thought it excellent that another boy there with his condition also shared his name! He still talks about him now.

It was a very long day and we were all shattered, but it was definitely worth it. We learnt so much about the drugs and procedures we had before only read about. We were able to talk to parents who had lived with LKS for a lot longer than we had, and who were further along the "journey", some beyond the surgery route. Suddenly you don't feel quite so alone.

James' condition seems to change frequently. Just as we feel confident that he is stabilising something changes; one of the drugs doesn't appear to work anymore; or the something changes at school and we feel like we have to start over with the explanations. We are alone in that there are no other LKS children in our area, but we now realise we are far from alone. We would recommend to anyone considering going to a family day to take the plunge and go! We were

made to feel relaxed and welcome and valued.

I (David) on the other hand was not looking forward to a 2-hour drive followed by a few hours in one of those dreaded places, A BALL PIT. After our initial trepidation of being with a group of people we didn't know, I soon felt part of the family. Discussing James' medication, being concerned about the level of steroids he was on, only to be told that other children there were on much higher doses than him. Talking through the fears we had as parents that only someone who had been through having a child with LKS could understand and being able to do all this while the children were happy and content to run about and only bother us when they were hungry or thirsty. The day passed very quickly, too quickly with still questions unanswered, but happy in the knowledge that we now had someone to ask. Now all we had to do was negotiate a 2-hour trip home with three over-excited children. No problem, they all went to sleep.

**Jo & David Gilhooly  
Derby**

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## **London Marathon 2005 'One more time'**

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YES IT'S TRUE - I have come out of retirement for one more crack at the London Marathon.

I have two goals this time around, the first to better my previous time of 3hrs 50 minutes and the second to beat the £6395 raised for Charity in 2002.

I will be raising money for:-  
FOLKS (Friends of Landau Kleffner Syndrome), supporting children with LKS and their families.  
and ERF (Epilepsy Research Foundation) which funds vital research to benefit the 400,000 in the UK affected by epilepsy.

I do appreciate that many of you were extremely generous in 2002 but this will be the last opportunity that the British public will have to see Paula Ratcliffe and John Conlon going head to head in competition. Remember, the gap between us last time out was only 11/2 hours!!!

It is also very unlikely, that I will be following Kelly Holmes as 'sports personality of the year' so, please, pledge a donation by either completing a sponsorship form, emailing me at [john.conlon@whitbread.com](mailto:john.conlon@whitbread.com) or sending a cheque made payable to FOLKS to Osborne Cottage, EGGINGTON, Nr Leighton Buzzard, Beds. LU7 9PD.

Thank you in advance for your support once again.

For those of you who think I have "weathered well" it's not that I've had Botox injections - it's because the photo was taken 3 years ago!

**Regards  
John Conlon**

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## **NICE guideline**

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CG20 The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care.

In October 2004 this clinical guidance was issued by NICE (National Institute for Clinical Excellence). The guidance itself runs to some 74 pages and is easily accessible from the NICE website. [www.nice.org.uk](http://www.nice.org.uk).

The key recommendations are as listed below.

**Key priorities for implementation**

**i) Diagnosis.**

- All individuals with a recent onset suspected seizure should be seen urgently (a) by a specialist (b). This is to ensure precise and early diagnosis and initiation of therapy as appropriate to their needs.

- The seizure type(s) and epilepsy syndrome, aetiology and co-morbidity should be determined.

**ii) Management.**

- Healthcare professionals should adopt a consulting style that enables the individual with epilepsy, and their family and/or carers as appropriate, to participate as partners in all decisions about their healthcare, and take fully into account their race, culture and any specific needs.

- All individuals with epilepsy should have a comprehensive care plan that is agreed between the individuals, their family and/or carers as appropriate, and primary and secondary care providers.

- The AED (anti-epileptic drug) treatment strategy should be individualised according to the seizure type, epilepsy syndrome, co-medication and co-morbidity, the individual's lifestyle, and the preferences of the individual, their family and/or carers as appropriate.

**iii) Review and referral.**

- All individuals with epilepsy should have a regular structured review. In children, this review should be carried out at least yearly (but may be between 3 and 12 months by arrangement) by a specialist. In adults, this review should be carried out at least yearly by either a generalist or specialist, depending on how well the epilepsy is controlled and/or the presence of specific lifestyle issues.

- At the review, individuals should have access to: written and visual information; counselling services; information about voluntary organisations; epilepsy specialist nurses; timely and appropriate investigations; referral to tertiary services, including surgery if appropriate.

- If seizures are not controlled and/or there is diagnostic uncertainty or treatment failure,

individuals should be referred to tertiary services soon (c) for further assessment.

(a) The Guideline Development Group considered that 'urgently' meant being seen within 2 weeks.

(b) For adults, a specialist is defined throughout as a medical practitioner with training and expertise in epilepsy. For children, a specialist is defined throughout as a paediatrician with training and expertise in epilepsy.

(c) The Guideline Development Group considered that 'soon' meant being seen within 4 weeks.

It should be noted that this is a clinical guideline, and defines what best practice should be - not what is currently available or provided.

The guideline also identifies the drug treatment strategy that can be used for the treatment of LKS identifying drugs that should be used and those to be avoided. It should be noted though that the treatment of LKS is almost as individualised as the child with epilepsy - and what works for one child may not work for another - although the symptoms displayed may be similar.

Syndrome	First line treatment	Second Line treatment	Other	Drugs to be avoided
Landau Kleffner Syndrome	Lamotrigine (Lamictal) Sodium valproate (Epilim) Steroids	Levetiracetam (Keppra) Topiramate (Topamax)	Sulthiame	Carbamazepine Oxcarbazepine

**Our son - his parent's story of progress**

It all started at the age of five when he started school. We were called in as the teacher said that he did not seem to understand simple things like "pick up the pencil". We sought some medical advice and were sent to see various experts

who suggested an EEG first of all which revealed spiked waves at night. We had several 24hr monitors over the next few years. He went to be assessed to see what level of understanding he had and it became clear that it was probably a brain decoding problem. This linked with the spiked waves at night seemed to point to a rare condition called LKS.

We tried various medications, including steroids over the next few years and went back every 6 months to see the specialists together with repeat 24hr EEG's which he hated. Then the spiked waves seemed to stop and he had normal EEG's.

He went to a mainstream primary school where he was 'statemented'

and had help in the classroom with his reading and writing. He then went and had help in the classroom with his reading and writing. He then went onto a secondary school which was quite daunting for him. Over the next few years he had the assistance of two wonderful helpers who made such a difference to him, helping and encouraging him in all his subjects. He passed 6 GCSE'S to grade C and above and we were so pleased for him. We never thought that he would be able to achieve this. He was given extra time and a reader for the exams.

He has since gone onto complete a National Diploma in Graphic Design which he passed and is currently studying for an HND in Graphic Design. This will be tough, but so far so good.

He is nearly 20yrs old now and when we look back over the years we feel so proud that he has achieved more than we could ever have hoped for. He is driving and although still struggles very much with written words, tenses and complicated English, he seems to get by somehow. All we hope for now is that as time goes by he will regain most of his language and understanding that he missed as a young boy and will be able to get a job and live a normal life and enjoy himself.

**Name withheld**

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## Useful Numbers and Contacts

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**AFASIC** - the association for speech impaired children  
08453 555577

**ICAN** - National educational charity for children with speech, language and communication difficulties. Runs 3 schools, Early Years Programme, Mainstream Support and Training Programmes  
0870 010 4066  
[www@ican.org.uk](http://www@ican.org.uk)

**SKILL** - supports students with disabilities in post 16+ education  
0800 328 5050  
1.30 - 4.30 Mon - Fri  
[www.skill.org.uk](http://www.skill.org.uk)

### **THE CHALLENGING BEHAVIOUR FOUNDATION**

Helpful leaflets and information on behaviour issues.  
01634 302207

### **THE NATIONAL SOCIETY FOR EPILEPSY**

Confidential helpline and range of information and leaflets + training for schools and carers  
Helpline 01494 601400  
10.00 - 4.00 Mon - Fri  
[www.epilepsynse.org.uk](http://www.epilepsynse.org.uk)

### **THE EPILEPSY ASSOCIATION OF SCOTLAND**

As above (but in Scotland!)  
0141 427 5225  
09.00 - 4.30 Mon - Fri  
[www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)

### **CONTACT A FAMILY**

Free helpline supporting families with any child with a disability or special need. Can provide advice on, amongst other things, benefits, education and respite care.  
0800 808 3555  
10.00 - 4.00 Mon - Fri  
[www.cafamily.org.uk](http://www.cafamily.org.uk)

### **RATHBONE SPECIAL EDUCATION ADVICE**

Charity providing free advice on Statements - useful to check with when you receive the draft statement or in a tribunal situation  
0800 917 6790

**IPSEA** - Independent Panel of Special Education Advice. Free advice on statementing, tribunals, obtaining correct provision etc  
01394 382814

### **THE GABBITAS GUIDE TO SPECIAL SCHOOLS**

Useful book to get from the library or look at information on the web.

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## And Finally.....

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Many of you may wonder what research is undertaken to help find a cure for this condition. Arguably very little however FOLKS is looking to change this. We are currently in consultation with some of the leading experts in this condition to establish where best to concentrate resources.

We can only make progress on this if we have the funds to do so. We are fortunate once again that John Conlon is prepared to go through the pain barrier to help raise funds. As much as we appreciate John's efforts it's only worthwhile if he gets the support he deserves. So I am asking if you can help. Enclosed with this newsletter is a sponsorship form. If all members could ask their family, friends and work colleagues to sponsor John we could raise quite a significant amount. The more we can raise the more we can put into research. The more research we do the more chance there is of finding answers to finding a cure for this condition.

It is not only money we need, we also need people to help. 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 give me a call on 023 80267719 or e-mail me at [richard@budnyj.freemove.co.uk](mailto:richard@budnyj.freemove.co.uk)

And finally a big thank you to Graham Storey and his team at Kingsmead Print Services who very kindly print and package our newsletter at no cost.

**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 8, Malibres Road, Chandlers Ford, Hants, SO53 5DT alternatively e-mail to [richard@budnyj.freemove.co.uk](mailto:richard@budnyj.freemove.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.

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## **FOLKS FAMILY DAY**

On Saturday 10th September 2005, FOLKS will be hosting another 'Family Day'. This year, it has been booked at Skallywags, Brierly Hill, near Birmingham. In order that we can make the necessary arrangement and give Skallywags an indication of attendance numbers **please complete this form and return to:**

Richard Budnyj

8 Malibres Road  
Chandlers Ford  
Hants  
SO53 5DT

**Aternatively e-mail Richard on [richard@budnyj.freemove.co.uk](mailto:richard@budnyj.freemove.co.uk) with the following details.**

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**I/We intend to come to the Folks family day on Saturday 10<sup>th</sup> September at Skallywags**

**Members full name**

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**Members address (including postcode)**

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**Please indicate the total number whom intend to come to the family day.**

**Adults**

**Children**

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**Many thanks**



