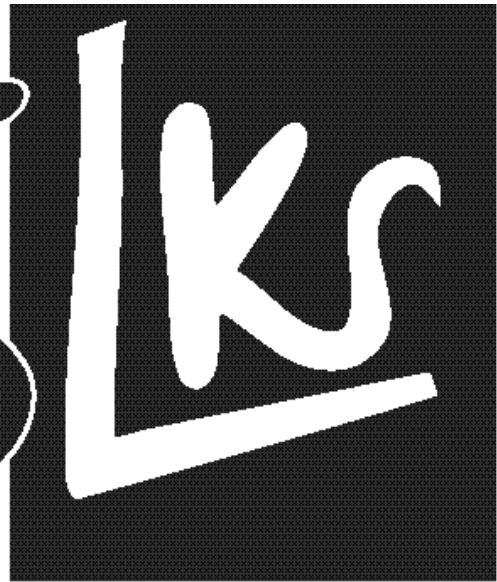


# FAMILY NEWS



Reg. Charity No. 1059499 (affiliated to Contact a Family) Honorary members: Professor B.G.R. Neville, FRCP, Professor of Paediatric Neurology Professor R.O. Robinson, FRCP, Professor of Paediatric Neurology Founder member: Vicki Horsewell

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## ABOUT F.O.L.K.S.

Our grateful thanks to Richard Crean for the long hours he put in to prepare a comprehensive database for F.O.L.K.S. Richard says "It has taken months to prepare but at last the job is done! Many members were good enough to complete datasheets on their LKS children last Autumn. This data, together with all the details of all our other members is now on one system. New members will have their registration details kept on the same system.

It will tell us at a glance a lot more about our membership. It will also provide a quick and easy reference for Fiona Kettell and Jackie Beagley when they take your calls on the F.O.L.K.S. Helpline **0870 8470707**.

Most importantly it will make it easier to put you on contact with other F.O.L.K.S. members or interested professionals in your own locality. Here is some of the examples of the information we have drawn from the database so far:

We have 215 members - of these, 129 have an LKS child. We have members in 12 countries - the largest number of members in any one county in the UK is Essex. We have 6 members in medicine, 9 members in education 6 members in speech

therapy, and 13 members who are relatives or friends of LKS families.

This kind of information will mean that we can ask specific questions of specific groups within F.O.L.K.S. For example, let's ask our speech therapy members "How should F.O.L.K.S. go about increasing awareness of LKS within the speech and language profession? Or "Should we be campaigning for more SLT hours to be delivered to our children?"

## F.O.L.K.S. DAY 1999

On June 19th, 1999 F.O.L.K.S. held its 3rd annual F.O.L.K.S. Day at the Exhall Grange Conference Centre at Coventry. Around 120 parents and professionals attended together with 34 L.K.S. children and their brothers and sisters.

While the Red Cross and helpers met the challenge of entertaining the children with bouncy castles, a space centre, a play bus, a clown, face painting, magic balloons and so on, everyone else got down to tackling L.K.S.



The first speaker of the day was Dr. Andrew Holton of Leicester Royal Infirmary who lectured on the theme of "Why treatment of Landau Kleffner is not more successful". Does that sound a bit

negative? Not at all. Dr. Holton gave a very thorough analysis of the reasons for the

enormous difficulties faced by families in securing diagnosis and treatment for their children from a paediatrician's point of view.

It was a welcome and effective challenge to parents and professionals alike to address these problems for the sake of all our children. The very fact that they were recognised in depth was a tonic for everyone.

We were privileged to have Professor Charles E. Polkey a leading neurosurgeon who did the first Multiple Subpial Transection in the U.K. and many more since.

He gave a very clear explanation of this operation and its rationale and there is little doubt that this surgical technique is now well established.

It was a pleasure to have one of our Honorary Members, Professor Richard Robinson return to speak to us again on some of the results of a study carried out at Guy's Hospital on the follow up of a group of L.K.S. children.

A brief summary of his address is given below and we look forward eagerly to the publication of his paper in due course.

Following a question and answer session with the experts and lunch, the afternoon session commenced with a very effective demonstration of an augmented communication aid by Jane Wicks of Liberator.

Martin Smedley, Senior Speech Therapist of Guy's Hospital ran a workshop session to deal with the communication difficulties faced by our children and of course, their families.

Mrs. Monica Uden of the ICAN school, Dawn House, Nottinghamshire gave a positive address on "Enabling the L.K.S. child to achieve".

An understanding of the epileptic condition can enhance the education of our children.

Finally the vexed subject of behaviour.

This year and in a different approach we welcomed Ms. Bodhanna Kvam of the London Early Autistic Project who described the Lovaas Intensive Behavioural Therapy now widely used to modify the behaviour of autistic children.

A successful Conference and inspiring us all to plan for 2,000 A.D.!

**A video of the day is available from Wizard Video Productions Ltd. of Petworth Road, Witley, Surrey. GU8 5LX. The cost is £5.95 per PAL (U.K.) copy, £22 per NTSC copy (U.S.) and £25 per SECAM copy (France etc) inclusive of VAT and P&P.**

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**A Summary of Professor Richard Robinson's Lecture to F.O.L.K.S. - June 19th. 1999**

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"It was 42 years ago that Landau and Kleffner produced their seminal paper on the subject and little new has happened since. In their paper they included a description of fits, EEG findings,

language difficulties and behaviour problems. It has since been suggested by Bishop that the age of onset affected the outcome. In addition "steroid sensitivity" was discovered. Very little else that is new has been discovered about L.K.S. because it is so rare.

Thus, most commentators when talking about L.K.S. report their experience of only a handful of cases. One needs to look closely at the nature of the fits, their frequency and severity, the nature of language disturbance, behavioural and other problems. Frank Morrell's work is a major contribution to the management of L.K.S. We need a better definition of the natural history of L.K.S. to assess treatment including surgery. One model of the natural history would be to look for correlations between the fits and the EEG during the acute phase and the subsequent outcome.

Over the last year we have looked at a group of children in a new study.

The children were assessed throughout the condition from the acute phase into the recovery period. The group consisted of some 18 children with a mean age of 84 months. The length of follow-up covered 7 to 180 months. EEG abnormalities in the temporal lobe were present in all, but 5 of the group had frontal lobe abnormalities. Behaviour was severely affected in 9 members of the group. The course of the disorder was fluctuant in 8 of the group.

Outcome of the study showed none of the group had continuing fits or primary behaviour problems. Only 3 of the group had normal language scores, 11 of the group had language scores of less than half their chronological age, 4 of the group had borderline receptive language and 2 of them remained very language

We have found some interesting correlations between the early EEG features and subsequent language outcome. These not only shed new light on the cause of the long term disability but may also be a guide in the timing of intervention with MST."

*Professor Richard Robinson, FRCP, Professor of Paediatric Neurology, Guy's Hospital, London*

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**F.O.L.K.S CHARITABLE DONATION**

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**"On 28th. May this year, Lady Ann MacLaurin, wife of Lord MacLaurin of Knebworth died very suddenly while on holiday with her husband. One of her wishes was to know and understand more about Landau Kleffner Syndrome which her grandson James, son of Neil and Ann suffers.**

**On her death donations to F.O.L.K.S. were requested and the amazing sum of £10,000 has so far been raised. This has shown to all Ann's family and friends the regard in which she was held. It would be Ann's wish that the money be used to give James and other children the opportunities to enjoy a fuller life**

**and we all hope that the money raised will be of use to such a worthy organisation."**

*Neil MacLaurin*

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**From The Founder Member**

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**F.O.L.K.S. has come a long way since the LKSPG (Landau Kleffner Syndrome Parents Support Group). The LKSPG began in the front room of my house in 1991.**

**REASON WHY?**

I received a letter signed "a desperate mother." She was pleading for information on MST surgery. A family contact in the medical profession had searched for information on LKS and had come across MST surgery that was being tried for some LKS children in Chicago. The mother contacted them to pursue this for her own L.K.S. child. She was informed that a girl in the U.K. (my daughter) was being put through a series of tests with a view for surgery. The mother was given my name and address and hence the letter arrived. I was appalled that she only lived in Stockport and knew nothing about developments that were being pioneered in Chicago, we soon became very good friends.

It was at this point that I decided that a support group was needed to collate and share up to date information with other L.K.S. families. So in 1991 three L.K.S. parents, Angela Paine, Ghislaine Burnett-Smith and myself met with a Contact a Family representative at my house - and the LKSPG was born. The LKSPG was registered with Vicki Horsewell heading the group.

A small information pack was put together to send out. My telephone soon began to ring with enquiries from other families along with speech therapists and medical professors, teachers, career advisers etc, all desperately seeking information. Many families just wanted to talk to another LKS family. As the list of families grew, more and more families were put in touch with each other and friendships and support shared. There were calls and letters as far away as Australia.

Contact a Family were a great help in the early days. I met with Victoria Burch when she came to England as she was doing her research for her LKS thesis as part of her degree course in America. It was shortly afterwards that Victoria moved back to the U.K. She became a great asset to the group and wrote the first LKS leaflet. This I sent to all LEA's in England, Scotland, Wales and Ireland and to all paediatric neurology departments. My phone began to ring more and more (so much for a rare disorder).

Eventually the LKSPG had to have its own phone line installed.

Professor Richard Robinson who was my own daughter's neurologist was also involved from the birth of the group, taking referrals etc. but

utmost he supported LKSPSG. My LKS daughter and her sister helped along with Linda Ross's children, filling envelopes, sticking on stamps and spending hours in the local dry cleaners using the photocopier.

We jogged along sending out information, dealing with phone calls, my husband wrote and produced the early newsletters. Ghislaine and Anthony Burnett-Smith raised enough money for the LKSPSG to purchase its own second hand photocopier (no more going to the dry cleaners).

We had grown very quickly in the early years. In 1996 we could register a charity. A committee was formed by LKS parents and professionals, they were Vicki Horsewell (*Chairman*), Mark Burch (*Treasurer*), Linda Ross (*Secretary*), Jackie and John Beagley, Fiona Kettell, Victoria Burch (*neuropsychologist*), Janet Lees (*speech therapist*) and Professor Richard Robinson from Guy's Hospital and Professor Brian Neville for Great Ormond Street (*medical advisers*.)

#### THE NAME

There were several attempts to secure the correct name with the Charities Commission but there were already other groups using the name that we wanted. Then an idea from Bob (Janet Lees husband), why not F.O.L.K.S., and you all know what it stands for, **FRIENDS OF LANDAU KLEFFNER SYNDROME**. So F.O.L.K.S., registered Charity number 1059499 went on the map. Janet and Bob created a web site on the Internet, F.O.L.K.S. ws now multi-national and more and more enquiries were pouring in from all over the world.

The first family Day was held in 1997 which was a great success, about 60 families met, some meeting other L.K.S. families for the first time.

It was a great opportunity to share experiences and to make new contacts. Today is the third family day with many more to come. I am eagerly awaiting the video that will be produced from today's event.

#### AND MY OWN DAUGHTER

For those of you who don't know her, she was a very extreme L.K.S. on a scale of 0-10, she scored about 20. She was the first to have MST surgery for LKS in the U.K. in 1992. Now she is a well related 17 year old. After surgery she went to Moorhouse School in 1993. Moorhouse School is an independent school for children with speech and language disorders. She is now at Grove Hill which is the post 16 Centre attached to St. Catherine's on the Isle of Wight. She had a completely normal sleep and awake EEG in April of this year and is now applying for a driving licence. She has had an interview and secured a Summer job in MacDonalds restaurants which she will start at the end of July. She also has a boyfriend, enjoys going to the pub and cinema and does all the normal things that you would expect from a 17 year old girl. She is

a very determined young lady despite still having reading and writing difficulties, her speech is still improving but she now has a future and a life after LKS.

*Vicki Horsewell*

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**Members of F.O.L.K.S. who regularly scan the Internet will have become quite used to families in the U.S. comparing notes on their MEG scans. Some of those families will have taken part in quite a large study which has been recently published and the Abstract of which we publish here. It continues the very difficult investigation into the cause of and treatment of children with autistic spectrum disorders with a comparison with LKS children. It underlines the need for thorough investigation and the valuable contribution of the MEG scan in that investigation. In the U.S. it is offering hope of improvements to children who might not have been considered as medically treatable. The work is dedicated to the memory of Dr.Frank Morrell. We are grateful to Dr.Lewine and Professor Neville and the journal "Pediatrics" for their permission to reprint these parts for your benefit and to all those engaged in such research for the benefit of ourchildren.**

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#### **MAGNETOENCEPHALOGRAPHIC PATTERNS OF EPILEPTIFORM ACTIVITY IN CHILDREN WITH AUTISM SPECTRUM DISORDERS.**

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#### ABSTRACT

**Background.** One-third of children diagnosed with autism spectrum disorders (ASDs) are reported to have had normal early development followed by an autistic regression between the ages of 2 and 3 years. This clinical profile partly parallels that seen in Landau Kleffner syndrome (LKS), an acquired language disorder (aphasia) believed to be caused by epileptiform activity. Given the additional observation that one-third of autistic children experience one or more seizures by adolescence, epileptiform activity may play a causal role in some cases of autism.

**Objective.** To compare and contrast patterns of epileptiform activity in children with autistic regressions versus classic LKS to determine if there is neurobiological overlap between these conditions. It was hypothesized that many children with regressive ASDs would show epileptiform activity in a multifocal pattern that includes the same brain regions implicated in LKS.

**Design.** Magnetoencephalography (MEG), a noninvasive method for identifying zones of abnormal brain electrophysiology, was used to evaluate patterns of epileptiform activity during stage III sleep in 6 children with classic LKS and 50 children with regressive ASDs with onset between 20 and 36 months of age (16 with autism and 34 with pervasive developmental disorder - not otherwise specified). Whereas 5 of the 6 children with LKS had been previously diagnosed with complex-partial seizures, a clinical seizure disorder had been diagnosed for only 15 of the 50 ASD children. However, all the children in this study had been reported to occasionally demonstrate unusual behaviours (eg. rapid blinking, holding of the hands to the ears, unprovoked crying episodes, and / or brief staring spells) which, if exhibited by a normal child, might be interpreted as indicative of a subclinical epileptiform condition. MEG data were compared with simultaneously recorded electroencephalography (EEG) data, and with data from previous 1 hour and/or 24 hour clinical EEG, when available. Multiple-dipole, spatiotemporal modeling was used to identify sites of origin and propagation for epileptiform transients.

**Results.** The MEG of all children with LKS showed primary or secondary epileptiform involvement of the left intra/perisylvian region, with all but one child showing additional involvement of the right sylvian region. In all cases of LKS, independent epileptiform activity beyond the sylvian region was absent, although propagation of activity to frontal or parietal regions was seen occasionally. MEG identified epileptiform activity in 41 of the 50 (82%) children with ASDs. In contrast, simultaneous EEG revealed epileptiform activity in only 68%.

When epileptiform activity was present in the ASDs, the same intra/perisylvian regions seen to be active in LKS were active in 85% of the cases. Whereas primary activity outside the sylvian regions was not seen for any of the children with LKS, 75% of the ASD children with epileptiform activity demonstrated additional nonsylvian zones of independent epileptiform activity. Despite the multifocal nature of the epileptiform activity in the ASDs, neurosurgical intervention aimed at control has led to a reduction of autistic features and improvement in language skills in 12 of 18 cases.

#### CONCLUSIONS.

This study demonstrates that there is a subset of children with ASDs who demonstrate clinically relevant epileptiform activity during slow-wave sleep, and that this activity may be present even in the absence of a clinical seizure disorder. MEG showed significantly greater sensitivity to this epileptiform activity than simultaneous EEG, 1-hour clinical EEG, and 24-hour clinical EEG. The multifocal epileptiform pattern identified by MEG in the ASDs typically includes the same perisylvian brain regions identified as abnormal in LKS. When epileptiform activity is present in the ASDs, therapeutic strategies (antiepileptic drugs, steroids and even neurosurgery) aimed at its control can lead to a significant improvement in language and autistic features, autism, pervasive developmental disorder - not otherwise specified, epilepsy, magnetoencephalography, Landau-Kleffner syndrome

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#### MAGNETOENCEPHALOGRAPHIC PATTERNS OF EPILEPTIFORM ACTIVITY IN CHILDREN WITH REGRESSIVE AUTISM SPECTRUM DISORDERS

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The issue of the contribution of subclinical epilepsy to autistic spectrum and developmental and acquired communication and language disorders is one of the most important in clinical developmental neurosciences. We need to know what proportion of these disorders are caused or triggered by epilepsy, to what extent the process can be reversed and what would be the mechanism of such catastrophic selective and global loss of cortical function. The model that has been used in the study reported by Lewine and colleagues in this month's issue is of a disorder that has an onset after a period of normal or near normal early development and their finding of seizure activity in the majority of these children has to be taken seriously. A recently published French study found a rate of 50% of epileptiform electroencephalogram

(EEG) activity in sleep in primary developmental dysphasia and this opens the question more widely to include both non regressive and pure language disorders.

The authors have separated what they call "classical Landau-Kleffner syndrome" from variants by the presence of wider impairments. However, we should remember that Landau and Kleffner included patients with wider behavioural impairments in their original description.

The main value of the study is to add further evidence to that of the Helsinki group that magnetoencephalography probably has a greater yield than traditional sleep recorded EEG and certainly from a short waking record and this appears to be related to the electrical characteristics of discharges arising in the Sylvian fissure.

Most of the problems of studies in this admittedly difficult area are illustrated by this publication.

#### REFERRAL BIAS

The criteria for entry into the study and source of the patient is not given so that no prevalence inference can be made. Perhaps more importantly patients may have been externally or even internally selected for having an epileptic EEG.

#### DELAY BETWEEN ENCEPHALOPATHY (ACUTE DETERIORATION) AND STUDY

This is a problem with most studies and could only be approached by population screening along the lines of the Checklist for Autism in Toddlers (CHAT) study.

#### THE LACK OF MULTIDOMAIN ASSESSMENT TOOLS

The article's analysis of the published data does not draw attention to the lack of appropriate assessment tools in both the corticosteroid studies and even the much quoted multiple subpial transection paper. In that latter study it is difficult to accept the assertion that language returned to age-appropriate levels in many without the data on language function being quoted. This problem is not fully dealt with in the preliminary report of their surgically treated patients where the outcomes are the Peabody Picture Vocabulary Test, which assesses one domain, and the Childhood Autism Rating Scale, which is mainly an ascertainment tool plus clinical observations.

These preliminary results show, as have others, that improvements can be seen by intensive treatment, including surgical, of children with autistic spectrum disorders and clinical or subclinical epilepsy.

The need for controlled studies with good assessment tools is becoming a matter of urgency because of the high rate of autistic spectrum

disorders in the community, their poor prognosis, and the understandable demands of families for the epilepsy stone to be turned.

*Brian G. R. Neville, FRCP*

*Department of Paediatric Neurology Institute of Child Health and Great Ormond Street Hospital for Children NHS Trust University College London Medical School, Wolfson Centre, Mecklenburgh Square London. WC1N 2AP United Kingdom*

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**Until recently MEG scanners were to be found in the U.S.A., Helsinki and Germany but not the UK. One such whole cortex, 151 multi channel machine has very recently been acquired by The Vision Sciences Department of Aston University in Birmingham. It is the first in the U.K. and funded by the Wellcome Trust. It is not yet clear when the machine will become available for use.**

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#### BUCCAL MIDAZOLAM

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A research paper published in "The Lancet" (Saturday February 20) has demonstrated that patients with epilepsy suffering life threatening seizures can be treated successfully by mouth.

The study was carried out at St. Piers, Lingfield and shows that the drug midazolam, when given by mouth, is at least as effective as the current standard treatment, rectal diazepam.

The study, carried out over a two-year (check) period, compared the results obtained by buccal (by mouth) midazolam with the use of rectal diazepam, currently the established treatment for convulsive status epilepticus (CSE). CSE - during which the patient suffers extended seizures - is associated with long term neurological damage, and can lead to death. There are at least 25,000 episodes of CSE every year in the U.K. with the highest incidence in childhood. The study results demonstrated that buccal midazolam was effective in ending seizures in 75% of cases and rectal diazepam in 59%.

"The key finding is that buccal midazolam is at least as effective as rectal diazepam" said Dr. Frank Besag, Medical Director at St. Piers." Obviously, it is a great deal more socially acceptable to administer medication by mouth, and we hope that in due course buccal midazolam will become the preferred pre-hospital treatment for prolonged seizures."

The research has been undertaken in a collaborative study between St. Piers and the Institute of Child Health (part of the Great Ormond Street Hospital For Children NHS Trust) The authors of the Lancet study are Dr. Rod Scott (Institute of Child Health), Dr. Frank

Besag (Medical Director of St.Piers) and Professor Brian Neville (Head of Neuroscience, Great Ormond Street Hospital for Children NHS Trust.).

**For further information and/ or a copy of the paper please contact Vivien Hepworth on 01342-831238 or 07957-438314**

**Note - the work is at research stage only and midazolam is not licensed - but it is hoped to be available in 18 months - 2 years.**

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### **The National Assessment Service for Children and Young People Epilepsy**

St.Piers in collaboration with Great Ormond Street Hospital have launched a national assessment service for children and young people with epilepsy. The three day assessment was launched early 1998. In its first full year of operation, 24 assessments were completed and numbers of children being referred to the service grew rapidly as new of its availability spread.

In light of demand, the medical team decided to launch a fuller, six week assessment for complex cases of childhood epilepsy.

A dedicated three-bed assessment unit attached to the medical centre was opened in November 1998.

While the three day assessment lays the basis for a medical diagnosis, the objective of the six week assessment is to provide detailed evaluation of personal, social and educational needs. Recommendations are made in the form of a detailed report when the assessment is complete. The report is intended to be used by families, carers and professionals to ensure that the most appropriate educational and social strategies are pursued for the individual child.

By the end of March 1999, four six week assessments had been carried out involving the whole St.Piers inter-disciplinary team - consultants, nurses, educational psychologists, therapists, teachers, and experienced support staff.

#### **APARENTS PERSPECTIVE**

I know I am not alone in finding the problems of getting an E.E.G. recording, let alone sleep E.E.G. both time consuming and frustrating. Trying to place electrodes on an unco-operative and frightened child who because of their communication problems cannot understand what is being done to them is traumatic for all concerned. Hoping that by sleep depriving them, they will fall asleep on cue and stay asleep while electrodes are placed on their head have in our case been met with disappointment. Even oral and I.V. sedation has been unsuccessful. When admitted to hospital for three days managed Jack to stay awake the whole time to elude the E.E.G. It was therefore, with some trepidation that I agreed to a three day assessment at St.Piers.

Predictably Jack would not allow them to glue electrodes to his head (I was surprised that he is the first child with whom they had not succeeded to do this with). However I wasn't surprised that sedation did not help. I explained that Jack was afraid of the wires (he never touches plugs, wires or sockets at home). They were very patient and we all had wires glued to our heads to convince him that it was safe. Jack remained unconvinced about the wires, but co-operated with having a cap (all wires cunningly concealed) on his head. It took a lot of time and patience (not to mention sweets from the nurses pocket) but Jack was won over and happily co-operated from that point on. The next couple of days saw visits from the nurses doctors and psychologist but mostly we spent hours watching videos (I brought a bag full of favourite videos toys and goodies - essential to survive the boredom).

While I was there I visited the new assessment unit where the six-week assessments are carried out (much nicer, newer rooms plus a soft play room and facilities for a parent to stay over).

I believe that both of the assessments may play an important role in the diagnosis, treatment and education of children with Landau-Kleffner Syndrome.

*Fiona Kettell*

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### **L.K.S. IN AUSTRALIA**

Imagine struggling with LKS in a Continent where you may never meet another family because of the distances between you and where there are no specialist speech and language schools, limited services for the disabled and where there is as yet no surgery option to name but a few of the problems..

These are the problems faced by our Australian counterparts the "Australian Landau Kleffner Association" they are an independent group have taken on the huge task of supporting, providing information to and campaigning on behalf of children with LKS in Australia.

Katherine and Richard Price (authors of "Landau Kleffner Syndrome: "AParents Guide" soon to be published in Australia) are the founders of the group and driven by parent power to achieve so much for the LKS children and their families. It all started with their own fight to get their son Tyler, diagnosed and then educated. Parents in need of information and contact travelling great distances to visit. At their own cost Katherine and Richard started, and continue to, send out a regular newsletter. Numbers of interested parents rose rapidly.

The stringent requirements for charities in Australia have prevented the group so far from registering as a Charity. They need to fund accountancy services. Any funds that they might receive as a Charity would be taxed at the new GST rate of 20% (similar to VAT in the UK)

anyway. It rather resembles David fighting Goliath with one hand behind his back but nothing stops LKS parents we have found.

In addition to the Newsletter, the group has purchased the first Earobics package in Australia at Hornsby Hospital, New South Wales (this is an auditory training program). Thanks to the generous donation made by one minister (the Hon. Alan Corbett). One of the most demanding tasks of a parent support group is the telephone counselling which Katherine says can last about 2 hours for a new and confused parent. They have experienced a growing increase in calls from neurologists, clinical nurses and other professionals. Several different

Information Packs are sent out that they have put together to deal with different aspects of LKS.

There are now support groups opening in each state as the rate of diagnosis seems to be increasing and involving clinical nurse specialists to help. On top of all this Katherine and Richard search the world for information for the group, attend conferences, write their book for funds. Next years plans include a sign language book of children's cartoon characters to help fund the Newsletter. All this without a fax, printer etc. and not forgetting the personal battles for Tyler who is still only 3! It would be nice to think that some Australian organisation could let them have such facilities to ease the physical, financial and emotional burden of the work which is essential for the LKS children and their families in Australia.

If anyone has any friends or relatives willing to help in Australia in any way they can contact Katherine on **INTERNET:kaprince@acon.com.au**.

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### **After 16 - What's new? Choices and Challenges for Young Disabled People**

The Family Fund Trust have recently published an information guide for young people and their carers who may need vital information to help them make decisions about the future eg, money, health, housing, work, friends, social activities, the Law, how to get your views across, how to get around and making choices.

The guide is free to young disabled people and their carers (£10 to others).

To obtain the guide, contact: The Family Fund Trust, PO Box 50, York, YO9ZX  
**E mail:info@familyfundtrust.org.uk**

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### **FURTHER FROM F.O.L.K.S.**

In the last 12 months F.O.L.K.S. have been able to prepare and circulate its Information Pack and a supplemented Pack to ensure that new families have some basic information about LKS as soon as they need it. The latest edition is

available on the F.O.L.K.S. web site. So popular has it become that F.O.L.K.S. has to get the French, German and Spanish versions ready. Our grateful thanks to all those who contributed to the preparation the Pack. Particular thanks to Kingsmead Publications for the gift of our splendid folders at short notice. F.O.L.K.S.

Especial thanks to Fiona Kettell who spent much of Summer building a system of contacts between families. We hope that you find this supportive and useful and we would be very pleased to hear how you find the new system. In addition to this work Fiona has been busy with the Helpline and we now have two Helplines with Fiona on **0870 8470707** and Jackie Beagley on **01582 411143**.

F.O.L.K.S. are pleased to welcome Hilary Heron and Cathy Melis to the Committee this year. There is so much work to be done that we have also recruited further members by co-opting Liz Boulton and Fred and Diane Eiffert. Liz is going to help F.O.L.K.S. prepare information about the schools that our children go to. It is important for families (and Education Authorities) to know what the options are and what is available but more importantly what the parental view of such services is. Liz is going to need the help of all of us to get this information together. Fred and Diane Eiffert will be the F.O.L.K.S. Day 2000 organisers. F.O.L.K.S. Day 2000 will be held this year on **3rd. June 1999 at St. Elizabeth's School, Much Hadham, Herts.** at their kind invitation. More details to follow in the New Year.

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**F.O.L.K.S. is everindebted to the efforts of those who raise money to support the group. This years generous donations have made it possible to plan projects to continue the task of supporting and informing families and professionals about the management of LKS. Ourthanks to:-**

*Hilary Heron and the Simonside Country Fair raised a magnificent £1,180 at a barbecue. Hilary then managed to persuade Barclay's bank to add another £1,000 to match.*

Sterling Software whose employees raised £500 from sponsored events including bike rides.

*Mailshot Marketing and Lesley James & CO., both of whom donated £100.*

Jan Crean and her sponsors who foolishly took the challenge for a five mile Fun Run and raised £140.

*Daniella Cowie who raised £30 by running a "Name that Rabbit" Competition at school.*

To the Hilton family and to Mario Vega for their personal donations to F.O.L.K.S.

Our best wishes to Don Anstey we were pleased to know of his rapid recovery from recent illness.

#### OUR LOSSES

MARK BURCH retired in June and F.O.L.K.S. is indebted to him for his support throughout the early years.

RICHARD CREAN retired at the end of October and relinquishes his editorial function to Steve Kettell. Our thanks go to Richard for his many efforts on behalf of F.O.L.K.S. but particularly for Newsletters and more recently his database.

F.O.L.K.S. NEWS welcomes all contributions, articles letters, comments for publication. If you have any item suitable for publication it should be sent to **P O BOX 749, Erith, Kent. DA8 3AU** by 1st March 2000. 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. For enclosure:

We should be grateful if you would take a few minutes to complete this DATA Sheet.

This will assist us in putting you in contact (should you so wish) with families with an LKS child in your area/country or with families whose LKS child has similar symptoms to those of your child.

Even if you do not yourself desire such contact any information you supply could be of assistance to others. Please return this form to the address above.



## F.O.L.K.S. Data Sheet

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Surname \_\_\_\_\_ LKS Child's Name \_\_\_\_\_

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Parents Forenames \_\_\_\_\_ LKS Child's Date of Birth \_\_\_\_\_

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Siblings Name(s) and Age(s) \_\_\_\_\_

---

Address \_\_\_\_\_

---

Country \_\_\_\_\_

---

Tel No(Home) \_\_\_\_\_ (Work) \_\_\_\_\_ Fax No \_\_\_\_\_

---

Best Contact Time \_\_\_\_\_ E-Mail Address \_\_\_\_\_

---

Doctors Names \_\_\_\_\_

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Hospital \_\_\_\_\_

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Age of LKS Onset \_\_\_\_\_ Age of LKS \_\_\_\_\_

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Diagnosis \_\_\_\_\_

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\_\_\_\_\_

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\_\_\_\_\_

### **Seizures:**

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Type of Seizures \_\_\_\_\_

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Frequency of Seizures \_\_\_\_\_

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Suspected Causes: <small>(please specify)</small>	<b>Birth Related</b>	<b>Viral Related</b>	<b>Vaccine Related</b>	<b>Other</b>
Behaviour Problems:	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Very Severe</b>
Communication Problems:	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Very Severe</b>
Speech Deficit:	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Very Severe</b>
Motor Difficulties:	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Very Severe</b>

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Current medications \_\_\_\_\_

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\_\_\_\_\_

Past Medications \_\_\_\_\_

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\_\_\_\_\_

Surgery/Other Treatments \_\_\_\_\_

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\_\_\_\_\_

### **Education:**

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School Name \_\_\_\_\_

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School Type \_\_\_\_\_

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Speech therapy **Y/N** (Details) \_\_\_\_\_

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Adult Support **Y/N** (Details) \_\_\_\_\_

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LEA Name (UK Only) \_\_\_\_\_

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Statemented (UK Only) **Y/N** \_\_\_\_\_

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\_\_\_\_\_

If you consent to the release of your Name, Address, Tel/Fax Nos., and E-Mail address to other LKS Parents please tick this Box.

Note: FOLKS is registered under the UK Data Protection Act - Reg. No. X3934029. Any information supplied on these Forms will be kept in the strictest confidence and used only for registered purposes being the pursuit of FOLKS' objects (being the relief of persons affected by LKS and related disorders; to advance the education of the medical profession and the general public on the subject of LKS and its implications for the family; and to promote research into LKS, to publish the useful results thereof, and to support organisations providing research into LKS), the provision of consultancy and advisory services, the undertaking of research and statistical analysis, administration and fundraising.