



October 2000

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**A Letter to FOLKS from  
Professor Landau...**

*Landau Kleffner Syndrome (or acquired epileptic aphasia) was first described in 1957 in a medical paper by Dr. William Landau, Professor of Neurology at Washington University in St Louis, and Dr. Frank Kleffner, a speech pathologist of the same. We were pleased to receive the following thought provoking letter from Professor Landau earlier this year.....*

*"...I was delighted today to discover the existence of your organisation. I am sure that Dr. Kleffner will share my enthusiasm. I learned about FOLKS from Ms. .... of Austin, Texas, about whose child I consulted several years ago ( she reports that he is doing very well.) As the enclosures indicate, the sad shame of Landau Kleffner is that it carries our names, because there has been no effective research on the subject for almost half a century!*

*I am also concerned about uncontrolled aggressive surgery on LKS children because tissue destruction is irreversible for a condition of unknown cause and variable prognosis. Of course, the basic information and emotional support of your mutual communication organisation are important. But shared sorrow and frustration is not a progressive enterprise. In spite of all the hopeful case reports and reassurances, the blunt facts are:*

*1. There is no scientific intelligence about the*

*cause of this condition.*

*2. There is no scientific evidence that any treatment or medication is more curative than any other, or even none at all.*

*Because LKS is a rare condition, we need a well-funded highly disciplined, multi-institutional research program, international if possible. The essentials of such a long term project are the establishment of uniform diagnostic criteria, many well controlled and thorough investigations of possible causes, and most important for the short term, rigorously controlled studies of medical treatment alternatives.*

*As its first priority, I hope that FOLKS will accept my challenge: a persistent political and fund raising campaign to establish a proper research program. There can be no quick fix. It can't be done cheaply. It's only necessary.*

*Do it!*

Yours William M. Landau, M.D.

**Discussion:** It's impossible to disagree with Professor Landau that more effective long term research is needed into LKS and research of the kind which employs vigorous effort into causes and treatment rather than mere clinical observation. Should there be aggressive intervention, limited intervention or no intervention in LKS without clear research results from different strategies, or a clear idea of prognosis and an understanding of what causes

LKS? Which intervention is best and for which child and at what stage? Usually science and medicine go hand in hand but scientific certainty isn't always available to those that practice medicine and so they fall back on an informed judgement and sometimes do so with good results. Yet it remains with the parents of LKS children to make these extraordinarily difficult decisions, hampered by the lack of consensus within the medical profession and the lack of scientific certainty about treatment. It would be quite wrong however to assume that we are no further forward than we were in 1957 and although we haven't achieved scientific certainty, we have a lot of information to help guide parents about what decisions need to be made. Many of the parents in FOLKS have given their children's data to us and we can see that certainly in the UK it takes an average of almost three years to reach diagnosis by which time the chances of recovery without residual disability would be remote. Professor Landau's letter provides an opportunity to review how far we have come and how far we still need to go.

Epilepsy as a disorder has been known since mankind could first record his experience of it and of those 3,000 years, it is only in the last 150 years or so that there was any attempt at a "scientific" approach to treatment. In the past they tried many things to cure epilepsy including ligatures, blood letting, cauterisation and exorcism. The stigma and burden attached to having a child which would exhibit the kind of symptoms of LKS must have been enormous. The English novelist Jane Austen had a brother who suffered epilepsy and "deafness" and was considered by late 18th century society to be "simple minded". The best that could be done by a well meaning middle class family was to put the child with carers outside their own community to be kindly looked after. In the absence of medical understanding, a quiet existence outside an institution was the best that could be done. Jane Austen learnt a \*sign language in order to communicate with her brother on visits and in his case at least, non intervention was preferable to the alternatives and he lived a healthy 72 years.

By 1957 the EEG had only been in use for some 30 years but had not yet reached the sophisticated range that developed through the next forty years with computerised recording, video telemetry, longer more comprehensive recordings (particularly sleep), ambulatory recordings and so on. The range of anti-convulsants available was relatively restricted, the now familiar names of lamotrigine, vigabatrin, topiramate, have only become available to children within the last 20 years, some even more recently. Interest in children's epilepsy and particular syndromes was only just

beginning. LKS was only given its official recognition as a separate syndrome by its inclusion in the International Classification of Epileptic Syndromes in 1985. In that context the paper of Professor Landau and Dr. Kleffner makes interesting reading. It consists of a very useful and detailed description of six children all from the Central Deaf Institute in St. Louis. Dr. Kleffner was apparently surprised that Professor Landau was not aware of this group of children within the Institute who had early loss of language (mainly receptive), associated with epilepsy but who had good auditory perception. All the children had seizures. The severity of the EEG abnormalities did tend to correspond with the severity of the language disturbance, being usually bilateral in the temporal lobes. It was suggested that the persistent epileptic discharges were responsible for preventing the language areas from functioning. So LKS was born from the description of this small group of children gathered in one place and a diagnosis of "classic" LKS became dependent upon the characteristics of this small group.

What did happen in the next 43 years? There have been a lot of publications, some studies, some case reports on individual cases or small groups of children nearly all of which conclude that more research is required. LKS seems to have been a syndrome which provided clues to other more common disorders. From the 1970s and 1980s we had the description of ESES (Electrical Status Epilepticus in Sleep) or CSWS (Continuous Spike and Wave) by Tassinari, Beaumanoir, Deonna and others. The persistent spike and wave discharges described were found to be the cause of severe neurological impairments in children. LKS and CSWS could then be seen as parts of a spectrum of functional disorders of childhood with an abnormal EEG. Various small scale studies tended to show that spontaneous recovery could occur but rarely if left more than a year and then severe linguistic lifelong handicap was a very common result. More recently in the 1980s and 1990s came the other important recognition of the larger group of children who undergo an autistic regression early in their development but who have an increased incidence of an abnormal EEG similar to that found in LKS. The work of Tuchman and Rapin in the United States with large scale EEG studies and indeed of the newer studies by MEG consistently demonstrated some neurophysiological similarities (and differences) between the conditions.

Surgery - there is no doubt that Multiple Subpial Transection remains experimental, not in the sense that so much more needs to be learnt about the technique but more needs to be learnt about which child can benefit. In 1995 Professor Frank Morrell published the first series of 14 LKS

children who underwent MST at Chicago. He suggested that MST can be an effective therapy for children with LKS but was the first to say that not every child with a severe form of LKS may benefit from this surgery as they were only at the beginning of the road in understanding the pathophysiological mechanisms of LKS and that further work was needed to refine the selection criteria for the right surgical candidate. There were some markers for success, - a clear unilateral focus and steroid sensitivity. It is disappointing that since that time there have been so many MST operations but so little of the results have been fully reported. We are still eagerly awaiting the results of the MST joint studies done at Great Ormond Street and Guys Hospital.

MST is carried out at three hospitals in the UK but is much more widely used in the USA. The work of Dr. Patil in Omaha will be of particular interest in the future. Dr. Patil has been using MST on children with multiple foci, often bilateral and therefore not classic LKS with significant improvement in many that is not purely judged by language recovery but by even more important social, behavioural and developmental gains. It is thought that some of these children are more likely to be subject to regression after surgery but not to the same extent as before and it is likely that much will be learnt from this work.

The growing availability of MST and positive parental reports about benefits suggest that it is an intervention that is here to stay. Here is an area where there needs to be much more international joint research and dissemination of knowledge in the professions.

Steroid therapy - long used for children with intractable seizures without certainty about its mechanism. Is it anti inflammatory, anti-convulsant or does it regulate immune dysfunction?. It is beyond doubt that it has an effect on the EEGs of a significant percentage of LKS children. The problem is maintaining benefits after removing steroids. Work on pulse dosing of steroids in children with PDD and autistic epileptiform abnormalities by Dr Michael Chez (reported in 1998) indicated a significant success in maintaining benefits. The Great Ormond Street study, expected to be published shortly, was a controlled study of 20 children treated with corticosteroids and did show that over half had a significant and sustained improvement. That is quite a weight of evidence to support a decision to use this therapy but what of the group who had no benefit? They demand a very close look at the nature of their condition. While these studies are helpful they don't touch the task of tailoring the remedy to the problem. The excellent study of Dr. Chez on

"Serum Autoantibodies to Brain in Landau Kleffner Variant, Autism, and other Neurologic Disorders" in 1999 approached that problem and further work along these lines would be invaluable.

Behaviour - tucked away in the 1957 paper is a sad little fact - that before diagnosis one family underwent psychotherapy because of their child's apparent "emotional block" soon after her loss of language. If we still live at all in the dark ages with LKS it is in the failure to investigate adequately the many neuropsychiatric problems that can beset children and then to dismiss them with an inappropriate label. Getting the label wrong results in a failure to alleviate intense suffering or treat it as an emergency. Behavioural disturbance has been consistently recorded from the outset but little else. The psychiatric description of some of the LKS children in 1957 was and remains very accurate - "The behaviour would suggest psychogenic regression but its severity would equal childhood schizophrenia while the retention of warm affect is against that diagnosis". What progress have we made in diagnosing, understanding and treating this problem? Today we may be less likely to face the "emotional block" diagnosis than the all embracing "behavioural problem" with support from negative readings from scalp EEGs that may never fathom unilateral epileptic status or intermittent seizures from deep within the temporal lobe. Is enough care taken to examine the periods of aggression and loss of self control when there hasn't been a seizure for some time but which may be related to it? In too many cases it is the parents alone who deal with the anxiety, the depression, the drug toxicity, the psychosis. This difficult area in children cries out for research on a scientific rather than an observational basis.

So here we are in the Millennium, and since 1957 we have improved EEG, SPECT, PET, MRI, functional MRI, MEG, MSI, MST, improved surgical techniques a vast array of new anti-convulsant, a better understanding of epilepsy generally and we still can't be as effective as we should for some children. Yet we must be better placed to carry out the multi institutional research into causation that Professor Landau rightly calls for. To have medical centres with a narrow interest e.g. - not interested in auto immunity when a particular child has strong signs of autoimmune dysfunction, or one not interested in surgery when all other therapies have failed, and so on results in "doctor shopping" because parents need to address all the issues within the brief span of childhood irrespective of the particular interests of neurological centres. It adds strain and cost to families to deal with issues this way.

There is a tendency amongst professionals to think of organisations such as FOLKS as groups for emotional support and ancillary issues. Such benefits although important are not the only purpose for which FOLKS was established but it was also to support research and to advance the education of the medical profession and other professions. The practical advantage to FOLKS of all your support and all the data we hold on your behalf is that we have become a combination of "national and international doctors waiting rooms" where families give each other information regularly of every aspect of LKS and related disorders. Of course it is not scientific but our children undoubtedly progress because of it.

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### Magnetoencephalography and LKS

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The development of neurophysiological investigations is probably the most important single reason for the better understanding of epilepsy that we now have and with it more rational and accurate treatment. There are a number of different ways now available to us for of looking for abnormalities within the brain - by looking at the structure itself with MRI, at blood flow and metabolism with SPECT and PET studies and the recording of electrical discharges by the familiar EEG. One of the newest technologies available to neuroscience is MEG (magnetoencephalography) and MSI (Magnetic Source Imaging) and one that has great significance for children with LKS and autistic regression.

What is MEG/MSI? - neuronal activity within the brain produces electrical signals which we would normally read from electrodes attached to the scalp. That level of current is a billion times smaller than that generated by a light bulb and works in an incredibly small fraction of a second of time. The skull acts as a barrier and it isn't always possible to make very precise inferences about the location of these signals. However the electrical signals from neuronal activity produce a very weak magnetic field which comes out of the skull and circles back in. MEG is the method by which these magnetic fields can be detected and recorded by very sensitive sensors. With the use of computers and mathematical formulae that data can be transposed onto MRI images and produces a picture showing very precise areas of epileptic activity. As MEG works in thousandths of a second, coming closer to the speed at which the brain functions it is possible not only to locate seizure source but the order in which seizures are activated. MEG has the advantage of being able to record its data with minimal distortion from the skull but it does not replace the EEG, rather it should be seen as providing

full but complimentary data. MEG is most sensitive to the signals generated from cell running parallel to the skull but the EEG is most effective from cells to the perpendicular. Comparisons with the two methods run simultaneously sometimes show activity apparent on the MEG and not the EEG and vice versa. In LKS activity is typically from the area in and around the peri- sylvian region which particularly lends itself to MEG recording. To have an EEG conducted simultaneously with MEG and then superimposed onto MRI is to obtain the most fully informative picture possible without directly invading the brain.

The development of MEG - in 1968 Dr. David Cohen pioneered MEG in a research setting and it remained for some years an expensive piece of scientific research equipment. MEG facilities are still mainly located in research settings all over the world as they require an expensive sheltered environment in a shielded room and they have high running costs. Scientists interested in researching every aspect of brain function and development needed MEG - foetal development, cardiology, auditory processing, visual processing, epilepsy, vascular abnormalities, tumours, trauma injuries, dyslexia and many other processes and disorders. Some of the early MEGs were not suitable for clinical use (being half head scanners only) but epilepsy was a very obvious subject for MEG and it was clearly going to be useful in epilepsy surgery where location of function and of seizure source is vital for limiting damage and for success. Interestingly, in the latter part of Frank Morrells MST research he also was using MEG data. Now every major neurosurgical centre in the U.S. uses MEG data for pre surgical evaluation and as an aid in surgery itself, as is the case in Helsinki which is the home of much research on the MEG. In contrast no MST surgery has yet been conducted in the UK with the benefit of MEG.

Throughout the 1990's there were a number of papers published that were consistently indicating how reliable and useful MEG was in surgery. Dr Patau et al in Helsinki found that MEG data considerably influenced the planning of surgery and was useful for focussing MST. Research across America echoed the same message when studying children and adults having epilepsy surgery, that MEG was more accurate than the EEG in localising the source of epilepsy particularly interictal (between seizure) localisation.

In October 1999 FOLKS NEWS we were allowed to publish the abstract of a study carried out at the University of Utah by Dr Lewine et al where MEG was shown to be significantly more successful in detecting epileptiform abnormalities in children with autistic spectrum

disorders than even the 24 hour EEG as a preliminary study into the study of autistic spectrum disorders.

MEG and the U.K. - on March 17th, 2000, the Wellcome Trust laboratory for MEG studies was officially opened at the Vision Sciences Department of Aston University. This facility had always offered neurophysiological investigations such as ambulatory EEGs but the purchase of a 151 channel whole head MEG scanner with funding from the Wellcome Trust was seen primarily as a research tool. However we were very grateful to Professor Graham Harding who is director of the department for indicating that this facility would be made available for some clinical use and could be available upon an NHS referral and purchase of appropriate services (sedation). Hopefully it will go some way to redressing the huge imbalance between the UK and the United States in its use of MEG and MSI for LKS children.

For the future - while the UK lacks woefully behind the major European countries and the U.S. in its use of MEGs for research it would seem very likely that the technology will see much greater clinical use. We were interested to hear from the Dr. Gary Green of the Department of Physiology at Newcastle University of the proposals made by a consortium of neurologists and neuroscientists for a MEG scanner, particularly to look at auditory processing. We hope that "Brainwave" will seek quickly achieve the funding for their project and wish it every success.

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### **A Transatlantic Investigation - A Parents View of Magnetic Source Imaging by Robert Hantusch**

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Our son Richard is now 8 years old. Since he was diagnosed first with epilepsy and then with LKS at the age of 4 he has had almost every type of neurological test that the UK can provide (numerous EEGs, two MRIs, SPECT). We want to explain what it was that made our family decide to cross the Atlantic for Magnetic Source Imaging ("MSI"), how it helped us, and how very grateful we will always be to the American families who provided us with information about it.

Richard had MST surgery at Great Ormond Street Hospital just before he was 6. This helped his language development, but after surgery his seizures increased and he experienced real problems with behaviour and learning. Just before Christmas 1999 we were told that while further surgery remained a possibility, it would require a definite epileptic source to be identified and that invasive brain monitoring would

probably be required before any decision to undertake such surgery could be made. We were not thrilled by the prospect of having to put Richard through a further surgical procedure in order to determine if another operation was possible and so we looked for an alternative.

Earlier in 1999 some American friends had sent us, and we had viewed with interest, a 2 hour videotape of a talk about MSI and its benefits that had been given to a gathering of Californian parents (including parents of LKS children) by Dr. Jeff Lewine (then of the University of Utah's Center for Advanced Medical Technologies in Salt Lake City). Having viewed the video again, and read the full text of Dr. Lewine's research paper that had appeared in Paediatrics in September 1999 (an abstract of which article was reprinted in FOLKS News 1), we E-Mailed Dr. Lewine to ask if it would be possible for Richard to have MSI testing. After faxing over some of Richard's medical notes Dr. Lewine responded that he thought it could help and the good news was that the Salt Lake Facility was at that time willing to undertake MSI testing on anyone who could pay. We therefore decided to take our holidays early this year in Salt Lake City.

Accordingly we obtained a letter of referral and more of Richard's medical records from Great Ormond Street Hospital in mid-February and booked Richard's MSI testing for 22nd March. As we were required to pay in advance as foreign patients, there was a 20% discount on the usual all-in cost of \$7,500 so there was only \$ 6,000 to pay for the testing (about £3,800 at the then rates of exchange). There then followed a period of intensive use of the computer to find and book air tickets and hotel accommodation in Salt Lake (and several days of effort to coax Richard into a photo-booth to have his passport photograph taken !).

An unexpected difficulty was travel insurance. The UK Department of Health and the Passport Office both strongly advise for very good reason that no one should visit the USA without adequate medical and travel insurance. However, what they do not do is tell you where to obtain such insurance for an epileptic child who has had emergency hospital admissions and changed his drug dosages in the previous year, and is going abroad for medical tests. The reason they do not is that it is in fact impossible to obtain any such insurance cover for a trip to the USA (Europe is different) At first no one was willing to offer any insurance at all for Richard; but after 3 days on the telephone I eventually arranged comprehensive cover for the rest of the family and limited cover for Richard for all risks except epilepsy/anything related to the MSI. It seemed unbelievable that no insurer at all, not even the Lloyds market and specialist brokers who write

cover for such one-off risks as sportsman's limbs and film stars' bodies, were willing even to consider at offering any insurance to cover Richard for risks related to epilepsy on any terms.

The family (the two of us, Richard and his younger sister) flew out on 17th March, and 23 hours after waking at home in England we reached our hotel in Salt Lake City. There was 13 hrs of flying in all. The first 10 hrs from London to Dallas went far better than expected.. The 3 hrs from Dallas to Salt Lake City was not quite so easy: it was a very crowded flight - it seems everyone wanted to fly to Salt Lake that Friday night - and not all of our fellow passengers were child-friendly but Richard's behaviour was exemplary.

Jet lag hit Richard with a vengeance and left him very epileptic for the first 24 hours with occasional out-breaks for the remainder of our stay in Salt Lake. It made him very, very anxious and depressed. Indeed it took over a month after our return for the full epileptic effects of the jet-lag to recede. However, we still managed to see some of the sights in and around Salt Lake City, and Richard enjoyed the facilities of the Hotel including a 24hour a day swimming pool.

C.A.M.T. was set in the beautiful Wasatch Hills. It wasn't a hospital and at first it was hard to feel at home in the research, computer based, non hospital setting although we had the services of a very experienced and sympathetic team of anaesthetist, nurse, and EEG technicians. They could not have been more helpful and it was difficult not to make comparisons with the over stretched NHS who never gave much thought about how far you travel, or whether you need to eat or sleep or wash or deal with other children during hospital stays. At C.A.M.T. they gave every thought. They were in the course of a research project of MEG studies on 500 ASD (autistic spectrum disorder) children so Richard's reluctance to be there didn't cut any ice. Richard resisted the sedation as violently as he knew how but they were not put off. They were very careful and competent and deeply aware of the issues that surround the handling of LKS and autistic children. We asked for them to take a blood sample while Richard was sedated. They gave us a list of tests which could be done - so we opted for the IG levels and the measles virus. They were a little surprised to find that this had never been done.

The scan lasted about an hour. It took place in a special sealed room but Richard was visible to us throughout and we were invited to watch whatever we wanted without being in anyone's way. He was monitored throughout very carefully. The MEG scan was conducted simultaneously with a 32 lead EEG. We sat by

the computer screens with Dr. Lewine and we learnt more about Richard's epilepsy than we had ever known before. Dr. Lewine had taken time before the testing started to talk us through both Richard's history and the entire testing process. During the testing Dr. Lewine also showed us in real time what being revealed on a bank of multiple computer monitors. Seeing spikes and waves from the MEG that were not being picked up at all on the EEG from the same area of Richard's brain at the same time was a real eye-opener. At that point the major thing to come out of the MEG was the fact that there was indeed still spiking from Richard's sylvan fissure - something that the MEG machine is particularly able to detect - and that it was adjacent to the site of the MST that Richard had had 2 years earlier. This was something that repeated EEG's here in the UK had been unable to demonstrate and for us this fully justified all the costs and difficulties of the entire trip.

Another part of the MSI testing is an MRI test, as the results of the MEG and EEG elements of the test are superimposed on 3D images of the brain produced by computer from the MRI results in order to aid in their analysis and help to localise any epileptic sources that are revealed. However, in Richard's case the MRI also revealed a problem that it later transpired had been missed 18 months previously when his last UK MRI films had been reviewed.

Two days after the testing we returned home extremely weary but considerably better informed about Richard's condition than we ever had been in the past; and we later learned even more from the full report on the testing that we and Richard's UK Doctors all received about 3 weeks later.

Was it worth the considerable cost and expense? We certainly think so. It is only a shame that we could not have arranged such testing for Richard earlier than we did; and that more children like Richard do not at present have the option to undergo such testing both at the stage of diagnosis and prior to any surgical intervention.

Two postscripts must be added to this report. First, and sadly, the MEG facility at Salt Lake closed at the end of June. The cost of running the MEG facility at Salt Lake ultimately proved to be more than the University of Utah and the Utah Health Department were themselves able or willing to continue to fund (apparently it took only a few paying referrals such as Richard each week and most of its throughput was on a research basis which had to be funded internally).

Second, and on a more positive note, at the time we booked Richard's MSI testing in Salt Lake there was no equivalent UK facility. However,

on the very day we flew out to Salt Lake a Wellcome Trust funded MSI facility (albeit using a less powerful MEG machine than the one at Salt Lake) opened at the University at Aston, and while no LKS children have yet been examined at this facility we understand that it is possible that it could now take limited clinical NHS referrals including children such as Richard. It would nice to think that in the future our children won't have to cross the Atlantic to take advantage of MEG technology

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### FOLKS DAY 2000

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Our annual FOLKS DAY was held on June 3rd at St. Elizabeth's School for children with epilepsy and learning difficulties. Set in the quiet green Hertfordshire countryside the school made a splendid venue and FOLKS are grateful to all at St. Elizabeth's not only for their warm welcome but for all their hard work and generosity before, during and after the conference. Their keen interest in children with epilepsy was very supportive and made the organisation of the day so easy.

The Essex Leisure Team provided activities throughout the day which challenged the children to take part. Twenty four LKS children and their brothers and sisters took part in abseiling and archery, inflatable mazes and slides amongst other things. Wizard Wink also worked very hard all day to entertain and amuse the children with balloons and magic. It is not possible to mention by name all those wonderful people, the carers who took on some pretty demanding challenges and met them so well - the staff from St. Elizabeth's, IPOP and the Red Cross as well as those from John Horniman School and others who enabled all our very different children to be safe and enjoy the day.

We were delighted to have Barbara Wilson with us who did so much to make the day possible by raising £1,400 by running the London Marathon and collecting sponsorship. Barbara undertook her first London Marathon in April with an injury to her ankle but as so much depended upon her

she went ahead and managed to complete the course notwithstanding the pain. It was a real act of determination and generosity. Thank you Barbara. In addition Maggie McMahon, her husband David, son Christopher and their daughter Melissa were able to join us on the day. Maggie took on a different but equally daunting challenge at the beginning of the year to raise funds for the children on FOLKS DAY by organising the very successful "Making Magic" Event.

One of the problems with FOLKS DAY is that we have to put into a short time all that we want to do - the chance to catch up with old friends, the opportunity to meet new members (and we do appreciate the effort that some of the families made to get to FOLKS DAY), the need to have an agenda with something for everybody and the inevitable AGM. Amidst it all John and Jackie Beagley organised a raffle which raised a splendid £198 for FOLKS. They both retired from the Committee this year and we are very grateful to them both for their work for FOLKS over the years. The AGM saw the election of a new Chairman, Fiona Kettell who is now the longest serving member of the committee as well as the telephone Helpline and we will undoubtedly benefit from her experience. Our thanks to Steve King for numerous services to FOLKS this year but particularly for sorting out the accounts which for the first time were subject to (and passed!) independent external examination. FOLKS are indebted also to Committee members Mina and Bharat Patel for organising the recording of the day.



**Parliament and Paediatric Epilepsy?** - This Conference was one with a difference. We opened with a look at wider issues when Stephen Twigg, the Member of Parliament for Enfield South and Chairman of the All Parliamentary Committee on Epilepsy spoke about his work for people with epilepsy. In politics as in life, personal experience is the strongest of forces behind the ability to recognise and remedy inadequacies and injustices and there is no doubt that Stephen Twigg is a powerful advocate. Mr. Twigg experienced bereavement from sudden death in epilepsy in his own family as well as in his constituency work but then found a depth of

ignorance about epilepsy across politics and government. He formed or revived an All Parliamentary Group of some 50/60 members with an interest in Health Service issues, special needs, discrimination and education. The group provides a place for organisations such as ours to put their point of view. To make a difference is an enormous task - to use public debate, to lobby government departments on so many issues is demanding work. FOLKS is grateful to Mr. Twigg for his invitation to FOLKS to address the All Parliamentary Committee on the much neglected problems of paediatric epilepsy. His advice is sound - if you want to make a difference you can write to your MP - you can get in touch and raise awareness.

**"Landau Kleffner Syndrome finds the cracks if not the chasms in the system...the array of problems in LKS is beyond the Health Service as presently constituted"** - those statements very accurately reflect the experiences of so many of our families within FOLKS. LKS is hard enough but the shortcomings of the systems, medical, educational and social undoubtedly adds very significantly to that hardship. It was helpful that this was acknowledged by Professor Brian Neville of Great Ormond Street Hospital in his analysis on the organisation of services for LKS children as they exist and as they should be. It was a great pleasure to welcome Professor Neville back to FOLKS Day after his absence last year with such clear ideas of what the LKS child needs such as more widespread child epilepsy services within child development centres, more specialist child neurology centres, a fully equipped neuroscience service for multiple investigation at tertiary level, more multi disciplinary assessments, more paediatric occupational therapist and a child psychiatry service geared to the complexities of LKS or at least paediatricians trained in behavioural disorders.

**LKS and Magnetoencephalography (MEG)** - we are grateful to Professor Neville for arranging for Dr. Ritva Patau to speak at FOLKS DAY at short notice. Dr. Patau is a paediatric neurologist with a special interest in epilepsy who works at the Low Temperature Laboratory and at the Central Hospital in Helsinki and has researched the use of MEG studies in LKS. Dr. Patau gave a very informative lecture on how MEG works in a different but complimentary way to EEG to identify the source of epileptic activity, its propagation and how it has helped in Finland in evaluating children already selected for surgery by drawing a neurological map for neurosurgeons. All children that have had MST surgery in Finland and those in the last few years in the United States have had the benefit of MEG data available to the neurosurgeon, a stark

contrast to the United Kingdom where no child has yet had such point of reference available to them. We have to salute the Finnish technicians ability to achieve MEGs on LKS children without sedation and their persistence as it can apparently take several attempts. Even with the MEG data Dr Patau was of the view that we still don't know which child would benefit from surgery and that it remains an experimental technique in terms of assessing outcome.

*FOLKS are indebted to Dr. Andrew Holton, Consultant Paediatrician of Leicester Royal Infirmary for his lecture. Dr. Holton has an undoubted gift for helping us understand so much of what is never explained by the medical profession to families and so we have reproduced his lecture below.*

**"Helping Your LKS Children to Learn"** was the title of the a lecture given by Victoria Burch, Neuropsychologist of St. Piers, Lingfield, Surrey This was a difficult subject to fit in a short space of time but many parents and teachers will find it helpful to think about why it is so difficult for our children with LKS to learn. Victoria gave a clear explanation for the reasons for the difficulties and brief outlines of helpful techniques. The epicentre of LKS is usually around the perisylvian fissure where incoming auditory information is understood. In the centre of the temporal lobes there are structures which are essential for learning and memory. The distance between the epicentre of epileptic activity in LKS and areas for language and memory are very close. One of the things that happens, not just in LKS but in severe epilepsy of temporal lobe origin, is that children find it very, very difficult to learn new information. The reason for that is because of epileptic disruption to the memory areas. There are also areas responsible for memory in the frontal lobes and children that have spread of epileptic activity further forward will have difficulty in new learning. Frequently the epileptic activity doesn't stay in the temporal lobes but spreads and it can spread, in fact, throughout the cortex on and off and disrupts learning in different modalities, it can disrupt vision, it can disrupt attention level mechanisms, it can disrupt the child's ability to relate to the world. If processing is interfered with then learning is going to be interfered with. A form of epileptic activity very common in LKS, ( in fact many clinicians would say that the diagnosis of LKS is dependent upon this type of epileptic activity ) is ESES, (electrical status epilepticus in slow wave sleep) or under its other name CSWS. The important thing about this kind of seizure activity that most children with LKS have, sometimes for extended periods of time, is that it disrupts the processing of recent experience. So that when children wake up in the morning, even

if the EEG is much better, that child is going to have enormous difficulty in learning. Victoria went on to deal with the problems of attention deficit, hyperactivity, withdrawal and the enormous problem of anxiety. Children who are aware that their skills fluctuate without them being able to do anything about it can become exceedingly anxious when they are faced with tasks that they have previously failed or tasks that they have succeeded at but then they wake up worrying why they can't do it. The anxiety causes an exacerbation of the attentional difficulties.

So what are the building blocks for helping the LKS child to learn?. - an EEG pattern that allows learning, adequate sleep, adequate attention control and an ability to relate to the world and to people, the ability to copy, to be and fairly calm and alert, not hyper-alert, to have a good system of communication. Finally the Individual Education Plan for where the child is now. That is something that schools and special schools in particular should be good at but aren't necessarily very good in the case of LKS. The reason for it is that most education programs are based on the premise that the child has a developmental disability and with lots and lots of practice that child is going to acquire skills and get better. If the child has severe LKS, is an acute phase and has lots and lots of epileptic activity, that isn't going to work. Teachers can get very frustrated when children can do something one day and not the next. The parents of LKS children frequently know far more about LKS , the basis of the disorder and how it affects children than the teachers do. It is often up to parents to educate the teacher or the speech therapist or whatever professionals are working with the child about this disorder which fluctuates. Most educational professionals are not used to working with such fluctuations. Victoria covered a number of different approaches such as incidental learning, intensive interaction and non directed play and we hope that we will be able to reproduce the full text of her lecture in due course.

On another more practical note we were able to benefit from hearing Mary Jennings, Senior Speech and Language Therapist of the John Horniman School, Worthing on Paget Gorman signing and cued articulation. Mary is a member of FOLKS and has built a some considerable experience of working with LKS children and their varying speech and language deficits. Gild Detering a Senior Speech and Language Therapist was able to assist us by tackling the subject of Picture Exchange Communication System in an afternoon workshop which was of great help.

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**FOLKS AT THE HOUSE OF COMMONS -  
from Fiona Kettell**

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Working on the FOLKS Helpline and also through my own personal experience, I am sometimes painfully aware of how the systems that should be helping our children, i.e. health, speech and language therapy, education, behaviour intervention and social services, etc. are frequently failing to meet our children's quite complex needs. Although as individuals many of us have tried to tackle these problems at the local level, we believe that government intervention is necessary.

It is almost half a century since Landau and Kleffner identified our children's problems as being part of a syndrome and yet lack of funding for research into LKS in particular and epilepsy more generally means that we still do not know its causes. On average it is taking three years for our children to get a diagnosis of LKS. In a condition where early diagnosis and treatment may effect the outcome, this is disastrous. Long waiting times for speech and language assessments delays referrals to community paediatricians and neurologists. The

lengthy educational assessment and statementing process is not designed to take account of our children's sometimes rapidly fluctuating needs. Behaviour intervention teams who may not always understand the impact that LKS has at a neurological level on behaviour, often leaves parents with feelings of failure, frustration and anger. Hard pushed Social Services are often unable to find the resources to help families who desperately need their support. These frustrations are not only shared by the FOLKS Committee and families but also by professionals who genuinely want to help our children. It took one of these professionals to set out a challenge to FOLKS to become politically active for me to set pen to paper and write to my local MP Stephen Twigg who heads the All Party Group on Epilepsy. In reply I was invited to tea in the House of Commons to discuss these issues further and to explain the work of FOLKS and the aims we hope to achieve.

Having a personal connection to epilepsy himself, Stephen Twigg was very interested in both our problems and the work we are doing and expressed interest in meeting with our medical advisors to explain the position of Parliament and Epilepsy to our parents at our FOLKS Day 2000. His address was well received with some very pertinent questions from both families and visiting professionals. During his talk he acknowledged the "breadth and depth of ignorance surrounding epilepsy" and stated that he saw the All Party Group on Epilepsy as being "an opportunity for the organisations who do work in the epilepsy field to have a direct input, a direct connection into Parliament". He has welcomed FOLKS and some of our "experts" to speak to the All Party Group at some point. This is an opportunity that we certainly intend to take.

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### **FOLKS EDUCATIONAL QUESTIONNAIRE**

A very big thank you to every one who took the time to fill in the educational data forms and return them. This wasn't a survey but a collection of further more detailed data to be stored in confidence on the FOLKS database. One of the major problems facing parents and carers of children with LKS is their education. Generally LKS children do not fit into any neat educational category and frequently professionals (educational psychologists, teachers, speech therapists etc.) can find it difficult to agree about how and where an LKS child should be educated. As a result it can be very difficult for parents/carers of LKS children to find the best way to educate their children. This being the case, the FOLKS committee has decided to do a questionnaire to establish:

How and where LKS children are currently educated and with what degree of satisfaction.

The experiences of LKS parents/carers in their dealings with Local Education Authorities.

As a result of this questionnaire we hope to be able to provide information to parents/carers and LEAs about the educational options open to them and possible school placements. We also hope to be able to provide some advice to parents/carers about the level of co-operation and understanding that might be expected from specific LEAs. We hope that this information may be useful not only in anticipating the service which may be expected from an LEA, but also to those who may be moving house.

We have included the questionnaire and we would be grateful if all parents/carers of LKS children could complete this. We have endeavoured to keep it as simple as possible and although it may seem lengthy, many of the questions only require a box to be ticked. LKS children can vary greatly in their symptoms/abilities and we have had to reflect this in the questionnaire. This has unfortunately added to the length. If you require more space for any particular answer than allocated in the questionnaire or you wish to make further comments, then please add these at the end or on a separate page.

As the number of LKS children in this country is not large, we would appreciate the maximum number of returns. (This is the begging bit!) The more information we have, the more we will be able to help LKS parents/carers in the future.

### **PLEASE HELP US BY RETURNING THE QUESTIONNAIRE.**

Questionnaires can be handed in on registration at FOLKS DAY 2000 (Not 2001!). Alternatively they can be sent to:

Liz Boulton  
12 Winchfield Close  
Kenton  
Harrow  
HA3 0DT

If you have any queries, please contact Liz on 020 8907 3797 (ideally not between 4.30pm and 8.30pm) or e-mail [Liz@DataPerceptions.co.uk](mailto:Liz@DataPerceptions.co.uk)

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### **Parents On Line:**

Much has been written by professionals about how families cope with the strain of bringing up children with epilepsy. Perhaps much more could be usefully written by families about how professionals cope with the families. There is a range of terms to describe our coping mechanisms -"repression" - "reaction formation" - "rationalisation" - that one has to wonder when jargon will end and common sense will prevail. And yes - there is possibly one for all of us too - "sublimation" - a term to describe

the deflection of grief and pain into creative outlets such as those found in helpful organisations. Whether it is right or not that we are all using our sublimated energies, our universal experience within FOLKS has been that LKS produces independent, strong-minded, knowledgeable, caring and generous families willing to use their time and their skill in helping in many ways and in spite of the demands of LKS children. One of those ways is shown by the parents who are using computer skills to help - the "Parents On Line".

Debbie Barber - is a mother of a little girl with epileptic dysphasia and LKS Variant in the U.K. Debbie is a long standing member of FOLKS and we were very grateful when she set up the LKS chat club for FOLKS.

"For those of us who have access to the Internet we all know how valuable it is in finding information on the web ( after all that's how I found FOLKS!) And exchanging e-mails with other parents. There is another element which can be very useful, a life saver; it enables people to come together to talk in chat groups. In view of this I decided to set up a yahoo Club for FOLKS with a chatroom facility. At the moment there are 16 members and a few of us chat regularly exchanging day to day news and getting support and advice that only another parent with a child with LKS can give. We would like lots of other parents to join our "virtual coffee mornings" and have a regular chat time one evening a week. There is a message board and a photo album, grab a cuppa and please visit the site and have a look. If you would like further information please contact me through the club, you will find us at <http://clubs.yahoo.com/clubs/lkssupportgroup>

Leslie Martin (U.S.)  
[Http://home.att.net/~jimlesmartin/index.html](http://home.att.net/~jimlesmartin/index.html) - Leslie ( known to many on FOLKSLIST ) created a beautiful website dedicated to and about her daughter Kayla. Kayla suffers from LKS/CSWS and her personal story, as it was and as it develops introduces the site. The other parts contain useful information on the conditions of ESES, LKS, LKSV and autistic disorders and on research and treatment. There are numerous links to useful organisations and other information on e.g. the ketogenic diet and VNS.

"When we bought the computer for Father's Day in 1997, I didn't know it would have become such a big part of my life and a Godsend. Kayla had her first seizure in December 1997 and in March the following year I decided to take some time and create a web site about her. Never did I think I would get the response I have got from it. It has evolved over time, just as Kayla has evolved or should I say regressed.

I learned a lot through other email lists and web

sites. After a year of being on some email support groups and having discovered that Kayla had more than just one epilepsy, her first diagnosis was Benign Occipital epilepsy in December 1997 and it wouldn't be until after her regression and finally getting a second opinion in July 1999, that I discovered she had ESES (also known as CSWS or Continuous Spike and Waves during Slow Wave Sleep). The incredible thing was she had it during the day but to less of an extent. We went through all the protocols for treating CSWS and to no avail wound up with problems and no results. We are in the waiting game of trying new meds. and hoping something will work for us.

I created a new support group at [http://www.egroups.com/group/Rare Epilepsy Syndromes](http://www.egroups.com/group/Rare_Epilepsy_Syndromes) in order to help others with a more rare diagnosis. I have about 23 members right now, it is a kind of a quiet email list but I am there for the moms that need it. I know how difficult raising a disabled child is and I want to be there for others that have difficulties finding information. I had called Dr. Michael Chez in Illinois asking for information. I retyped this information onto our web site in order to get the information out to others. ESES/CSWS is so mis-diagnosed when doctors never even see a case in their lifetimes it is so rare. So I thought that since it was so hard for me to find information for it on the net that I would put it there for others to have also. Why hold back good information when it is so desperately needed by others. I would do an injustice to Kayla if I didn't give back what I have got from others."

Kay Stammers ( U.S.) - <http://trainland.tripod.com> - "Welcome to beyond Autism - All Children are Exceptional" is the statement that opens Kay's web site. It is so absolutely packed with information covering every aspect of autism and LKS and epilepsy that its hard to break away. A number of the links are relevant only to parents in the United States but many are of real practical use for all. It is divided into four sections, "Favourite Links" - e.g. on Communication, on Education, on Autism, on LKS and seizures, on PECs, diets etc, "Fun Stuff" - a unique collection of on line activities and links for children with and without disabilities ( a real help in school holidays ), " Abstracts and Articles on medical issues and Late Breaking News" - particularly for US members or if you generally want to know what is happening elsewhere.

"The main reason I started the site was to provide PECs (Picture Exchange Communication System) resources. Communication is one of our kids biggest problems and it can prevent them having so much frustration if they can just find a way to communicate their wants and needs. There were no sites available at that time with PECs pictures that parents could access and so many of the school districts won't provide communication software for

parents to use at home. The site just sort of took off from there.....

Another reason for starting the site was to have a "one stop" place for parents and professionals that were starting out on autism, LKS and other disabilities to provide comprehensive resources of information on teaching, methodologies, education and "special " education resources, IEP information, augmentive and communication assistance with assistive technology information, disability legal information and much more! My latest obsession is the "Late Breaking News" section that is updated daily.

I remember how frustrating it was trying to find out reputable information on autism, LKS, seizures, IEPs, communication, knowledgeable medical and education professionals and I wanted to help others avoid some of that and at least have a decent starting point for information resources.

The site has been an obsession for me and very rewarding, I have received nothing but positive feedback on it and I have found that even the school administrators and personnel are checking it out and passing it on to the parents of their students."

Edna Bizzell ( U.S.) - <http://sites.netscape.net/stutchr>.

Edna of FOLKS list is a teacher and mother of Rebecca who has L.K.S. The site is dedicated to Rebecca and contains her story together with resources on TEACCH and early intervention programs.

When Rebecca stopped speaking, we felt very frightened and very alone. Searching for answers to the why and wherefore became if you will our personal obsession. We ran into a lot of roadblocks along the way. As much as we wanted answers and refused to give up, most professionals could offer little in the way of answers. Indeed most doctors really did not know what was going on.

The greatest lesson I discovered was that parents know their child better than anyone. One of the people who examined Rebecca did not know what was wrong with her but suggested she behaved like an Autistic child ...but too social. That perception turned out to be the final piece of information I needed to get Rebecca tested for L.K.S., having already ruled out tumours and stroke. With that assertion I looked at everything I could find about Autism, and found the TEACCH web-site which listed many autistic spectrum disorders. I read each one until I came across L.K.S. While reading I told my husband 'My goodness this is Rebecca! Trusting what I knew about my daughter, I became aggressive in finding someone to do an E.E.G. to confirm my suspicions.

Before the test was even done I developed my website. I wanted to give other people my personal experience with a rare disorder. I have received a

wealth of e-mail from people all over the world, who need information, and to know they are not alone. I hope it does that. I pray more parents with rare disorders might do the same. We are not alone!

Note:

For those interested in the neurology of LKS and epilepsy see

<http://emedecine.com/NEURO/topic547.htm> and also <http://emedecine.com/NEURO/topic182.htm>

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**"Landau Kleffner Syndrome:  
A Parent's Guide" - by Richard and  
Katherine Price.**

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One of the common early experiences of families who are given a diagnosis of LKS is a feeling of bewilderment and a desperate need for practical clear information. That need is rarely met. This book written by Katherine and Richard Price of The Australian Landau Kleffner Association is just the book to help parents understand the complexities quickly, get hold of resources ( Australian) and has numerous suggestions for different strategies. It has the advantage of being based upon real understanding of what parents need to know and what they can expect. The cost is \$20 Australian and it is available from R. and K. Price, 80 Galston Road, Hornsby, New South Wales, Australia. Congratulations go to Richard and Katherine for all their hard work and especially upon the birth of their daughter Nehrys..

"Chrissy's Story" - by Jane Gregory

The author of this moving book is a journalist and the subject of her book is Chrissy, her 16 year old daughter. Chrissy experienced the most severe episodes of tantrums and crying in cyclical bouts throughout most of her childhood. The book demonstrates how impossible it can be for even the most articulate and literate parent to have such a condition diagnosed. A round of hospital tests produced no result nor did a range of treatments, sedatives, special diets and alternative medicine. The Park Hospital in Oxford and Great Ormond Street Hospital suggested that Chrissy had "behavioural" problems. After much research by her mother and continuous battle to get a diagnosis Chrissy was eventually found to be suffering from cyclical depression and epilepsy and only then was she able to have an effective drug regime. The book is published by Jessica Kingsley ( ISBN 183028746). Jane is also the author of "Bringing Up A Challenging Child - When Love is not Enough".

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**WATCH OUT FOR :**

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"A new web site called [www.disabledinfo.com](http://www.disabledinfo.com) has just been launched. The aim is to be a "one stop site" for all disabled people. The webmaster

welcomes ideas and information. There will be a shopping mall, travel and leisure sections added later in the year".

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### Further from FOLKS

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#### IMPORTANT TO NOTE:

Change of Address - FOLKS now have a new postal address to avoid recurring problems with PO boxes changes. When writing to FOLKS please address mail to:

*3 Stone Buildings ( ground floor ),  
Lincoln's Inn,  
London WC2A 3XL*

Post sent to the existing PO box address should continue to reach us until February 2001.

FOLKS 2001 - will be on 2nd June, 2001 and will be held again at St Elizabeth's School, Much Hadham, Hertfordshire.

The FOLKS from California - we were delighted when FOLKS LISTER Peggy Simons, husband Marc and children, Stephen, Rachel and David decided to pay a visit to London in August for some intensive sight seeing. One big problem - Rachel (12) has LKS and is very successfully on the American ketogenic diet but would customs let Peggy import her particular dietary requirements - could she buy cream, butter, oil, cheese with the right percentage of fat? The Ministry of Agriculture, Food and Fisheries was a little surprised by the request to import meat and fish for an epileptic child and some of the manufacturers of mayonnaise didn't quite understand why we needed full fat in a particular brand rather than the fashionable low fat versions. Peggy travels with her computer to calculate Rachel's meals - and one only need to look and talk to Rachel to see that all the effort is so worth while for her. She experienced a considerable improvement in her EEG with the diet and is not taking any anti-convulsants. By the time we met up with the family they had already visited Kensington Palace, Buckingham Palace, the Royal Mews, The Tower of London and Tower Bridge and were heading off to Edinburgh for the Tattoo, without any of the family showing signs of jet lag! Despite their hectic schedule we managed to catch up with them for an afternoon in London and compare experiences. Talking to Peggy and Marc it became very clear - that the problem of delayed diagnosis is sadly, as common across the Atlantic as it is here and that awareness of LKS within the medical profession needs to be extended in both countries. Time with them was all too short but we learnt a lot from them all. - from Margaret Hantusch

Walking for FOLKS- Edna Bizzell of FOLKS List

and mother of Rebecca (LKS) is raising awareness of Landau Kleffner Syndrome in North Carolina. Edna, mother of six, the youngest of whom is Rebecca and a recently qualified teacher, features in the article "Parents on Line". Not content with this Edna wrote a piece on L.K.S. which was published in the local paper during USA's "Autism Awareness" month. In October Edna and her family are going to take part in a "Walk for Epilepsy" where they will wear T-shirts with the FOLKS emblem on the front. It would be nice to see the FOLKS logo around North Carolina- hope you all enjoy the walk.

Fund Raising - One of the problems of a relatively rare disorder like LKS is that the number of members tends to be on the low side but what we lack in quantity we make up for in quality. There seems to be no end to the enterprise and talent displayed in raising funds. At FOLKS we are very proud of the fact that almost all funding has come from the parents, families and friends of children with LKS. The fact that FOLKS can get information, support and advice out to families and professionals in 26 countries has been only made possible by their hard work and generosity. There is never enough space to print the letters of thanks that FOLKS receive on your behalf but there is no doubt that as a Charity we are helping to increase the understanding of LKS and so improve, sometimes very directly, the lives of LKS children. Well done everyone and thank you.

"A Story of Time" - The staff and parents of Chipping Hill Infants School in Witham, Essex, decided to do something special to celebrate the new millenium. With the enthusiastic encouragement of headmistress Chris Heard, the idea was conceived of writing and producing a very special play that would cover key events from the last 2,000 years - "A Story of Time".

The school generously decided that all proceeds should go to two charities - the Tuberous Sclerosis Association and FOLKS. These were chosen as there were two local children who would have gone to Chipping Hill School had it not been for their disabilities.

One of those children is my son James who has a variant of LKS. My daughter Zoë spent three very happy years at the school, so when the idea of raising money for FOLKS was floated I was only too happy to help. Little did I realise that this help would in fact entail not only contributing to the script, but also appearing in the play itself. So it was that I joined the merry crew of the staff, parents and pupils who pulled together to write, produce and appear in the play. And what a success! From set designers to costume ladies, from stage hands to make-up, the team spirit was tremendous and the children were a revelation. Word spread so quickly from the open dress-rehearsal, that Mrs. Heard had

to press- gang hardly any members of the audience to ensure four full houses. The net result - some £600 for FOLKS! There is even talk of the script being revived for the next millenium!- from Ian Tapster.

Charity Cricket - a fascinating account of how to make cricket more interesting! Each year the Camphill Sports and Social Club at West Byfleet, Surrey hold a charity cricket match to raise money for some of the larger charities. This year the secretary of the Club, Andy Cowie ( and brother to committee member, Martin Cowie), decided to help a smaller group like FOLKS.

The match consisted of 30 overs per side, each team member paying £2 to play and then "fined" £1 if bowled out for a duck, 50p for no ball or wide and £5 for king pair ( 2 ducks in a row!!!) They also sold a few beers during the match hence the £5 charge for a king pair!!!!!! A really splendid effort as £250 was raised and sounds like a lot of fun.

Sponsored Supper for FOLKS - other members of the Cowie family were not to be out done by Andy's efforts at the cricket match. Member Gill Cowie ( Martin and Andy's mother) had the very bright idea of holding a dinner party and at the same time raising £65 for FOLKS. We hope you all had a pleasant evening.

**Sponsored Slim** for FOLKS - three ladies did exactly the opposite and raised a total of £142.50 for FOLKS through a sponsored slim. We have to thank Brenda Bolingbroke, Elaine Camis and Louise Fitzpatrick from Addlestone, Surrey for their self sacrifice and their success.

**Donation** - a generous donation of £100 was made from F.O.L.K.S. members Mr. and Mrs. Butler from Northern Ireland.

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 3. Stone Buildings ( ground floor ), Lincoln's Inn, London. WC2A 3XL by 1st February 2001. 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.



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

Surname	LKS Child's Name			
Parents Forenames	LKS Child's Date of Birth			
Siblings Name(s) and Age(s)				
Address				
Country				
Tel No(Home)	(Work)	Fax No		
Best Contact Time	E-Mail Address			
Doctors Names				
Hospital				
Age of LKS Onset	Age of LKS			
Diagnosis				
Seizures:				
Type of Seizures				
Frequency of Seizures				
Suspected Causes: <small>(please specify)</small>	Birth Related	Viral Related	Vaccine Related	Other
Behaviour Problems:	Mild	Moderate	Severe	Very Severe
Communication Problems:	Mild	Moderate	Severe	Very Severe
Speech Deficit:	Mild	Moderate	Severe	Very Severe
Motor Difficulties:	Mild	Moderate	Severe	Very Severe
Current medications				
Past Medications				
Surgery/Other Treatments				
Education:				
School Name				
School Type				
Speech therapy Y/N (Details)				
Adult Support Y/N (Details)				
LEA Name (UK Only)				
Statemented (UK Only) Y/N				

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.