Newsletter March 2004

Contents

Introduction from the Chairman

Folks family fun day 2004

Educating LKS children in a mainstream setting

Choosing a school for your child

LKS children in Specialist Schools

Useful Numbers and Contacts

A Family Story – Marathon, Meg Scans and Surgery!

Drugs Information Link

Data Base Update Sheet

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

Introduction

May I take this opportunity to belatedly wish you a very Happy New Year, and hope that as a FOLKS member, with all its implications, your situation might be alleviated in some way during 2004.
As your new chairperson I will endeavour to do my utmost to ensure that FOLKS is run as efficiently as possible and that the Committee is proactive and positive in all its dealings.
FOLKS have been wonderfully supportive in helping our family cope with my son's problems, and as chairperson I am now in the privileged position of being able to give something back. I am determined that you will receive all the support and help FOLKS is able to offer.

Yours sincerely

Angie Conlon

Folks Family Fun Day

Great news!
Folks are holding a family fun day on Saturday 11th September 2004
The event will be held at Snakes and Ladders in Abingdon – an indoor Children's play centre with excellent facilities.
You will remain responsible for the care and supervision of your own children (maybe bring a helper with you?) and it will be a superb opportunity to meet with other families, talk, swap stories, find out up to date information and have fun. Food is available at Snakes and Ladders but please bring your own if you would prefer or require special diets.
More details will follow nearer the time, but please indicate your interest on the data sheet attached and please put the date in your diary now so that as many families as possible will be able to get together.

Educating LKS Children in

Friends of Landau Kleffner Syndrome
3 Stone Buildings, Lincoln's Inn, London, WC2A 3XL
Tel: 0870 8470707
Internet: http://www.bobjanet.demon.co.uk/lks/folks.html
E-Mail 101361.2530@compuserve.com

a Mainstream Setting
Janet Pain

Educating children with LKS is never straight forward – the range of problems is as individual and varied as the children themselves. This study collates information from a small group of children - probably the minority group of children with LKS - that are currently in mainstream schools, or language unit provision within mainstream schools.
The new Code of Practice for children with Special Educational Needs, and all recent Government policy regarding education, is strongly in favour of "Inclusion" – that is educating all children within a mainstream environment whenever possible. In fact, it is the duty of the LEA to provide mainstream placement for any child whose parents wish for such a placement. Of course, as parents we all know that this is not always the best for every child and that for many children a specialist environment with a high level of support is much more appropriate. This investigation attempts to look at what is currently working for some families and what the factors are that make it successful.

The first thing that comes over from talking to this group of parents is that the fundamental "key" to success is a supportive school. The majority of children where the arrangement is working were already at school before they became ill and this encouraged the school to stay involved with the family and adapt the provision to the child's needs.

Q1 Statementing – how did it happen, was it easy, did you agree with mainstream provision, were the reports written by professionals to support the statement useful?

All the children had statements of Special Educational Need, except one who was awaiting final statement documents. Most people reported that the procedure had been straight-forward, although it is always very drawn out (about 26 weeks), some people were still in dispute over the level of funding. Some people had had the additional problem that their child had not been on the Code of Practice at all when they became suddenly and acutely ill and required a lot of support. This is something that doesn't "fit" with the system, which assumes 2+ school terms at the school based level of support before a child is referred for assessment. Everyone had agreed with the school named in the statement although some had subsequently moved to a more suitable school. No one was currently waiting for a special school place to become available, although several were looking at alternative provision when their child reached secondary age. (Specialist provision or Private Education to get small class sizes). Some people did feel that their child might have achieved more had there been a specialist setting or a language unit place available in their area, but had opted for local provision rather than travelling out of their area.
Almost everyone had at least 1 unhelpful or un-supportive "professional" on their case. Sometimes this was a Speech and Language Therapist (SaLT) who didn't understand the need – even discharging the child altogether; sometimes it was an Educational Psychologist (EP) – like the one who never tested a child's comprehension of the written word (later found to be <5 at age 11). There was an equal number of excellent people, both SaLTs and EPs who had gone way beyond their "duty" in supporting the child and the family through a difficult time.

Free advice on Statements is available from a charity – Rathbone Special Education Advice – 0800 917 6790
Local parent support groups can also be very helpful with the process.

Q2 Is the school informed about LKS – are Individual Education Plans (IEPs) well written and do they "happen"?

The best schools had sought out information, taken it on board and learnt. Often the schools that were supportive had some relevant previous experience, had staff that had worked in special schools, or had a lot of experience of children with special needs. Several people felt that their school might not have been so keen to take the child on if they had appreciated the complexity of the needs! Many felt that the school was not used to dealing with the multi – agency involvement/ number of specialists some of our children see.
Individual Education Plans (IEPs) were written by the school, sometimes with involvement from the parents, and most people felt they did "happen". Schools were less good at taking on outside ideas, suggestions from parents, speech therapists, or professional advice obtained outside of the LEA. The biggest "wait" seemed to be to obtain a computer, generally at least 6 months from when the child was recommended to have one to use in class.

Q3 Was the school knowledgeable about, and prepared to cope with Epilepsy?

The majority of children in this "mainstream" group didn't have a major problem with seizures. Most schools were informed and happy to deal with it. Some schools had no "policy" on epilepsy but had been happy to take it on, writing a policy together with a care plan and training staff to deal with it.

Q4 How does your child behave at school?

Generally the children were coping with school although many had had bad patches, especially during Steroid treatment. Some people had moved school because the initial placement had been unable to deal with challenging behaviour.

Q5 What about Speech therapy?

Some people have SaLT through education and some through health. In both cases it can be erratic and some children have had long periods without therapy even at times when they have desperately needed it. Often the

therapist will leave just when they have got to know the child and you have to start again with someone new. Sometimes the therapist was just suggesting things for the school to do with the child and not giving any direct therapy. There can be a problem in finding a suitable specialist therapist with any experience of working with aphasic children.

Q6 Social groups, peer groups and acceptance by other children – is this a problem?

There was a big range here from people that felt their child had no problems socially, to people who felt their child was often completely isolated. This was especially true during periods when the child had problems with their speech or behaviour. Some children had been "bullied" or "teased" about their language or their weight (when on steroid treatment) – the main factor here seemed to be the age of the child – the older you get the crueler other children are! Children often had "a" friend or liked to play with the younger children. Some families had found the set up of Language Unit provision had isolated their child socially. A number of school's ran some form of small group support on social skills. This situation varies a great deal between schools as some offer a lot of small group teaching and some had the children supported entirely within a whole class situation.

Q7 Progress – how does your child get on at school?

Most children were functioning at the low end of normal or below normal. Interestingly there was almost a 50:50 split between children struggling with English/reading and those struggling with maths. Only one parent reported that their child was working at normal levels in all areas. The level of support available had a high impact on children's learning. Generally the child was unable to concentrate or access what was happening in class without 1:1 support. The level of support offered ranged from 100% to 10 hours/week. 1:1 support also seemed to impact on the stress the child suffered and on the number of fits they were experiencing. (i.e. More support = less stress = less fits). Levels of noise in the classroom were often a problem and the child would become unable to concentrate or follow what was happening.

Q8 What are your biggest concerns?

The biggest concern was over the maintenance of the statement at a sufficient level of 1:1 support, since children generally were learning during those supported periods and not during the other times.
Many people were also concerned about the peer group, how accepted their child was, and about their child having real friends. There was the underlying worry about future periods of regression and about how the child would cope as they got older.

The biggest advantages people cited were maintaining 'local' relationships rather than travelling long distances for special provision, accessing a wider curriculum and enabling the child to be as 'normal' as possible. It was evident that, for some people, Mainstream could work given sufficient 1:1 support. No-one I spoke to was actively considering changing the provision for their child for a more supported environment.

Education – choosing a school for your child

Janet Pain

Two years ago I began a quest to locate a suitable school for my LKS daughter, then in year 5 at a mainstream Primary school, in preparation for her transfer to Secondary Education at the end of year 6. I hope my experience may be of use to others as they look for the "best match" in their area.

How do you start?

I started with information from my own LEA and neighbouring LEA and looked for 'special' schools on the Internet. It took some time to draw up a list of places to consider looking at, as the information available from these sources is very general and doesn't give a profile of what sort of child might fit. Once I had a list I phoned and e-mailed for brochures. Again these were of mixed quality and some did not make it clear who they catered for.
The next step was phoning. This was very time consuming as the person I needed to speak to was usually teaching during the day and in meetings after school. Phoning back later in the day generally got no reply or an answer phone as the school secretaries went home at 4! However, most schools were helpful and eventually rang back – although I did have one interesting conversation when I was put through to the person in charge on 'the unit' (I had asked for the language unit), to find that the school had two units and they had put me through to the person in charge of the inclusion unit, for 15/16 year olds who were in trouble with the police!!!
Once I had all the information collected I then short-listed places to visit.

Visiting Schools

Again this was very time consuming and emotionally draining. Each visit lasted about 2 hours and re-running my child's history each time I found quite depressing as, inevitably, you are explaining some painful things and re-living a traumatic experience. (At least that's how it was for us as our daughter's onset, age 5, was very sudden and dramatic.)
I found I gained far more from the visits than from the brochures as you could see the school in action and how the children were working. No school will be an exact fit for a child with LKS, so you need to prioritise their needs and look for the best match.
I looked at a wide range of schools: specialist language schools, moderate learning

difficulty schools, mainstream schools with a language unit, and our local secondary school. Almost everywhere I found caring, committed people with a wealth of expertise in working with language disordered pupils. I could see positive points in each place:

Specialist Language Schools:-
There was a very high level of support here, with signing used throughout the school alongside speech. Each class had a teacher, therapist and support assistant for 6 – 10 children. Because of the specialist nature of the school many of the children were severely disabled and the focus was on basic communication and life skills. My biggest question mark over this type of school is how an LKS child, if their I.Q. is normal, would fit with SLD children, especially during periods of improvement/ lessening of epileptic activity?

Moderate Learning Difficulty Schools:-

A whole range of learning difficulties were in these schools, including a large percentage with language problems. There was again a high level of support, signing being used throughout the school, and all lessons being "language checked" by a specialist to make sure they were accessible to the language disordered children. Overall the children admitted into these schools were below average I.Q., so you would have to judge for your own child how this would fit. It is also a fact that these schools are largely pupilled by boys (most classes had only 1 or 2 girls) and I felt this would be difficult socially for a young teenage girl. The range of subjects offered was limited by the small size of the schools and probably couldn't cater for a language disordered child with very poor language skills but near normal maths/science ability.

Language Units in Mainstream Secondary Schools:-

I looked at some very different schools in this category. Some offer minimum withdrawal – perhaps only a few sessions a week to work on language, speech therapy or social skills. The children are then supported in the main school with an assistant going with them to other lessons, and often supporting a group of children in that class. You have to judge whether this would work for your child. Could they cope with the pace and frequent changes, being personally organised enough to move around the school and having a lot of different teachers?
Another unit I looked at (ICAN in mainstream) had a much higher level of support, about 50% timetable. The set up here allowed the group (6 children) to work in the unit for all conceptual subjects – English, maths, geography, history & R.E. – and in mainstream for science, P.E., music, technology etc. The same staff from the unit supported the children in mainstream classes. There was a high level of therapy on offer, individual and group, and a lot of sessions on social skills – effective communication for successful relationships. The thing I liked about this set up was that it would suit an LKS child with normal I.Q. but language problems, as there was access to normal curriculum anywhere the child could attain it. For example, if a child was good at maths they could attend mainstream maths classes, they could also move between the mainstream and the unit as the need arises, an important factor if your child has a fluctuating condition. Most children at this school were taking and achieving a range of GCSE's, practical and certificate of achievement courses.

Local (non unit) Secondary School:-

This school is very familiar to me as my other children have all gone there. However, since none of them were on the Code of Practice, I didn't really know how the school would respond to a child with LKS. I visited the Special Educational Needs Co-ordinator. The school was supportive and was using a range of strategies to support children with difficulties. The level of support in class and withdrawal from lessons was at least equal to some of the unit provision I had seen. This was achieved mainly by withdrawing from the 2nd Modern Foreign language lessons, so that children rarely missed lessons they needed to catch up on. What was lacking here was professionals with experience of working with language disorders of the unpredictability and complexity of LKS. There was a lot of expertise with dyslexia, some of which would be useful, but I felt an LKS child here would still be disadvantaged. There was little, if any, access to therapy except at a basic non-specialist level. I felt that a language disordered child in this environment would be unlikely to achieve their best potential, not least because they would spend too much of their time in the lowest ability groups with disaffected & disruptive pupils.

What Next?

How do you persuade the LEA to give you the placement you want? I find that within SEN there is a wide variety of people and attitudes. LEA's have categories and they would like all children to "fit" into them. Unfortunately most LKS children don't, and that gives them a problem! They don't fit because of the uncertainty of the course of the illness. SEN assumes that progress is forwards, even if it is slower than in a normal child and the ultimate goal is less. LKS children can make progress forward and backwards in an unpredictable way in a year/week/day/½ hour! LEA's rely on predicting levels of a child's attainment 1 – 2 years ahead. I couldn't even hazard a guess for my child!

Most provision assumes a particular profile – but what fits for you?

Learning difficulty schools and specialist language schools:– Very basic skills, alternative communication widely used, no exam courses generally on offer.

Moderate learning difficulty: – Fairly low achievement across the range of subjects, vocational courses and some foundation level GCSE's offered, but generally quite a poor range of subjects.

Mainstream schools with unit provision:-
Very varying levels of support on offer but the full range of GCSE's normally available. (Some schools withdrew pupils from modern foreign languages). I felt that only 1 school I looked at could truly respond to the range of ability my child displays and give access to realise whatever potential she has for academic achievement. Also this school could offer therapy as needed, support in social skills, and, because of the way it was organised, could respond to periods of regression or recovery.

What else can you do?

Talk to everyone you can. I've met speech therapists by chance at social gatherings, people with special needs children in different situations, health visitors, teachers, dyslexia specialists. Every bit of information and every idea you accumulate is potentially useful because you are **THE** key person to draw the picture of what your child needs. Be a bore and ask everyone!
Make sure that reports written about your child reflect how it really is. I found that my speech therapist was making the reports as positive as possible to 'encourage me!' However, this is not an advantage, as the LEA will make its judgements on reports and test results. Make sure that the tests used are the ones that show the problem. My daughter can do some tests really well (she's had a lot of practice!) and others not at all. One speech therapist told me, on the basis of looking at one test result, that my daughter's speech was normal. She hadn't ever spoken to her or she would never have come to that conclusion. I challenged her to go and do that before she made such sweeping judgements!
Find out who your 'friends' are. At different stages I have found tremendous support from different people. It might be a health visitor, a teacher, Headteacher at your current school, paediatrician, speech therapist, dyslexia specialist etc. Know who will represent your case positively to the LEA and enlist their support as much as you can.
Be prepared for hard work, time consuming effort and a battle! The LEA doesn't want to spend money and they want your child to be in the cheapest, most local provision. Know what you want and why and don't give up pushing. I have been so fortunate to have a supportive primary school. They have gone out of their way to provide for her needs in the best way they could, and have enabled her to remain in mainstream because of the level of provision they have been prepared to put in. Many people I know are not so fortunate, so if you are make sure you acknowledge what the school does – support its fund-raising, become a governor, write a nice letter, help in class – whatever you are able to do to keep them on your side and encourage their support. The rewards are there for a school that is helpful. My daughter's Primary School have told me how things purchased for my daughter (books, computer programmes etc.) are very useful to a whole range of other children, who would never have access to such resources if they weren't purchased for her!

Postscript

Subsequent to writing this article my daughter was offered a place at the school of our choice and started there in September 2003. The hard work seems to have paid off as she is making excellent progress and the school are enormously supportive in helping her integrate and overcome her difficulties. All the staff are aware of her problems and there is a good level of understanding of epilepsy in the school as well as the complexity of language difficulty LKS children suffer.

So, my final comment is **'Never give up'.** There is help available, should you need it, on attending a tribunal to get the placement that is right for your child.

Specialist Schools
Marie Riddle

In the last FOLKS newsletter I wrote a piece on "Educating our children". Carrying on from Janet's article on choosing a school for your child I wanted to write a little on specialist schools.

Assuming you have gone through the stages that Janet has and found that no local school seems suitable for your child, the next stage is to look at the Specialist independent schools, what the authorities deem an out of county placement. These schools have detailed knowledge of particular areas, i.e. speech and language, epilepsy, autism and have trained staff and detailed knowledge of your child's condition.

How do you find these schools?

Use local information i.e. your local branch of AFASIC (Association for all speech impaired children) as to their experiences. Maybe precedence has been set as to help or facilities given to a pupil. Maybe you can find a number of parents that have the same needs and so can put a joint case together.

If you have had an independent Educational Psychologist report prepared then the EP could guide you as to school provision.

Information can be found on specialist schools in a publication called "The Gabbitas Guide to schools for Special Needs" which can be found in the reference section of your library. This is a good starting point for contact information. It explains the types of children they cater for i.e. speech and language disorders, epilepsy, autism etc…

The Internet is a great resource. Visit the school's web site. Download their latest OFSTED report. Read as much as you can.

In an ideal world you would then request that the LEA sends your papers to the school(s) you want. However, these specialist independent schools are not cheap and so a good case has to be made. Inclusion is the key word at the moment. A lot of the specialist provision that was available is disappearing. There used to be schools that were labelled Mild, Moderate and Severe Learning Difficulties. Now they are being merged. This means that a child bordering on mainstream, who may have entered a school that was deemed "Mild" now faces the full gambit of learning difficulties that are manifest in a school that caters for "Severe Learning Difficulties". Some Mainstream schools have language units but sometimes our children's needs are more severe than that and there is no provision that falls between these two extremes.
If your child is currently in a mainstream provision and onset of LKS has come quickly it is more than likely that your child may not have a statement. It is important that this is addressed immediately.

What is a Statement?

A Statement describes all your child's special educational needs and the special help your child should receive whether it be money, staff time or special equipment. It is important that this document accurately reflects your child's needs. There should be a number of reports from experts such as Educational Psychologists Speech and Language therapists, Occupational therapists – whatever input is necessary and it is also important to bear in mind that you might need your own independent reports from experts that will be prepared to act as witnesses later in a tribunal if required.

Statementing is a major topic in it's own right and it is imperative that it is written well. There are a number of organisations such as IPSEA (Independent Panel for Special Education Advice) that can help as well as NAS (National Autistic Society) and AFASIC. If you can afford them, commission independent reports on your child from the relevant experts. There are also a number or publications that you can get from the DfES (Department for Education and Skills). These are free publications which can be obtained by calling the Dfes publications centre on 0845 602 2260.
The ones to request are: -
Special Educational Needs (SEN)
SEN Code of Practice
Inclusive Schooling
SEN Toolkit

It is important to read these documents in order to ascertain your rights and the rights of your child. If you do not agree with the statement then you have a right of appeal at a tribunal. I would strongly urge you to hire experienced legal representation if this is the road you are now travelling. Maybe a letter or two from them will save going down this route. Keep channels of communication open and maybe this will prevent going to tribunal but ultimately if there is fundamental disagreement this is where the matter will be resolved. Sadly this route takes a lot of time, effort and money and is emotionally draining. You will need expert witnesses and reports and a lot of determination.

Visiting schools

It is important to have an idea of what you require from a school. Make a checklist, talk to them on the telephone, and then visit the school. It is important to visit the year group that your child will be entering. Can you see your child there? Are there other children with similar needs? How big are the classes? What strategies do they employ for behaviour/rewards/discipline? How would specialist help be given? What age range do they take them to? In fact all the questions you would ask of any school.

Some schools have a list of parents you can contact - call them. Most of all, does it feel right? Will it be a partnership or do they think they know it all. This is the most dangerous of faults. Some of the non-specialist schools can be far more flexible and open to ideas.

Boarding

It is possible that the school that fits your child's needs may be far from home. How do you and your child feel about boarding? A lot of these schools feel it is better for the child to be at school at the weekend even though you would want to bring them home. Visit the accommodation; is it dormitories, shared or separate rooms. Ask what personal effects your child would be allowed to bring with them and what activities they would engage in after school. Do they have access to activities outside of school, such as cubs/brownies, youth club? How often can you speak to them during the week? It might sound a silly question but one school had a designated night for me to call my son (a Thursday), he was seven and homesick.

Speak to the care staff. They will be the ones who will be with your child after school through to school the next day. Look at the common room and the facilities it has. Can they bring their bikes into school? How many televisions are there? The children they mix with after school may be different to their class group so look at the peer group. Check out the canteen and see how flexible they are over the menus or if your child has special dietary requirements can these be catered for.

In these schools there is a far higher proportion of boys then girls, therefore it is likely that girls will be placed together in one house unit, not by age/ability range like the boys.

How will they keep you updated with your child's progress? Will they use a home book, telephone contact, the odd conversation in the car park? What is their policy

on homework and keeping you involved – if that is what you wish to happen?

A lot of these schools insist on you changing your child's GP to be the school's GP whilst still keeping your consultants.

Specialist epilepsy schools and there are only 3 recognised as such by the Department for Education, have closer links with the medical community i.e. Great Ormond Street. They have a more detailed knowledge of epilepsy and can cater for the more severe epileptic episodes.

Transport may be an issue. Will the authority provide a taxi with an escort or will they expect you to take your child to and from the school and pay you nominal expenses? How frequently will they provide transport … once a week, once a fortnight, or just the beginning and end of each half-term?

There are so many factors to consider, not forgetting how will it impact on the rest of your family. It is important to get the right placement for your child, one where your child can feel safe and learn and one that can cater for their needs as they change. Talk to as many people as you can so you can make an informed decision for your child.

Useful Numbers and Contacts

AFASIC – the association for speech impaired children
08453 555577

ICAN – National educational charity for children with speech, language and communication difficulties. Runs 3 schools, Early Years Programme, Mainstream Support and Training Programmes
0870 010 4066
www@ican.org.uk

SKILL –supports students with disabilities in post 16+ education
0800 328 5050
1.30 – 4.30 Mon – Fri
www.skill.org.uk

THE CHALLENGING BEHAVIOUR FOUNDATION
Helpful leaflets and information on behaviour issues.
01634 302207

THE NATIONAL SOCIETY FOR EPILEPSY
Confidential helpline and range of information and leaflets + training for schools and carers
Helpline 01494 601400
10.00 – 4.00 Mon – Fri
www.epilepsynse.org.uk

THE EPILEPSY ASSOCIATION OF SCOTLAND
As above (but in Scotland!)
0141 427 5225
09.00 – 4.30 Mon – Fri
www.epilepsyscotland.org.uk

CONTACT A FAMILY
Free helpline supporting families with any child with a disability or special need. Can provide advice on, amongst other things, benefits, education and respite care.
0800 808 3555
10.00 – 4.00 Mon – Fri
www.cafamily.org.uk

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

IPSEA – Independent Panel of Special Education Advice. Free advice on statementing, tribunals, obtaining correct provision etc
O1394 382814

THE GABBITAS GUIDE TO SPECIAL SCHOOLS
Useful book to get from the library or look at information on the web.

A Family story – Angie & John Conlon and their son Michael

A brief history
Michael was a lively outgoing little boy and a real "peoples' person." He had started his pre-prep school in September 2000, aged 4 and was making good progress. Michael's problems began with brief moments before breakfast when he would appear to "freeze" as if he had seen a ghost and would say "Mummy, I can't hear you, I can't understand what you're saying." Afterwards, he was totally unaware that anything had happened.
Between Christmas and April, the "freezing" episodes had concluded and Michael began experiencing weekly absences, which were also noticed by friends and teachers. In April 2001 when Michael had his first EEG, it was of no surprise to be told that the result showed abnormal electrical activity. Our "normal" little boy was now officially suffering from epilepsy! Sodium Valporate (Epilim) was introduced but the absences became more frequent.
In April 2001, Michael's first reading test showed that his ability was that of a 6 year old, but by July his speech was beginning to slur, he was struggling to remember words and his basic understanding was deteriorating rapidly. The seizures became even more uncontrolled and so Lamotrigine (Lamictal) was introduced too. We were referred to a Child Neurologist for assessment and further EEG's and an MRI Scan were carried out. By the end of August 2001, Michael had lost his speech and was struggling with basic living skills. A sleep-deprived EEG led to a diagnosis of LKS and a high dose of steroids was introduced. The results were amazing – by the end of week 1 Michael had regained his understanding and had a 50 word vocabulary. By week 2, he could make 5 to 6 word sentences. The steroids were then reduced and he began to regress.
It soon became apparent that Michael was incapable of coping

with the demands of school, who were indeed, inexperienced in dealing with his issues. We therefore, looked after him at home and began to pursue the statementing process with the Local Education Authority.
In December, we saw Professor Neville at Great Ormond Street Hospital, by which time Michael had again lost his speech. His understanding was that of a 2 ½ year old and he was extremely cushionoid from the steroids. His seizures were still uncontrolled and his behaviour appalling to say the least! It was decided that the daily dose of steroids should be replaced with a high dose of weekly pulse steroids.
As we toasted in the New Year we hoped for a better 2002. Unfortunately that hope was soon dashed as we experienced emergency hospital admissions. More anti-convulsants were tried, alas, with no success. It had become clear that the medication was struggling to manage Michael's epilepsy and we were considering putting Michael forward for MST surgery.

The 2002 London Marathon

It had been a lifetime ambition of mine to run the London Marathon but I'd never had enough will power or a real reason to run – until now. Angie and I were out for dinner with friends in December 2001 and I was explaining that I would love to run the Marathon and raise sponsorship for FOLKS. Little did I know that our friends were involved in a charity and offered me an entry. I gratefully accepted, and realising that for the next four months I would need a lifestyle change, polished off the bottle of wine! Or was it two?
I joined the Leighton Buzzard Fun Runners who gave me lots of hints, tips and provided me with a training schedule. I soon noticed that on training runs, everyone had lightweight clothing and running shoes, whilst my fleece-lined tracksuit and trainers added about six pounds to the task.
Having decided to purchase some appropriate kit, I arrived at the local running shop and when asked what I was looking for I set out my requirements - nothing too expensive, low key and loose fitting to hide my curves. I achieved the COST goal by purchasing from the sale section, but the kit was skin tight and fluorescent!!!
Sporting my new look, I set about the training. I used January to get fit and moved into February with a weekly schedule of one 6 mile run and one 45 minute stamina session, together with a long run at the weekends which commenced at 10 miles and built up to 22 miles by the end of March.
There were lots of occasions when the training was tough – especially when Michael was in hospital or when a sleepless night was followed by a 13+ mile run.
There were many factors pushing me on – first I was not going to let Michael down and secondly, the offers of sponsorship were starting to flow in.

Sunday 14th April 2002

The big day arrived and as I prepared to leave home, Angie gave me a final pep talk, "There's lots of people sponsoring you, pace yourself and make sure you finish!"
Finish, I thought! I was planning to break away from Paula Radcliffe at 20 miles and a winning debut would give me automatic selection for the Commonwealth Games!!
The race itself was an amazing experience. It provided an opportunity for the likes of me to compete in the same race as, The World Champion, The Olympic Champion and The World Record Holder - something that does not happen very often. The crowds were supporting me with the same passion and interest as enjoyed by the elite runners.
I quickly settled into my stride and tucked in behind the leaders – well, half an hour behind them. The crowd were superb – tremendously vocal and cheering us all the way round. Everything was going fine up to mile 18 when I hit the wall. What actually happens is that around 18 to 20 miles, the body runs out of fuel and looks for fat to convert to energy. In addition, the body starts to shut down non-essential functions so overall things get tough.
By 23½ miles, I had started to get a second wind. The crowd were still cheering right along the Embankment and as I turned into the Mall and saw the finishing line, the pain and the 9,000 odd runners ahead of me had disappeared – all the hard work and preparation seemed worthwhile.
Crossed the finishing line was very emotional – I felt a real sense of achievement. I had done it for Michael and also raised some funds for FOLKS. On reaching the repatriation area, I saw Angie to whom I owed so much. Many people have a Marathon story but she was the unsung heroine – supporting me during the training and helping me to believe that in these difficult times you can still achieve so much. Also my family was there, not only cheering and encouraging but, most importantly, supplying the post marathon banquet.
Well eventually, the limbs stopped aching, the blisters healed and the "old physique" soon returned to its former glory.
I would like to thank all those who gave me both financial and moral support – it really did make a difference.
The total sponsorship raised was £6395!

Oh, by the way, I finished in 3 hrs 50 mins, coming 9,212 out of over 33,000 runners.

Meg scan in Helsinki – Monday 15th April

The morning after the London Marathon and we were heading to Heathrow Airport for a 9.00 am flight to Helsinki, Finland.
We had been advised that a MEG Scan could help with Michael's pre-surgical investigations and also in determining the nature of his epilepsy. We knew that this was not usually part of the investigations in the UK but we were determined to have it included. After lobbying Professor Neville he acknowledged our request and he referred us to Dr

Paetau in Helsinki.
I made the initial contact with Dr Paetau, who was very proactive, extremely supportive and even provided us with a social worker, Irmeli Langford who helped us to arrange accommodation and flights.
We were met at the airport, by Irmeli, who transported us to our hotel. That evening we met with Dr Paetau at the Hospital. She went over Michael's history and took us to where the MEG scan would take place. She suggested we could take the opportunity to do the MEG scan there and then (without sedation). This proved absolutely disastrous as Michael made it perfectly clear that he was not going to co-operate. Dr Paetau decided that the MEG Scan would be best done under sedation as originally scheduled the following day.

Tuesday, 16th April

The time difference made it a particularly early start for us. The post marathon euphoria was subsiding and John was now unrecognisable as the 'athlete' of a couple of days previous. We arrived on the ward at 8.00 am, 6.00 am UK time! We asked Dr Paetau how long it would take to get the results and she explained that it could be anything from one day to several months to build the model (a combination of the MEG Scan and MRI).
Michael was allocated his own nurse and Dr Paetau's team made us feel totally reassured and confident that he was in safe hands.
The MEG scan took about 1½ hrs to complete and we were told that diazepam had been given in order to obtain spike-free monitoring. The initial view was that the activity was widespread. Dr Paetau set about interpreting the results. I must admit that at this stage I had concerns as to the likelihood of both a speedy and positive result.
During the planning of the MEG scan Dr Paetau informed us that the MRI scanner at the hospital where she was based was not available for at least another 6 weeks. Again her positive approach to our cause was overwhelming as she hired another hospitals MRI scanner on Michael's behalf so that she would have both sets of results to work with.
Dr Paetau returned in the early evening and reported that she had some initial good news, in that the MEG showed a clear focus in the right Sylvian cortex. She also commented that it was very rare to get such a clear result, so quickly. Dr Paetau said that she was now able to make the model using both sets of data and would take us through the results later. We could barely hide our feelings of relief and optimism. This was the break we so desperately needed. At 8.00 pm she returned to explain to us what the data meant and to answer all our questions. We left the hospital an hour later. The day had been a landmark but we appreciated that we were only a short way into the battle against LKS. For the first time we had a very clear indication that surgery was an option and confirmation that Michael had LKS – a diagnosis which had been questioned given the extent of his seizures since Christmas.

We cannot speak too highly of Dr Paetau, her team and the value of the MEG scanner. We were fully supported from our first communication with Dr Paetau. We were treated as "friends" and given clear explanations with open discussions. During our day at the hospital in Finland, Dr Paetau had been with us for over 13 hours – She was an absolute star!

The Importance of a MEG Scan

I appreciate that it may not provide additional data for every child but as a parent, my advice is that it is ESSENTIAL to have it included in pre-surgical investigations.
This point has been further reinforced in that Michael's methohexitone suppression test showed bi-lateral simultaneous spikes, which may have ruled out surgery in the absence of the results of the MEG.
However, the MEG in Michael's case at least asks questions of the other tests and the initial feedback we have had from other parents is that they too had bi-lateral sources on the methohexitone test but a single focus on the MEG – which had proved to be accurate. Dr Paetau was not surprised that there were contradictory results between the tests and that the MEG in her opinion was definitely correct in this case.

I do not have all the answers but this experience has left me with two overriding thoughts:

- The Meg Scan must be part of the pre-surgical investigations.
- We have a MEG Scanner here in the UK, but sedation for our children cannot be provided. We have to do whatever possible to change this position.

We spent Wednesday in Helsinki reflecting on the previous two days and Thursday at Great Ormond Street hospital for further tests. By Friday evening we were both exhausted. I had to smile when John told me a fellow Marathon runner had called to say "I hope you have taken it easy this week"!!!
The18 months prior to surgery were an absolute nightmare, EEG's, MRI's, a MEG scan, a methohexitone suppression test, trying medication after medication; implementing a gluten/casein free diet, herbalism, homeopathy, cranial-osteopathy and still our little boy continued to deteriorate.

Trip to see Dr Smith, Rush Epilepsy Centre - Chicago

After the encouraging MEG results from the trip to Helsinki and the disappointing results of the Methohexitone Suppression Test, we asked ourselves the question – what else could WE do whilst we waited for GOSH to review Michael's situation?

First, we talked to other parents in FOLKS and they suggested that we spoke with Professor Polkey at Kings College Hospital to gain the benefit of his experience in LKS.

Professor Polkey has officially retired but kindly agreed to meet with us, privately, to review Michael's condition and suitability for surgery. Professor Polkey confirmed the diagnosis of LKS and suggested, that if we decided to pursue the surgical route we should act as quickly as possible given the severity of Michael's epilepsy. He recommended that we should have a WADA test and if that was consistent with the MEG than MST could be performed.

We were also introduced to Professor Polkey's successor, Mr Richard Selway who also reviewed Michael's records, echoed Prof Polkey's thoughts and left us feeling far more positive about the way forward.

Then, another LKS parent, Theresa Fazio suggested we bring Michael over to meet with her son's neurologist Dr Smith at Rush Epilepsy Centre in Chicago. Her 8 year old son Steven had undergone MST surgery 2 years before. She had continually sung Dr Smith's praises and so little persuasion was needed.

The decision was made and following a barrage of desperate phone calls, we were given an appointment date with Dr Smith on Friday 14 June. We were due to fly out on Wednesday 12 June and so this gave us two working days to compile all the information pertaining to Michael's case.

Gathering all the notes from various sources was a time challenge (when is LKS not so?) but without the information the trip would be pointless. The team at GOSH pitched in and came up trumps by handing us all the relevant information we would need before the flight the next day. Armed with MRI scans, EEGs, MEG data and Methohexitone Suppression Test results along with a file heavy enough to warrant hand luggage, we headed for Chicago.

The plane journey was eventful to say the least and probably the hardest challenge of all. As the 'fasten seat belt' lights went off Michael began introducing himself to all the passengers by shouting, screaming, throwing everything to hand and walking up and down the aisles, constantly. John truly believes that he walked to Chicago with Michael, with the only respite coming from a 2 hour session of cleaning/playing in the cabin crew galley. The British Airways crew were brilliant, extremely understanding of Michael's behaviour (unlike a number of the passengers) and looking to help us in any way they could, including an upgrade of seats to give Michael more leg room.

We arrived in Chicago mentally and physically drained. We are fortunate enough to have family living in Chicago so we were able to stay with them for a couple of days and the remainder at Theresa's house. I think, our presence, in anyone's home for a whole week, would be too much to expect – our cousin's lives were turned completely upside down during our stay!! They were all very accommodating with Theresa being able to provide an LKS friendly safe haven - no explanations or apologies needed.

We were hoping that the appointment with Dr Smith would provide a clearer understanding of Michael's condition. His seizures had become so severe over the last 4 months that the diagnosis of LKS was being questioned with the suggestion of a possible degenerative brain disorder.

The data from the EEGs, MEG and Methohexitone Suppression Test were contrasting so we were keen to hear Dr Smith's opinion as he has a wealth of experience in interpreting and evaluating the various pre-surgical data.

The first impression we got of Dr Smith and his team was how positive and approachable they were. After meeting Michael, studying all of his notes and discussing with John and I Michael's developmental history he was able to confirm the diagnosis of LKS.

He outlined the action plan very simply: with LKS the child should outgrow the seizures and behavioural problems during teenage years and the goal is to reach this age with the minimum amount of disability. He explained that there is a 2-3 year window to recover the functions affected by the epilepsy, however, if the skills are not regained in that timeframe the child is quite likely to be impaired. In Michael's case medication was clearly not providing a satisfactory solution and we were therefore considering surgery.

Dr Smith's ability to interact with Michael was impressive and really quite exceptional. This was the first time that Michael seemed to enjoy a hospital visit and it was very enlightening – I wish that Dr Smith had been on the plane with us on the way over!!!

Surgery

Dr Smith explained to us that although MST may appear simple and straightforward, the importance of an experienced surgeon in this field was crucial as the risks from surgery are real. We talked about surgery in Chicago vs London and Dr Smith took us through the experiences of Rush. He was extremely complimentary of Prof Polkey and commented that his team had performed as many MST operations as anyone and that they had achieved good results, which had been published.

Contrasting Data

Dr Smith had previously experienced contradicting data between the EEG/MEG and Methohexitone Suppression Test of which the MEG proved correct. He was not able to comment on Michael's Methohexitone Suppression Test results and suggested that we should rely on the MEG.

Next Steps

In terms of what to do next we were advised to have the WADA test at Kings College Hospital to confirm the MEG results. If the findings were consistent with the MEG then Michael would undergo MST straightaway, if not, then we would have to think again. Thankfully the WADA results confirmed the MEG results

The trip to Chicago for us was

invaluable. Dr Smith gave us nearly 2 hours of his time and he was, as Theresa had said, quite fantastic.
Our determination to explore every avenue has had positive results. We feel we had gathered as much information as possible and have left no stone unturned. Michael's case was indeed complicated, however, the decision to perform MST was agreed. The surgery performed by Mr Richard Selway took place at Kings College Hospital, London on the 3rd October 2002 and the results 18 months post-op have been miraculous.

I appreciate that I am fortunate enough to have been able to pursue all the available options but I hope that the experiences shared will benefit other parents in the same predicament.
I would like to thank my best friend, Theresa Fazio in Chicago, who was an inspiration to me, never letting go of my hand and leading me the whole way. I am also indebted to Professor Polkey for his constant support, to Mr Selway for his knowledge and his skilled hands and last but by no means least to Dr Ritva Paetau for giving us the evidence enabling us to push for surgery.

Michael has been accepted by Moor House School in Hurst Green, Surrey and is due to start in September 2004. Our next challenge is with the Local Education Authority.

Finally…

There is some excellent information on drugs on a website Medicines.org
There is a specific guide on epilepsy drugs which is both comprehensive and well written:

http://medguides.medicines.org.uk

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

We should be grateful if you would take a few minutes to complete this Contact 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**.

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: Birth Related/Viral Related/Vaccine Related/Other (*please specify*) ....

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 G

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 fa mily; 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.

P.T.O.