

Newsletter

April 2007



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

******Celebrating 10 years of supporting parents, carers and professionals******

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Introduction

Warm greetings to you all. To try and avoid repeating myself, I thought I would look back at my previous newsletter introductions, and to my amazement, I noticed that I have unintentionally and consistently referred to the weather and the seasons!! Well, I guess, as these form a basis of the world in which we all live, what a great, way to express my feelings for how FOLKS has grown over the past year and no doubt, will continue to grow.

Winter has its wonderful moments, but it is always a relief to say goodbye and let go of the sombre darkness, the cold winds and the bare trees. The arrival of Spring with blankets of snowdrops, daffodils of every variety and new-born lambs in the fields is such a magical time of promise and expectation that it is impossible not to be inspired and our spirits uplifted.

Inspirations for 2007 are already pushing ahead with gusto. Amy Alsop ran the Bath half marathon on the 25th March, and has very kindly donated all her sponsorship to FOLKS. Closer to home, our next fun runner will be my husband John who will be running this year's London Marathon on the 22nd April. John is training unbelievably hard, running 20 miles each weekend with shorter runs in between. He is getting up at 5.00am to run before he heads off to work and he can't help but wake me to let me know!!!! Roll on the 23rd April – a lie-in at last!! Please refer to the fundraising section of the newsletter to read more about events raising money for FOLKS.

FOLKS is indeed very fortunate to have such committed individuals to raise money for our Charity, and I, on behalf of the Committee, would like to thank each and every one

of them. To learn more, please log on to www.friendsoflks.com where you can also find details of how to donate directly to FOLKS either through PayPal or by popping a cheque in the post to our Secretary (address on last page of newsletter).

Previous years have seen extremely successful FOLKS Family Days, with the Parent's Day of 2006 being equally successful. For 2007, we are planning another **Family Day**, a great opportunity to meet other families in similar situations to yours and to share your LKS experiences. A problem shared is often a problem halved. Saturday **22nd September** is our provisional date, but please keep a constant check on our website www.friendsoflks.com for regular updates.

This newsletter is overflowing with information, you may want to grab a box of tissues, I certainly did as it took me right back to when we were in the same desperate situation. I hope you will find it both interesting and beneficial. If only one snippet of the content helps you move forward in some way, then the Committee's goal has been achieved. Please bear in mind that this newsletter is for you so if there's something you'd like to be included please contact anyone of the Committee and we will be happy to accommodate. In between newsletters, if you want to contribute to the website by perhaps submitting an article, or advertising your fundraising event for FOLKS, then do not hesitate to either e-mail Richard or ring the helpline.

Last, but by no means least, a very important issue that I have to share with you. The majority of the Committee

members have almost gained their long-service awards, and it is likely that without new blood on the Committee, FOLKS will cease to exist. I realise that it is impossible to even consider being a Committee member if you are in the depths of despair with the challenges of LKS. However, if you are at a point where you can see light at the end of the tunnel, bringing your contributions and recent experiences to the Committee would be invaluable to the ongoing success of FOLKS. The Committee is extremely receptive to new ideas, and as part of our commitment to keep FOLKS thriving, we welcome new members with open arms. If this plea strikes a chord with you, please

think seriously about contributing to the FOLKS effort, many hands make light work. Make a difference by contacting any one of the Committee, either by email or via the helpline.

Clear EEG's and seizure free children is our aim

Bright blessings to you all.

Angie Conlon
Chairperson

Case histories from members

George's story

George is our third child of four and as with our other children, developed well and reached the usual age milestones. His first words were at about nine months "Mum, Dad, Ta, All Gone". Between the ages of one to two his speech comprised of short sentences "Daddy bring me presents and Cup of tea, etc". George was a happy and contented child mixing well with other children.

He attended playschool and later before his fourth birthday started nursery, he made good progress with nothing unusual to report at the parent evenings. After a month, sleep became restless and he awoke frequently and complained of pains in his legs and a severe constant bowel problem which lasted until successful surgery. His behaviour started to deteriorate, he was irritable, lashing out at anyone around him.

In April 1995 his behaviour became even worse, the school noticed and added a possible hearing problem too. At home this became more noticeable and he started acting strange, with pickiness over food, rolling his head and eyes at the dinner table, we thought he was just pulling faces.

In May, following many GP appointments, a hearing test was to be arranged, but before this happened the whole nightmare unfolded. He awoke one morning losing everything, he became totally aphasic. We took him straight to hospital where we met Dr Croft (Community Pediatrician). After explaining the prior events, he suggested that George could have LKS, subsequent various tests including an MRI scan and a sleep deprived EEG confirmed his early diagnosis. We were very fortunate to receive such an early diagnosis and moreover that the discovery was by a Community Pediatrician, particularly as it was only after the consultation with Dr. Croft that George had his first seizure.

Over the next few months, George became unable to attend school, his medication was Carbamazepine but this only made him drowsy. Further deterioration in sleep and behaviour, spoke on a single word basis, he started to leave the ends off words "Mu for Mum, Ba for Bath and so on". He could no longer recognize environmental sounds and in all his confusion, responded with aggressive rage attacks at his family members. These attacks always coincided when his seizure activity was

high.

July came and George suffered a series of large seizures that took the rest of his speech and so he was taken back to hospital to be monitored. After making contact with the LKS support group, we were given the names of two Professors. We managed to get George referred to Prof Robinson at Guys. Following assessments the diagnosis was confirmed and a course of steroids were prescribed. The reaction to the steroids was incredible, hyperactivity, running around the house uncontrollably and throwing everything he could get his hands on, it would take both of us just to restrain him. After a further week some speech did return, but these were desperate times and we were left disillusioned about the benefits and whether we could even cope. When he was in these modes he was a danger to himself and all around him. When George was able to speak, he explained the sensation he was feeling by pointing to his forehead, saying "it's in there" and when he was well would say "it's gone".

Vigabatrin and Lamotrigine were added to his medications and the next few months were much better, his speech and understanding returned and he slept throughout the night. But this did not last, in October seizure activity increased and he was as ill as before, on occasions he would just drop to the floor. In December he was back on steroids again and although speech and understanding returned so did the hyperactivity and rage attacks, our youngest child bore the brunt, frequently he was in serious danger.

Early in 1996 all medications became ineffective. His seizure activity increased again and George was reduced to his bed, sleeping for hours and unable to even feed himself.

In June 1996, George was referred to Prof Polkey at Kings and after a series of EEG's and Telemetry (comparison of an EEG and a simultaneous Video Recording) had MST surgery in August. He awoke from the operation calm, alert and showed affection again, he spoke and after a few days pronounced his words correctly. He rejoiced in his well being and saying "they have took it out". The operation seemed a success and George grew in strength, started at a local language unit in September and made good progress.

For the first six months of 1997 he started to deteriorate, slowly at first with behaviour and understanding affected and then rapidly by July with the worst seizure activity to date. It completely disabled him, leaving him bed-bound and unable to carry out any of life's basic functions. He spent the next month in our local hospital before being transferred to Guys. His breathing had now become affected and the doctors described him as "being in status". Following daily steroid therapy, George finally emerged and the rest of the year his condition remained extremely variable with patchy speech and understanding.

In January 1998 the downward spiral started again and he was referred again to Prof Polkey for possible surgery. We were desperately worried, he was slipping away again, but unlike before there were no options, all medicines had been exhausted and already on a daily course of steroids, his only effective therapy. George had telemetry for several days until the team were confident they had found the focus of the activity.

In April he went into theatre and emerged after a long day without the procedure carried out, they could not locate the focal point to operate. Electrodes were positioned directly on his brain for further telemetry/EEG and the hope of a more accurate reading. In the mean time they explained three possible options, resection, a vagal nerve stimulator, and to re-operate (MST) within days the readings were good and the latter chosen. He returned to theatre and within hours of the operation his recovery was remarkable, he spoke immediately asking for a drink. He went from strength to strength and gaining speech and understanding, a boy he befriended prior to the operation, described the transformation in George saying to his dad "it's like a miracle" and it certainly felt like one.

George was now enjoying his longest period of good health since acquiring LKS, his medications had been significantly reduced and the steroid completely dropped. He started John Horniman School in September on a residential basis and made good progress, despite obvious language difficulties associated with the syndrome.

Attending a specific Speech & Language school had massive benefits such as small class sizes, a structured routine and lots of visual aids along with intense SLT. We all learned Paget Gorman signing to support his language. During his time at JH School, George's medication was reduced to nil and he was seizure free, his language and confidence improved significantly.

At twelve years old he transferred to Dawn House School in September 2002. All hospital referrals had now completely finished and George grew stronger and stronger. He coped with the transition well and enjoyed the mature surroundings. He has made good friendships which remain from JH school as well as the current. He has matured, using public transport unsupervised to cinemas and various clubs with other students.

During his time at Dawn House he has made good steady progress in all areas, but last year saw a massive leap and great excitement from the staff. Annual speech and

language test results soared, with things suddenly clicking into place. This year he will be taking 5 GCSE exams whilst attending one day a week at West Nottingham College.

George has grown into a well rounded individual with a good sense of humour. He has become one of the gang with his elder brother's friends enjoying going out and unfortunately a taste for my lager! He is kind and considerate, his own health experience has made him sensitive to others who are either ill or have difficulties. He has represented the school captaining the football team and competing in athletics. He loves all outdoor activities including skiing, paragliding, white water rafting and has developed a real taste for adventure. He is already looking forward to learning to drive later this year.

Looking back at his life we never thought he would achieve so much. We are indebted to the fantastic treatment by Guys and Kings College hospitals and the specialist teaching at both schools. We are looking forward to the future with great optimism, and with his further education place at Dawn House School agreed by the LEA, who knows what highs he can aspire to.

Marcus's Story

Marcus was born in May 1989 after a normal pregnancy and without any complications. He was developing normally with an outgoing personality and slightly ahead of his peers. In June 1993 Marcus went to the doctor for his pre-school booster injection as he was going to start a prep school in the September. That night he had his first seizure which was an extremely frightening experience. He was rushed to hospital where we were told it was a febrile convulsion and not to worry as they are quite common in young children.

Three months later, exactly the same thing happened and again the hospital told us not to worry as it was another febrile convulsion. Another three months later, (February 1994), he was admitted to hospital after his third seizure and was given an EEG and prescribed anticonvulsants. After trying Epilem and Tegretol we settled on a relatively new drug called Lamotrigine which seemed to suit Marcus and have the least amount of side affects. Marcus seemed quite well until May 1994 when his teacher noticed he was not always responding in class and suggested that he might have a hearing problem. We also noticed at his 5th Birthday party he was not fully understanding the magicians' instructions and not carrying out simple tasks.

Marcus was therefore sent for a normal hearing test and also another test where electrodes were placed on his scalp, both came back clear. Then gradually over the following months, Marcus was having difficulty remembering words and lines to nursery rhymes. His ears became very sensitive to loud noises and he couldn't always identify sounds like the kettle boiling and an aeroplane going over the house. He became fearless which meant having to make sure the front door and all windows were permanently locked and sharp objects out

of sight. His eating became a nightmare as he refused food that wasn't a certain shape or colour or looked the same as the picture on the box. This all coincided with his speech becoming slurred and suddenly my clever 5 year old who could read and write had regressed to a toddler.

In September 1994 Marcus was seen by the neurologist at the Luton & Dunstable hospital, who on our first visit wasn't sure what was wrong but on our return gave us the diagnosis of LKS. He wasn't very sympathetic and told us there wasn't anything he could do, but for us to accept the situation and live with it. I was adamant that he was wrong and so went home to research LKS. I found the number on the internet of the support group, which had not been going very long and contacted Vicky Horsewell. Her advice was to get Marcus referred to G.O.S.H., to be seen by Professor Neville and to get him put on steroids as soon as possible.

Our first appointment with Professor Neville was in October 1994 where Marcus was prescribed steroids and it was suggested we learn sign language in order to communicate with Marcus. He was also given an MRI scan which was normal, a SPECT scan and numerous EEG's. We were told about the side effects of Steroids but decided to take the risk, apart from the obvious weight gain and the moon face he escaped all the other side effects. Marcus responded well to the steroids and both his speech and understanding slowly returned. Unfortunately, on weaning him off after 3 months he started to regress. After a year Professor Neville decided to trial him with pulsed steroid which was a high dose every 2 weeks. This was changed to one high dosage every Saturday which had the desired result.

This worked very well and kept Marcus stable, as we were told if we could maintain him until early teens then the chance of any permanent damage being done to the speech and language area of the brain was minimal. Professor Neville also suggested for Marcus to try the Ketogenic diet, so in August 1996 he was admitted to

G.O.S.H. for 5 days to start the diet. The ketogenic diet is a diet high in fat and low in calories where everything has to be weighed as the calorie intake is very low. The diet was hard going for Marcus as he was permanently hungry, but he was seizure free during that time. Unfortunately, it didn't have any effect on his speech and understanding.

The next 5 years went by with the usual drug regime of anticonvulsants and steroids. I can still remember those little plastic medicine cups sitting on the side with tablets in, waiting to be taken without fail before school and before bed. Marcus struggled at school but always tried hard even though he was always at the bottom of the class. Marcus was weaned off of the steroids in August 2001 then the anticonvulsants in June 2003, (his last fit was in Sept. 1998). He was now 14 and fingers crossed we could now see the light at the end of the tunnel. Marcus started to improve significantly during his last 2 years at school (which is the first time he had been drug free) and gained a very impressive 8 GCSE's, with 2 A's, 2 B's and 4 C's. He then left school in July 2005 and went to St.Albans College to do a 2 year BTEC National Diploma in ICT.

We are now in January 2007 and to our utmost amazement Marcus has just been offered a place at Herts University to study Computer Science. He has also just received his provisional driving licence which is something I thought might never happen. Marcus will be 18 this year and off to University, I find it hard to believe that 14 years ago we thought his life might be very different, but we never gave up. My biggest thanks go to Vicky Horsewell for setting up the support group and giving me such valuable advice and Professor Neville for his expertise in LKS. Without these people he might not have been as lucky as he was.

I hope you have enjoyed Marcus's story and thank you for taking time to read it.

Jessica's University research assignment

Jessica Heard is a University Student in Australia studying Speech Pathology who researched LKS for a special education subject. Jessica said "I thoroughly enjoyed researching and writing about LKS as I was completely unaware of it until my lecturer mentioned it during class as a type of acquired aphasia. I have learnt a lot from doing this paper and I will follow any studies on it in the future".

We thought we should recognize her efforts by sharing her completed paper with you. This is her completed work. Foreman (2005, preface) states there is no particular teaching approach to use for each individual disability. Rather, that special education is about good teaching – adapting the curriculum, planning teaching strategies, using positive interactions and collaborative work. Normalisation is based on the concept coined by Bank-Mikkelsen (1969 as cited in Foreman, 2005 p4) and forms the basis of the special education policies of today. Wolfensberger (1995 as cited in Foreman, 2005, p4) considers this concept to be an extension of the Social Role Valorisation Theory, in which everyone has a social

role to perform. He believed that for people with disabilities to be included, they need to be given roles that are valued by the community. Foreman (2005, p12) believes that inclusion is based on a different philosophy than mainstreaming and integration, the difference being that it extends beyond education and into society. The philosophy of inclusion (Foreman, 2005, p9) states that all students with a disability should be able to use similar educational facilities to students without disabilities.

Some essential skills for including students with disabilities (Foreman, 2005, p28) relate to curriculum, adaptation, planning and classroom management rather than to a specific knowledge of each particular disability. However, when a teacher has a student with a disability in their classroom, it is their responsibility to provide the best support and optimal learning environment for the child. To do this, it may be useful to do some reading into their student's condition so as to be in the best position to provide for the child's individual needs. A specific disorder has been investigated below, as well as ways to

support children with this condition in the classroom.

Landau Kleffner Syndrome (LKS) is a condition affecting children only, predominantly between the ages of one and seven years of age (Price, 2005, p3). It is characterised by epileptic activity (usually only seen during sleep by monitoring the child's brain waves using electroencephalography) and the loss of previously acquired language skills (Lees, 2005, p242). There may also be visible seizures, motor difficulties and in 50-70% of cases, behavioural or social difficulties (Price, 2005, p26). LKS is a rare and complex condition as it often takes some time for the parents and professionals involved to see the whole picture and make a diagnosis (British Landau Kleffner Association, 2006). It also covers a broad range of varying levels of language loss and the child's language skills can fluctuate. It is not abnormal for a child to first be investigated for autism, mutism, deafness, behavioural problems or verbal dyspraxia.

The diagnosis is based upon the child's history and assessment. An important part of this history is the parents' records of their child's skills, particularly language, to serve as a baseline. A multidisciplinary team should assess the child, including medical, psychological and speech pathology services.

The language difficulties are often first observed as problems understanding spoken language (Leong & Joshi, 1995, p621 and Price, 2005, p24). These receptive language difficulties may be seen in an inability to understand complex or longer instructions, to understand previously known vocabulary or even a loss in the ability to recognise environmental sounds (such as traffic). Children with LKS also occasionally become intolerant of certain noises, such as music. Expressive language may also be affected, seen by sentences that are reduced in length, the use of more simple sentence structures, word-retrieval difficulties or pauses (British Landau Kleffner Association, 2006). Some children also have intonation and voice quality affected, sounding slurred, jerky or hesitant. The effects may be so severe that the child has no speech at all and may resort to gesture. Reading may or may not be preserved. In some cases, social interaction is also affected, with similar effects to those with autism. They may lose the desire to interact or have difficulties with eye contact or facial expression.

Cognitive skills are often less affected than language skills (British Landau Kleffner Association, 2006), although there is usually some impairment. This has implications for their education, as it is important to continue to develop these skills at such a critical time. The child may also present with difficulties in memory and attention (Price, 2005, p 7 and 26), particularly for language-based tasks. Children with LKS often have behavioural difficulties, such as hyperactivity, attention deficits, impulsiveness, mood changes, disinhibition and aggression. These behavioural changes are often thought to be the child's reaction to the frustration of the condition, that is the social and emotional impact of a sudden loss of language abilities. Motor abilities are also affected (Price, 2005, p25), such as unsteadiness, in-coordination, tremour, jerky movements, weakness or strange posture.

There are several treatment options (British Landau Kleffner Association, 2006): to treat the seizure activity (by the use of anticonvulsants) and therefore reduce the effect of the disease process or to provide support to encourage optimal recovery. The best steroid treatment effects are on those children who have Auditory Agnosia (that is, they are unable to understand speech) only, and no other additional impairments. Brain surgery is another option, which is only occasionally used when no other treatment method has been successful.

The prognosis is that some children make a good recovery; however, many have residual impairments as this condition often occurs during the child's critical window of development, leaving irreparable damage (Price, 2005, p28). Typically, the outcome is better if there is a later onset of the condition and/or as the period of sleep epilepsy reduces. The prognosis also improves the earlier the diagnosis is made (Price, 2005, p28). Children with prior language difficulties tend to have worse outcomes. Also, the greater the number of areas impaired, the worse the prognosis. As LKS covers such a broad range and number of impairments, it is difficult to predict an individual's outcome as this would be affected by a number of factors including: age of onset, active disease length, response to treatment and regression. In general (British Landau Kleffner Association, 2006), approximately half of children with LKS make a good recovery, one-quarter make a partial recovery and the final quarter has significant persistent impairments. It is not uncommon for a child with LKS to experience remission or regression (Price, 2005, p48).

LKS can be a distressing condition to live with as it is unpredictable and the child is often conscious of their loss of abilities, leading to frustration. It is also accompanied in most cases by low self-esteem and mood changes as the child is adjusting. It is important for the child to continue to spend time with existing friends as well as being encouraged to develop new relationships, perhaps with other children with language problems (British Landau Kleffner Association, 2006). It is also a stressful and overwhelming time for the parents as their child goes through mood changes and behavioural issues. The parents may also feel uncertain about their child's progress, as the condition is so fluctuant and variable. This means that treatments are uncertain and parents may be discouraged that their child is not making any improvement, as progress is so difficult to detect. As LKS is so rare, there is little knowledge in the community about the condition. Consequently, parents may find differing views in educational services about which approach to use with their child.

Language is the primary method of communication; therefore it is fundamental to every day living. Children with LKS need a comprehensive program to support them both at home and at school, as those involved in the child's care should provide an integrated approach supportive of the child in all environments (British Landau Kleffner Association, 2006). Some simple strategies include: using simple language, creating an optimal

listening environment, visual reinforcement or offering alternative or augmentative communication. Everyday tasks could become a dangerous situation for a child with LKS, for example they may not recognise the sound of a horn beeping when crossing the road. An intolerance to certain sounds, such as music, may lead to restricted outings. The parents are the primary caregivers as they spend the most time with their child and therefore detect changes in their child's condition, also making the decisions. Therapists work closely with the school teacher, often implementing many of their recommendations during class-time. The child is reviewed regularly to monitor any change in ability.

School is an important support mechanism for recovery as it presents as a major vehicle to carry out treatment. At school, the child's learning is supported as well providing a place of stable social structure (Price, 2005, p48). As LKS is so variable and the needs of each individual child are different, educational placement choices also vary. In children with good recovery, mainstreaming school may be the best choice. Those who show less recovery may also do well in a mainstream school with the aid of learning support aid. Children who are affected more profoundly by LKS may benefit from learning sign language, the services available in Australia being Makaton Sign System, Signed English (used in the Department of Education's curriculum) and Auslan (Price, 2005, p46).

Due to the fluctuating nature of LKS, there are many cases where children have had multiple educational placements for each stage of their disorder: during regression, the acute phase, recovery and stabilisation (British Landau Kleffner Association). Regardless of what placement is chosen, the school must be able to adapt to the fact that the child's condition can fluctuate, making their progress erratic. The school's support should therefore be responsive to this. The condition can also fluctuate within a day – children with LKS are prone to

fatigue and have concentration difficulties. Teachers should be aware of this and timetabling may need to be adjusted accordingly. Teaching methods implemented in a typical classroom are often verbal. However, as children with LKS' non-verbal (cognitive) skills can still be average or above average (Price, 2005, p25), a suitable method of teaching them would be to use non-verbal strategies. Therefore, tasks that are heavily language-based may need to be modified.

Children with LKS have the same rights as any other child with a disability (Price, 2005, p50). Some key factors which lead to successful schooling (Price, 2005, p48) are flexibility; good communication between the parents, school and other professionals; regular monitoring of abilities; when those involved in the care of the child are motivated to learn more about LKS; and a strong social network. Some ways in which to support comprehension are seating the child near the front of the classroom; repeating verbal instructions; using a slower speech rate; providing an optimal environment, e.g. reducing background noise; allowing the child longer to respond; breaking tasks down into smaller parts; and using visual processing cues (as this is usually relatively spared).

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Fundraising

Last year was an excellent year for fundraising but 2007 looks like it could be even better. However, we must not get complacent so we ask that you get your thinking caps on and see how you can help. Maybe you have a family member, a friend or even a colleague at work who is looking to run a marathon or hike up a mountain and would be happy to help raise funds for FOLKS. We have a number of worthy people running full and half marathons which seems to be the most popular way. So a special mention to John Conlon, the Magees, the Zoppinger family and good luck to you all. However there are other ways and Ros Kenny advised us of an event being organised in Ballyshannon, Co Donegal, Ireland during the bank

holiday weekend in August. It is a joint venture between her uncle, Brendan and her brother, James. James will be taking a pool team from the Manchester League to play against Brendan's pool team in Ballyshannon. The proceeds are to be divided equally between FOLKS and Parkinson's Disease, Donegal. Lets hope they raise 'pots' of money!

If you or someone you know has an idea and you need help getting sorted then please let us know. You can download sponsorship forms from our website and we will happily provide FOLKS' T-shirts, leaflets and posters.

Study of Melatonin use in Epilepsy

Approximately 10-30% of patients with epilepsy continue to have seizures despite medical treatment. In addition, a number of these patients are not candidates for epilepsy surgery. Therefore, it is this group of patients for whom

alternative treatments may be helpful. Melatonin is a hormone that is naturally produced by the body. It is released each evening from the pineal gland in the brain. Its exact role is not known, but is believed to have a large

impact on sleep promotion. Melatonin has been used in many neurological conditions including Rett's Syndrome, Tuberous Sclerosis, and Autism.

In previous studies, it has been shown that not only is melatonin helpful in regulating sleep, but it also has anti-seizure properties. Seizures are thought to be the result of an imbalance of neurochemicals and the seizures themselves lead to the production of substances called free radicals which can be damaging to brain cells. Melatonin appears to enhance the major neurochemical GABA, whose function is to stop or inhibit seizures. In addition, melatonin blocks the neurochemical glutamate which promotes seizures.

Lastly, Melatonin is an anti-oxidant which means that it blocks the bad effects of free radicals such as brain damage. There have been numerous studies in animals which show melatonin's effect in blocking seizures and protecting the brain from damage caused by seizures. In one study, the use of melatonin improved the effect of some anti-seizure medications. There have been a few studies in small numbers of humans which show a significant improvement in seizure control when melatonin

is used in conjunction with anti-seizure medications. None of the patients in those studies reported any side effects from melatonin.

The rationale of the use of melatonin in epilepsy patients is two-fold. First, it is well known that sleep deprivation can trigger as well as worsen seizures. Therefore, if a patient's sleep cycle can be regulated then perhaps seizures would be better controlled. Secondly, it is also known that seizures (whether they occur during the day or night) interfere with sleep. Therefore, stabilizing a patient's sleep patterns, may improve seizure control. Melatonin is given between 30 minutes to 1 hour before bedtime. The dose is 3 to 10 mg. Some patients may require even higher doses. Melatonin is a naturally produced hormone which has been shown to be effective in small groups of patients as well as in animal models. It also appears to be safe and well tolerated in patients. Melatonin can be considered as an alternative treatment in addition to standard seizure medications.

The above article was written by Josiane LaJoie, MD. New York University Medical Center.

www.med.nyu.edu/cec/images/melatoninarticle.pdf

And Finally.....

Firstly, a big thank you to all the contributors of this newsletter particularly the parents for writing the case histories. For those of you with young LKS children hopefully these stories provide encouragement. Marcus' and George's case histories demonstrate how tough LKS can be on the child and their family but also that through perseverance there is light at the end of the tunnel.

Secondly as previously stated our next **Family Day** is provisionally booked for **22nd September 2007** so please mark this date in your diaries and calendars. Our aim is once again to hold it somewhere in the Midlands. We will let you know more details in the Summer.

And finally as I have stated in previous newsletters we

would gratefully welcome new blood to the committee. We have lost a few committee members over the last two years without replacing them. We meet up every other month for a couple of hours. If you don't feel you can join the committee but still wish to help FOLKS in some other way please contact us 0870 8470707 or e-mail us at info@friendsofllks.com.

Many thanks and I look forward to your continued support.

Richard Budnyj
Secretary

F.O.L.K.S.NEWS welcomes all contributions, articles, letters and comments for publication. If you have any item suitable for publication it should be sent to Richard Budnyj, Secretary, 8 Malibres Road, Chandlers Ford, Hants SO53 5DT, alternatively e-mail to info@friendsofllks.com. F.O.L.K.S. does however reserve the right to omit or edit items where necessary. F.O.L.K.S. NEWS is published to provide general information to parents and carers of children with Landau Kleffner Syndrome and to interested professionals. The contents are not and are not intended to be, a substitute for advice from a qualified medical practitioner, preferably one experienced in the management of this complex disorder.

Executive Committee:

Angie Conlon (**Chairperson**), Richard Budnyj (**Secretary**), Steve King (**Treasurer**), Cathy Cowie, Martin Cowie, John Conlon, Robert Duncombe, Patrick Magee, Marie Magee.