

Aussie F.O.L.K.S.

Issue 1

Autumn, 1998

Aussie F.O.L.K.S. - c/- 80 Galston Rd Hornsby 2077 Ph (02) 9482 8425

Introduction

Welcome to the first edition of Aussie FOLKS. This newsletter has been established to provide support for parents with children who have disabilities as a result of epilepsy. Our goal is put parents in contact with other parents in their local area and provide valuable information about what services are being available within your local community.

The newsletter came about as a result of my own son's diagnosis of Landau Kleffner Syndrome. We could not find anyone to contact within Australia about his condition and as a result of extensive internet searches, found parents overseas. Their organisation is called Friends of Landau Kleffner Syndrome, or FOLKS, we have since lodged an application and all being well we will become Aussie FOLKS.

Since then we have found a few LKS children within Australia, but numbers are very low so we decided to expand our newsletter to include anyone with has a child who has a disability as a result of epilepsy and who are willing to share the good the bad and the ugly experiences they have had in getting services for their child.

As most of you are aware the Epilepsy Association no longer runs such assistance so it is up to the parents to do it themselves. The newsletter cannot survive without parental input, so please put pen to paper one night when the kids have gone to bed and let us know where you are and what services you are getting in your local area. There are currently no fees for this service although if our numbers expand rapidly a mailing fee may apply in the future.

Karen Price

Parent Contacts

Each month we will be bringing you a list of parents and their contact details. We will provide the parents first name, the child name, a brief outline and a contact phone number.

This months contacts are:

1. Felicity has Kyle, 5 yrs Landau Kleffner Syndrome, uncontrolled seizures
Coogee Ph (02) 9665 8304
2. Carolyn has Ashley, 7 yrs Landau Kleffner Syndrome.
Grafton Ph (02) 6642 7478
3. Sue has Mathew , 4 yrs, Landau Kleffner Syndrome and other complications,
Brisbane (07) 3350 4165

Professionals

We will also be bringing you a list of professional bodies which others may know about in either our local areas or overseas.

This months professionals are:

1. Dr Annie Bye, The New Children's Hospital Randwick, Sydney (formerly Prince of Wales Kids Hospital).
Ph (02) 9382 1111
2. Dr Buccannan, Westmead Children's Hospital Westmead Sydney.
Ph (02) 9845 2300
3. Dr Jim Pelekanos, Mater Hospital, Queensland.
Ph (07) 3252 6692
4. Ms Browyn Parry-Field, Speech Therapist,
Royal Children's Hospital Melbourne
Ph (03) 9345 5549

Parent's Responses

This section will consist of parents writing about their experiences and giving their opinions of different medical professionals, services, equipment or drugs. We are not governed by any political bodies so the onus will be on the parents to research the information in the newsletter until they are satisfied that they are making the right decision for their child. We believe one parent's nightmare may be another's miracle cure.

Each newsletter will have a series of questions to answer in regard to treatment and experiences. Responses will be published in the following newsletter.

This month's questions :-

1. How do parents cope with sleep deprivation generally, and especially when their child is in hospital?
2. Have you had respite services? If so, how helpful was it? What services have been the most useful/helpful? Which haven't been useful/helpful?
3. What do you think would make things easier on a daily basis?

If you have any questions that you would like to find answers for, please let us know. Some one out there may have the answers you have been looking for.

Landau Kleffner Syndrome

Each month we will provide an article on a particular type of epilepsy. Feel free to send us your comments, after all this is your newsletter and without your feedback it will fail.

This month's article is about Landau Kleffner Syndrome. LKS is a rare form of childhood epilepsy which, in most cases, results in a severe language disorder. The cause of the condition is unknown. There is no cure as yet, only management.

All children with LKS have abnormal epileptiform activity in one or both sides of the brain. These activities occurs during the child's sleep, although some children may also have seizures during the day. These seizures can be controlled by medication with varying amounts of success. There is no relationship between the type and quantity of seizures and the severity of the language disorder. These children also have difficulty understanding spoken language, especially comprehension. They may also fluctuate from mutism to telegraphic phrases. At first the parents believe their child may be going deaf, but the children all have normal auditory function tests.

Expressive language may also be affected. Some children lose their speech sporadically, others completely. The epileptiform activity tends to cease around puberty, but the language disorder may remain for life. Again, severity of seizures does not indicate the extent of language disorder. Most children find an expressive output through sign language and if the LKS is severe enough or long enough will find themselves assimilating into the deaf community.

Behavioural problems are also reported, although whether this is due to frustration and anger related to LKS or true autistic type behaviour, research is yet to tell us. These

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behaviours include hyperactivity, poor attention, depression, and irritability. Most LKS children are very poor sleepers.

The diagnosis of LKS can take a long time and many parents will tell of numerous misdiagnosis before LKS is finally discovered. This can be very frustrating for the parents who know up to seven years prior to receiving their child's diagnosis that something is seriously wrong. Common misdiagnosis include Attention Deficit Disorder (ADD), Attention Deficit and Hyperactive Disorder (ADHD), Autism, Aspergers Syndrome, deafness, Pervasive Developmental Disorder (PDD) and a variety of non specific behavioural management disorders. Remember that the type of diagnosis you get determines your accessibility to vital services, so it important that if you are not happy with the services you are getting that you continue to pursue an accurate diagnosis to get access to the best care that is available for your child.

Most neurologist will never see a case of LKS in their entire working lives, so it is hardly surprising that they know very little about the condition. This is why it is important for the parents to research their child's condition themselves and choose a neurologist carefully. Valuable time can be wasted attending doctors surgeries and receiving little or no substantial help.

Current management for LKS includes medications, Total Communication therapies such as sign language and speech therapy, and surgery. For those interested in investigating more on surgical options in Australia, the Mater Hospital Queensland has just opened an epilepsy ward for children who are having difficulty getting their epilepsy controlled by medication. Dr Jim Pelekanos is the pioneering paediatric neurologist currently involved in surgical techniques.

Next month's article will be on Lennox Gastaut Syndrome.

Contacts For LKS

Aussie F.O.L.K.S
C/- 80 Galston Rd
Hornsby
NSW 2077
(02) 9482 8425

F.O.L.K.S.
PO Box 749
Erith
Kent DA8 3AU
United Kingdom
<http://www.bobjanet.demon.co.uk/lks/home.html>

MUMS Parent to Parent Network
C/- Julie Gordon
150 Cluster Court
Green Bay
Wisconsin 54301 - 1243
1 920 336 5333
<http://www.waisman.wisc.edu/~rowley/mums/home.htmlx>

Ms Browyn Parry Fielder
Speech Therapist
Royal Children's Hospital Melbourne
Flemington Rd
Parksville
VIC 3052
(03) 9345 5549

Rush Medical Library
<http://www.rush.edu/Med/Epilepsy/newsletter.html>

That's all for this edition. Remember, this is your newsletter and it can't survive without your input.