

Aussie FOLKS

Issue 4

Summer, 1998

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

Merry Christmas and Happy Chanukkah to one and all. Yes, I can't believe a year has gone by but we have made it through our first year of publication. Hot on the heels of a very late 3rd newsletter is our Christmas edition. In it we will be discussing our plans for Aussie FOLKS over the next year and hopefully receiving some public comment on avenues you wish us to pursue.

Our four main goals this coming year will be as follows:-

Firstly, there is an election in March 1999 for NSW and now is the time to write to your local candidates and ask them what they intend to do to provide services for your local area. You could also write to the current government and opposition members in education and disability as well (or if you are like me have a standard letter written to all members on computer that way you can compare responses). What we need from them is an assurance that our needs as a sign language using group will be met. Enclosed with this edition is a letter outlining our aims and we ask that you give this to the early intervention/rehabilitation centre that you attend so that they may reply to us.

Secondly, We want to create a mini dictionary that other organisations can purchase in which all the signs for children's favourite television characters will be in, such as Sesame Street, Banana's in Pyjama's and Thomas the tank engine. Currently, the Auslan Dictionary does not have the days of the week nor the seasons of the year, this will require you to send our booklet to your local deaf community or sign language using school. Hopefully we will be able to provide them with a comprehensive booklet of the most important things our kids want to talk to us about. If all goes well, we hope to charge a small fee to aid with postage and material costs of our newsletter. We will be in touch

with further details later in the new year. Right now everyone deserves a good holiday.

And thirdly, we are going to create a booklet for newly diagnosed parents of LKS children. In it will be everything you need know and take with you to your physician's and educational centres. We feel that most parents would prefer to take their booklet with them rather than continually explain to others what LKS is and how it manifests itself. Especially when it comes to explaining the fluctuations that occur with LKS it is often very hard to explain to a new doctor or teacher, that yes Johnny is doing better today but that does not mean he will be well by the end of the week. Many parents and doctors contact regularly about this issue, it is not only the most baffling part of the disorder but also the most in need of repeated education.

And last of all we are about to go on-line with Aussie FOLKS. The newsletter will be put on line in the New Year, so that other interested parties can download them to reduce printing and mailing costs. The format will be the same but we will remove the parent and professional contact section for privacy reasons.

If there is anything that our parents wish us to pursue this coming year don't hesitate to drop us a line we are interested in anything you have to say. Don't forget what you send in is what we publish so remember your one article a year. Don't assume someone else is doing it for you, we need all the information we can get.

Karen Price

Disclaimer

The contents of this newsletter are for informational and educational purposes only. While every effort has been made to ensure accuracy, readers should not rely on the information provided herein as a substitute for consultation with a qualified health professional.

Condolences

This year has probably been the most emotional for us as a family. As you know when we started this newsletter we thought we would be writing to 12 parents. Of course that blew out in our second edition to 400 contacts. What we didn't expect and are still coming to terms with as a family is that as our son's condition fluctuated throughout the year so did everyone's else child to the point where by July of this year we had received notification of four children who had lost their lives. Whilst we respect the parents right to remain anonymous, on behalf of everyone associated with Aussie FOLKS we offer our heart felt condolences as you come to terms with your loss. Some parents have asked to remain part of Aussie FOLKS and we welcome any assistance, or advice you wish to offer. We certainly still feel that you are part of our extended family and hope to maintain that relationship over the coming years.

Congratulations

Of course with all the downs came the ups. Our son spoke for the first time this year and then didn't for four months. We fought and won some early intervention services for our child, as did some of the other parents in the group. Such a small sentences and yet it does not express the hours of work it took to achieve, and it certainly is something all parents should be proud of having achieved for their kids as it is no mean feat. Of course we won the Epilepsy Associations "Three Wishes" Competition so the newsletter is definitely moving forward, ready for 1999.

Just for Laughs

What do you get if you put a speech therapist and LKS child in room.?

A child who can speak in a box.

Thanks to Janet Lees from FOLKS (UK)

Holidays

Speaking of holidays, the Queensland Spastic Association currently runs holiday homes (the Labrador units) in Queensland for parents. Each apartment is provided with it's own respite worker, so the respite worker takes over the care of the disabled child whilst the remaining family gets a well deserved break. If anyone one is interested please give them a call, one of our parents (Noelene) has used this service and tells us it was the best decision of her life. (See Contacts)

Parent Contacts

Each month we will bring you a list of parents and their contacts details. We will provide the parent's first name the child's first name. a brief outline and a contact phone number. This is a voluntary section and you can receive a newsletter without placing you name here. These parents are actively seeking others in the same situation in order to share their experiences and provide support for those who are newly diagnosed.

1. Therese has Mathew, 3yrs
Epilepsy and Developmental Delay
Ryde Ph (02) 9802 0828

Therese has recently established a disability support group for parents in the northern suburbs of Sydney so if you are interested in joining her group or giving her some support give her a call.

2. Karen has a little boy with Dyspraxia
Kirrawee Ph (02) 9545 4786

Although Karen's son does not have epilepsy she has had considerable difficulty obtaining sign for her son and has asked us to put her in our contact section so that she may contact other parents in her area to create a signing support group.

Best of luck to both of our parents I hope all goes well.

Professional Contacts

Contact Evelyn or Ben Ashcroft
Kit McGrath Learning Centre
(02) 6643 5688
Grafton

Kerry Elder
Lindamood Program
Waverleigh
Narromine 2821
(02) 6889 8366

Overseas Contacts

Here are some parents from overseas that would like to contact other parents.

1. The Hantusch Family
"101361.2530@compuserve"
2. The Beagley Family
"john@toomey.tslnet.co.uk"
3. Richard Crean and family
(aka Ted the Ed)
"Richard Crean@msn.com"

Parent Responses

CAER testing

Wonderful news on the Cortical evoked response (CAER) test. Professor Phillip Newall at Macquarie University Audiology department has announced that should any of our parents require the CAER test here in NSW they can make arrangements to accommodate a handful of children per year. Those still struggling with the "is he or isn't he deaf" can now get the document that satisfies the Department of Education criteria for a deaf school without the long travel to Melbourne.

Kit McGrath Learning Centre

For LKS kids who are not using sign language we have recently discovered places our parents are tapping into in the auditory-verbal areas.

Carolyn graciously sent us to Evelyn this quarter. Evelyn Ashcroft is a lovely lady who runs the Kit McGrath Learning Centre in Grafton (see professional contacts section). Evelyn runs the reading program, which aids those children who are having a hard time keeping up with their peers. Her son, Ben, has just completed the Lindamood Program. This is an auditory-conceptualisation program, whereby the children are prompted in their speech by a key word or letter. So for all those who have children who require auditory re-training rather than sign, she would be a great person to talk to about the Kit McGrath centre in your area.

Linda Mood Bell Program

For those interested in the Lindamood Program, it is run by Kerry Elder in Narromine (see contacts section). The Lindamood program addresses kids and adults with auditory discrimination problems. The course teaches the person to feel the sounds being made by their mouths, until they become phonetically perfect. Kerry is currently looking for professionals or parents to train in this field. The course is for two weeks in one solid block and the fee is \$900 dollars. Any professionals interested in this please give her a call, classes have a minimum of six students so group bookings are a preference.

Fast ForWord

Fast ForWord is a computer package designed to assist children with auditory discrimination problems. This package is one of the standard packages used in the U.S. and has had remarkable results with LKS & Autistic Children, Hyperactive and

Continued from Page 3

ADD children, Children with Down Syndrome, Aspersers, Developmental delay and Pervasive Developmental Disorder. This package is run by speech therapists in the US. It works by simply placing head phones over a child's ears then playing a noise. Every time the child matches up the noise an interaction occurs on the computer. The children very quickly learn to discriminate long and short sounds and then progress to complex sounds such as those used in words. Up until now the computer package has been very expensive and unable to be brought into Australia, not mention that speech therapist were the only one's qualified to use it.

We are pleased to announce that Fast ForWord has come to Australia . If you want to learn more and get on their training program, contact the Royal Melbourne Hospital (speech therapy department). Their current training program begins in December and is already booked out but more are planned very soon.

Earobics

For those not wanting to make the trip to Melbourne, a condensed package called Earobics is available without training and can be installed onto any computer that has a CD drive. The cost for this package varies from \$59 US to \$299 US depending on whether you buy the home or the professional version. A program will last a child from age three to seven years, then from seven to eleven years. Not that expensive if you compare it to private speech therapy sessions and the results to date indicate that children using the package have a better prognosis than those using speech therapy alone. Bear in mind that speech therapists in the US must have a Masters degree to practice whereas over here they do not. (See Contacts)

We have just bought the home package and hopefully can give you our opinion of it shortly.

Makaton Sign Book

Okay, for all those still on the signing bit, the Makaton Vocabulary book is available for \$14 from Newcastle Uni (see contacts). I personally love this book as it has around 60 everyday signs in it. I have all my signs cut up into tiny bits and stuck around my house, so all the signs for washing, bathing and shaving are all stuck right there on the bathroom wall. An easier way to learn signs if they are right in front of your face.

Signed and Captioned Video's

For those looking for signed and captioned video's to help your child learn to read, there are several on the market.

1. The Tasmanian Variety Club sells signed Nursery Rhymes at \$27.00, Ph (03) 62 23 1886 or 44 7074, PO Box 893 Sandy Bay TAS 7005.
2. The Deaf Theatre sells (Auslan Signed) "Toddies Tales" Deaf Fairy Tales for \$29.95 (from Australian Communication Exchange)
3. The ABC shops in your area sells, Spot's First Adventure and First Walk (7 stories in each tape) on captioned video and three Thomas the Tank Engine captioned video's valued at \$19.95each.
NB. There are only 60 tapes captioned a year on this so distribution goes to schools first, so it's first in best dressed remember to check if it is captioned at the counter before you buy it.
4. Disney has just produced "Songs of Life". These are a collection of four tapes with a combination of songs from the Lion King, Aladdin, Beauty and the Beast, Hercules movies, put to words etc. These can be ordered at any Grace Brothers store. \$19.95each

Continued on Page 5

Continued from Page 4

5. The Parent Council for Deaf Education also has a large number of captioned videos that can be rented, the fee is \$30 deposit and \$5 dollars a week to accommodate postage. If not returned in a month the deposit and fee are deducted from your VISA card. Cathy Clarke Ph 9871 3026, fax 9871 3193

F.O.L.K.S. (ARD) U.K.

I have recently been speaking with Richard Crean (aka Ted the Ed). He is the editor of Friends Of Landau Kleffner Syndrome (and related disorders) in the United Kingdom. He is also an LKS parent. They are a large organisation of some 80 LKS families and are affiliated with the Great Ormond Street Hospital in London. Until recently the heads of this organisation were the two leading experts on LKS. Their organisation is totally different to ours but I would recommend that those who are not on their membership join. The fee is £10 a year and for that you will receive four newsletters a year, but more importantly you will become part of their research group and during the year they will send out questionnaires to you to fill in so that the real people can tell the experts what we already know. The best part is that they publish the answers to us as well. Next edition we will send out their LKS and Siblings article. They are also the distributors of the LKS video at £18 plus P&P (see Contacts Section)

Epilepsy And Autism (part two)

We will be holding over our Epilepsy and Down Syndrome for another quarter, we recently received more extensive information on Epilepsy and Autism and felt that since our last edition focused solely on diet that we should include more information on general areas of Epilepsy and Autism.

Reading material

Title: "Mummy have to go Potty, A Parent's guide to toilet training"

Author: Jan Faull, M.Ed

Publisher : Raefield-Roberts Publishers

ISBN : 0-9650477-0-9

Title: "Does This Child Need Help" ?

Author: Christine Johnston

Publisher: Australian Early Intervention Association

ISBN 0 646 16170 9

Title: Makaton Vocabulary Australia

Author: Special Education Centre

The University of Newcastle
NSW 2308

(02) 4921 6293

Contacts

F.O.L.K.S.

PO Box 749

Erith

Kent DA8 3UA

Contact Richard Crean

(Overseas prefix then) Ph 01460 72054

Fax 01460 75773

e-mail Richard_Crean@msn.com

Royal Children's Hospital

Flemington Rd

Parkville

VIC 3052

Ph 9345 5522

Parent Council for Deaf Education

PO BOX 4748

North Rocks

NSW 2151

Ph (02) 9871 3026

Fax (02) 9871 3193

Earobics
Cognitive Concepts
P.O. Box 1363
Evanston IL 60204-1363
Call 1-888-328-8199
Fax 1-847- 328- 5881
Web site : www.cogcon.com

Gifted and Learning Disabled Support Group
C-o NSWAGTC
PO Box 65
Homebush West
NSW 2140
Contact:
Marilyn (02) 9456 1396
Anne (02) 9958 4093
Jane (02) 9787 1833

West Syndrome (Infantile Spasm) Association
Contact Kathy Schultz
Ph (02) 4323 1235

Queensland Spastic Association
Labrador Holiday Units
55 Ridgeway Ave
Southport QLD 4215
Contact Carolyn Roper
(07) 5532 2088 phone
(07) 5591 7725 fax

Australian Vaccination Network
P.O. Box 177
NSW 2479

Next issue:
Epilepsy and Downs Syndrome

Don't forget to send in your articles. It's your
newsletter so what you get is what you give.