



Friends of Brain Injured Children ACT (Inc) Autumn 2012

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CONTACT INFORMATION

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Mandy Hudson – Office Administrator

A member of **SHOUT Inc**
(Self Help Organisations
United Together)

PRESIDENT'S REPORT

Good networking is one of the factors that helps a small group such as ours to thrive. Friends of Brain Injured Children assists our children's families in two ways; by helping to fund extra therapy and by providing information that can help families do the job they want.

Our network has developed over the years and is now a valuable factor in helping us to help families and children.

Our membership of SHOUT and ACTCOSS gives us access to links and services we would have no other way of achieving. At SHOUT we have our desk, computer and filing, printers and much more. Our phone is answered professionally in business hours, our computer system is upgraded, we are kept informed about the latest developments in the sector, and FBIC is represented at various community showcases. ACTCOSS provides useful training and sector representation for us.

Carers ACT and Noah's Ark are great allies. Did you know that Carers ACT funds our three parties, as they recognise the value of family support and linkages? And that Noah's Ark offer us their lovely rooms for parties for free? This help is appreciated, as it allows us to use our funds to support therapy for the children.

Our relationship with Disability ACT has developed over the years. The staff are aware of our work and have changed their financial assistance from a small annual grant to a Contract for Service. This new status will allow us to develop and grow over the years as we try to meet the needs of more and more children. Disability ACT takes a great interest in our activities and offers help when needed.

Our various donors and sponsors form a vital part of our network. For instance the Snow Foundation's regular sponsorship provides therapy funding to all our families who request it, which ensures the children can access a reasonable amount of extra therapy. Parents are most appreciative of this help. The Kirk Family Foundation also provides generous support to several of our NSW families, making a huge difference to those children. Both these sponsors are very interested in the progress of the children they assist.

Many other donors have helped over the years. I think they are pleased to help children in need. Sometimes they give money, or it could be the design of our letterhead and pamphlets. One way or another they hear about us through various networks and offer help.

We are developing a useful network of therapists outside Canberra. Mengde Yu recently visited Canberra and saw a number of children and we have neurotherapist Ian Hunter, also from Melbourne, coming on 20-21 April. FBIC is able to cover the cost of these visits, and families can then avoid all the bother and cost of taking their children to Victoria.

We have links to many like-minded organisations, such as the Cerebral Palsy Alliance, Children with Disability Australia, Brain Injury Australia and the National Brain Injury Foundation. All these organisations are valuable sources of information and influence.

The most important network of all, I believe, is the FBIC family network. So many parents have joined FBIC because another family told them about us. Families share their knowledge about treatments, as well as their strength and hope. I love to watch mums and dads interacting at our parties. While the children are having a good time their parents are able to get some support and encouragement

from each other. Some good friendships have resulted.

Our committee will continue to develop our networks. Without them we would be unable to achieve so much for our beautiful children.

Libby Steeper

FAMILY INFORMATION

Welcome to the Sliwka family and the West family. Two new lovely little boys to add to our numbers. We are sad to say goodbye to the Weller family, but we will stay in touch.

Libby Steeper

CANBERRA VISIT BY MENGDE YU

Friends of Brain Injured Children sponsored another visit to Canberra by Mengde Yu in February. He is well known to many of our families because of his years of treating children with brain injury. I am always amazed at the way he observes a child, and then pinpoints the area that needs attention. He then shows the parents what to do to correct the problem.

The appointments filled up very quickly. Unfortunately a number of children had to miss out on this occasion. We are all grateful to Sean McCandless, who arranged the whole visit. He even made the sandwiches for lunch at Noah's Ark, and picked up and delivered Mr Yu to the airport. Thanks Sean. And thank you to Noah's Ark for the use of their premises.

This visit he saw some of his old clients and updated their treatment plans. It was gratifying to see the progress the children have been making and how he focused on incipient problems and showed how to correct them.

Some of our new children had their first session with him, including the three-year-old Heath twins. Their parents, John and Jae, were impressed with the way he focused on the boys' key problems, how easy his assessment was to understand, and his practical advice. John felt more hopeful about the boys, saying, "He was very positive and also realistic."

Mr Yu has agreed to come back later in the year. He told me treating young children is hard work, as he can only use close observation of the child and has to develop a treatment plan that the family can manage. He saw six children on this visit, but maybe we can persuade him to stay a little longer and see more kids next time.

Wii Nintendo Games Floor boards designed for people in wheelchairs - Demonstration at Darryl's Den

Darryl's Den has imported two Wii Nintendo Games Floor boards specially designed for people in wheelchairs.

We are inviting parents and children to come along and try this fantastic invention. The boards are a wonderful way to get young wheelchair bound children/young adults and the not so young to engage with others, family friends in a way that was not possible before the Wii balance board was invented.

Where: Darryl's Den Holt Hub, 80 Beaurepaire Crescent HOLT ACT

When: 14 April 2012 11am – 2pm

Contact: For information please call – Cheryle Parkes on 0417682868

Darryl's Den also holds Paediatric Massage classes. If you are a parent and would love to make a difference in your child's life you can come along and get some hands on experience from our qualified therapists .

The Amazing Second Skin – Body Splint Effect

I am writing this article to share with others the amazing experience that we have had with Second Skin Body Splint. Earlier this year I was fortunate enough to have had a therapist recommend its use for my son Kamran. For those of you who don't know Kamran, he is my 14 year old son. He is physically severely disabled and has a combination of low and high muscle tone. This muscle tone issue has, over time contributed to instability in his pelvis, trunk and shoulders. As he has grown, the weight of his arms has contributed to a chronic shoulder dislocation. In addition, low tone has led to the development of scoliosis.

What is Second Skin?

Second skin is a therapeutic device that has been specifically designed for my son to achieve certain goals. He achieves these goals through wearing the splint daily, for up to 8 hours. Based on the assessment process that was undertaken to get the second skin made for Kamran, some of the goals of wearing the splint include:

- Supporting shoulder posture and alignment
- Improving sitting posture
- Maintaining spinal alignment and
- Improving symmetry and stability through the

pelvis, trunk and shoulder areas.

Maintenance and Functionality

The splint is light weight, very easy to take on and off (takes about 5 minutes for each) and requires little maintenance – washed once a week and lied flat to dry out of direct sunlight. It looks a bit like a baby romper suit except it is not a full body suit. The suit comes about mid-arm length (stopping above the elbow) down to mid-thigh length. It is made out of the same material that is used for victims of fire accidents. It has zippers that are done up around the arms all the way through to the shoulders, a large zipper from the chest area down to the belly button area and then separate zips for each leg that ensure the suit fits snugly around each leg up to the hip area. As you may have guessed from this description and the picture above, Kamran, who wears nappies, is easily changed as the bottom half of the suit is independently able to be opened.

What benefits have been noticeable?

Early benefits include:

- Better muscle tone - especially in legs and arms
- Less dislocation in shoulders
- Better alignment of his spine
- Better positioning, especially when sitting and when in standing frame
- Ability to eat better (not sure how this has happened but it has!)
- Better bowel function!
- Breathing is less laboured and he appears to be less congested after feeding.
- In addition, he feels better within himself and the first time I took the skin off, he threw a tantrum!
- In addition, Kamran seems more comfortable in it than out of it and I suspect it has assisted relieve some pain that he may have been resigned to living with.

Who can I contact for more information?

If you would like me to give you more information from a parent perspective, feel

free to call me, Sirla Jafri, on (02) 6254 6249 or 0447 425 180.

Or the Second Skin clinic at:

PO Box 2210
Bondi Junction, 1355 NSW
Tel: 1800 657 055(toll free)
or (02) 93860812
Fax: 02 9386 0827
Email:
sydney@secondskin.com.au



Sirla Jafri

ARTICLES FROM PARENTS...cont'd

Oxygen Therapy

There is now a Hyperbaric Oxygen Therapy Chamber at Manuka Massage Therapy in Manuka. Cost is \$85 per session of if you buy a book of 10 it's \$65 per session. Kerry is the lead therapist there and is really wonderful in answering questions on the therapy and how it works. Apparently the recommended number of treatments is 30 for benefits to be permanent. Eligh has had 20 thus far and I think his babbling has improved (although still no real speech from him)!

Manuka Massage is open from 7am - 6pm Monday to Fri & from 9am Sat and Sun.

Neurofeedback

I'm still continuing with neurofeedback with Eligh and I've seen huge improvements in his concentration & behaviour. It's also helped reduce his tantrums. This is done as you know with Noel Eastwood at Learnwise in Belconnen.

Neuro Development Therapy

Last year I engaged with Ian Hunter to assist me with putting together a program for Eligh that covers all areas of his development following the principles set up by the Institute for the Achievement of Human Potential (www.iahp.org). I was so impressed that I

ordered and have read the following books which I am more than happy to loan out to parents who may be interested;

What to do about your Brain Injured Child
How to teach your baby to read,
How Smart is your baby,
How to teach your baby to be Physically superb
Naturally Better

These books whilst great for well children, really reinforce techniques that can be used to help our brain injured kids and I'm getting some great results with Eligh. These books can be ordered online from www.gentlerevolution.com or there is a website in Melbourne developed by a mum (Kristen Morrison) with a Down Syndrome child who also stocks some of these titles. Her website is <http://naturallybetterkids.com/>

I've completed the developmental assessment for Eligh and developed a daily program for him which covers off activities for all areas of his brain (physical and sensory) which I'm also happy to share with parents if they're interested.

G Therapy

Recently I looked into G Therapy (www.g-therapy.org/) as I came across it when I was doing some research and I'm happy to share my experiences with parents should they be interested, although I can't advise on the successfulness of the therapy, though I did speak to some parents who had tried it and swore by it. G Therapy does not seem to be well known and I certainly wouldn't be able to recommend it, but I did have many discussions with the Dr (Guvant Oswal) who developed it.

It's costly and difficult to obtain, but can be arranged to be collected. I myself did not go ahead with it, but I thought I would mention it should other parents query this with FBIC.

Kelly Price.

CONDUCTIVE EDUCATION

Gabi Monus, our ACT expert in Conductive Education, is seeking registration to provide holistic therapy under the Better Start Initiative.

If you want Conductive Education for your child, enlist with the Better Start Initiative now and benefit from free therapy.

Gabi also plans a Mums and Children's group at Cranleigh. This is a fabulous opportunity. Please contact Gabi on 0415 347306 for more information.

NATIONAL BRAIN INJURY FOUNDATION

The National Brain Injury Foundation owns and manages a hydrotherapy pool in Hughes. The pool runs at 35 degrees and has spaces available for organisations and community groups at very competitive prices. If you have a group that may be interested in using the pool out of peak times (before 9.00am most days or after 6.00 and weekends) the prices are even cheaper.

We also have a wheel chair accessible vehicle available for use. We only ask for a donation to help maintain the vehicle and the fuel tank returned full.

Paul Cubitt
Operations Manager
National Brain Injury Foundation
Ph: 02 6288 1117

Fax: 02 6288 5749
REPORT ON MOBILITY
ASSISTANCE
WORKSHOP...

On Wednesday March 7th I attended a talk called 'Where Tablets Fit In' by Dr Graeme Smith. Grahame works for the not-for-profit organisation Ability Technology, their main goal being research into new assistive technology for people with disabilities. They have an excellent website, which has loads of great products and reviews www.ability.org.au. The presentation was hugely popular and, consequently, was fully booked when I asked to attend.

Fortunately, our benevolent leader, Libby, managed to secure me a place. It was disappointing to see that about 12 people who had booked and not shown up, but that's the downside of running a free presentation. Ability Technology plan to run another one at Hartley Lifecare Assistive Technology Centre on the 14th of May that will probably attract a nominal fee.

For the presentation, Grahame Smith walked the audience through the latest developments in the world of tablets and how they can assist people with disabilities. He compared Tablets to computers and PDAs (such as smartphones and blackberries), and he compared different types of tablets against each other (such as I pads, android based tablets and the new windows based tablet). He also spent a large amount of time discussing the various

programs and apps available for tablets that are specifically targeted to assist people with disabilities. His basic conclusion was that the technology is only as good as the applications that it supports. People interested in using a tablet as a piece of assistive technology should look carefully at what they need it for and what applications are available. For example, there are limited programs that are switch accessible on the Ipad.

He also concluded that with the amount of consumer demand and momentum in the marketplace that there will be a lot of development in the way of new apps (for tablets) specifically designed for people with disabilities.

For more info contact me via email and I can forward you the full presentation.

jimsharrock@internode.on.net

EARLY CHILDHOOD INTERVENTION ACT REPORT

Early Childhood Intervention ACT is the local chapter of the national organization ECIA.

We are a not-for-profit organization. Our ACT group comprises of parents and professionals who volunteer their time to work together to promote the interests of young children with developmental delays or disabilities.

Our objectives are to:

- Promote the importance of early intervention to the growth and development in young children with developmental delays and disabilities;
- Enable and empower families who have a child with a developmental delay or disability; and to
- Encourage acceptance and support of these children and their families.

As part of working to meet ECIA objectives conferences and professional presentations are organised. The 10th Biennial ECIA National Conference is to be held in Perth from 9th to 11th August. For information about this please go to

www.eciaconference2012.com.au .

On the local front, presentations and workshops are arranged for our members and other interested people.

Our most recent workshop is one which, due to popular demand, is regularly presented. This is the 'Positive Approach to Pees and Poos' Workshop, presented by Dr. Irmina Nahon PhD, Pelvic Floor Physiotherapist and specialist in working with families of children with additional needs.

Irmina has a wealth of knowledge and many years of working with young children and their families.

At her presentation, Irmina provided physiological information about the development of young children and how a delay or disability can impact on toilet use. She also provided very practical ideas and strategies around the topics of planning, readiness clues; record keeping and starting toilet training.

For sale on the evening was a new pack to the ACT 'One Step at a Time – A parent's guide to toilet skills for children with special needs', Continece Foundation of Australia, and produced by the Victorian Continece Resource Centre 2010.

New members of ECI ACT Inc are always welcome. For membership information please email

eci_act@shout.org.au or, download a membership application at the ECIA website www.ecia.org.au , link to Chapters then ACT.

Pam Cording
President, ECI ACT Inc
March 2012

DISABILITY INFORMATION SUPPORT HUB



This exciting new venture is a co-location of services for people with disability that includes Belconnen Community Services, Woden Community Services, House with No Steps and Disability ACT. The DISH brings together shared expertise, skills and knowledge and a consolidation of resources into one accessible space in Belconnen.

Call: The DISH@oatley on **(02) 6205 9331** or Disability Information Service **(02) 6207 1086**

Email: disabilityact@act.gov.au

Website:

www.dhcs.act.gov.au/disabilityact

Visit: The DISH team at 60-62 Oatley Court Belconnen

CANBERRA DANCE

THEATRE for children and teenagers with special needs **SATURDAYS** (during school terms) join anytime during the term.

CDTeens aged 13 - 18 years, 9.00 - 10.00am, \$10.00

An energetic and dynamic class drawing on various dance styles.

Jumping Moves

5-12 years. Tween Moves and Jumping Juniors have joined forces!!

10.15 - 11am, \$10.00

An energetic, fun and funky class with cool moves.

Phone: **0435 025 365**

Email:

canberradancetheatre@gmail.com

NEW AFTER SCHOOL AND VACATION PROGRAMS FOR CHILDREN AND YOUNG PEOPLE WITH HIGH NEEDS INCLUDING THOSE WITH AUTISM

Black Mountain School Northcott Disability Service

Northcott Disability Service will deliver an after school and vacation program starting first term 2012 for teenagers with high needs including those with autism. This program will be based at Black Mountain School. Ten places will be available at each program per day.

Contact: Taryn Bankier, Area Manager,
Northcott Disability Services

Ph: 6297 6899

Email: taryn.bankier@northcott.com.au

Belconnen Community Centre Belconnen Community Service

Belconnen Community Service will deliver an after school and vacation care program for teenagers with high needs including those with autism starting first term 2012. This program will be run from the Belconnen Community Centre. Ten places will be available at each program per day.

Contact: Sonya Roelofse, Ph: 6264 0252

Email: sonya.roelofse@bcsact.com.au

Cranleigh School

Belconnen Community Service will also deliver an integrated vacation care program for ten weeks each for children with high needs. Ten places will be available later in 2012 for children with disability and ten places will be available for children without disability.

Contact: Lee Pederick, Ph: 6278 8106

Email: lee.pederick@bcsact.com.au

Malkara School Communities@work

Communities@work will deliver an integrated vacation care program for ten weeks for children with high needs. Ten places will be available later in 2012 for children with disability and ten places will be available for children without disability.

Contact: Lee Maiden, Executive Director,
Children's Services, Ph: 6293 6514

...ABOUT BETTER START...

Better Start provides funding for early intervention services. To access Better Start children with an eligible diagnosis must register before they turn 6 years old. Families will have until the child turns 7 to access the funding.

Children are eligible for Better Start if diagnosed with one of the following disabilities:

Cerebral palsy
Deafblindness
Down Syndrome including mosaic Down syndrome
Fragile X syndrome with full mutation
Hearing impairment
Vision impairment

To contact and register for Better Start call the Carers Association in your state or territory on 1800 242 636

For more information go to www.betterstart.net.au

Other sources of assistance and support are

Carer Allowance and Carer Payment

www.centrelink.gov.au

Medicare

www.medicare.gov.au

My Time Peer Support Groups

www.mytime.net.au

Raising Children network website

www.raisingchildren.net.au

State and Territory Disability Services.



HOLIDAYS HOMES FOR FAMILIES

Ronald McDonald House—please check out the website for more details—
www.rmch.org.au

OR
Starlight Foundation—follow the links
www.starlight.org.au

Remember, for all your equipment needs, including nappies, please call ACT Equipment Service
6205 2599

OUR COMMITTEE

PRESIDENT: Libby Steeper

VICE-PRESIDENT: Ngairé Kinnear

TREASURER: Rory Mulligan

SECRETARY: Sanders King

PUBLIC OFFICER: Rory Mulligan

COMMITTEE: Ron Cruikshank & Jim Sharrock

STAFF: Mandy Hudson
AUDITOR: John Kyatt

FBIC is pleased to announce that Ian Hunter will be visiting FBIC on 20-21 April.

Ian has worked as a brain injury therapist since 1975 and is in demand all over the world.

His treatment applies the principles of normal development to the treatment of brain injured children. The techniques he offers are determined by the needs of each child and have to be applied with correct frequency, intensity and duration.

Although Ian lives in Melbourne he carries out a large part of therapy using Skype.

Ian is giving a free seminar at the Pearce Community Centre hall at 10.00-12.00 on Friday 20 April. This is a great opportunity to hear from such an eminent neurotherapist. His work has relevance to the way other therapies are used and will be of interest to all Canberra therapists who work with children with brain injury.

For parents, he will provide a clear explanation of your child's problems and an approach to deal with them.

We have a number of appointments available on Friday afternoon and Saturday with Ian. If you would like to take advantage of this opportunity call Libby on 6286 1439 or email libbysteeper@gmail.com. We can discuss the costs of appointments and available times.



WEBSITE INFORMATION

Our website is becoming a source of information for all our members and associated organizations.

If you have any information regarding your child's therapies, public notices, or just a blog, the website is a great way to get information out there.

If you have any queries about the website, please give Mandy a call in the office: 6290 1984.

www.fbic.org.au

FBIC IS PROUDLY SUPPORTED BY THE FOLLOWING:



Self Help Organisations
United Together