

FRIENDS OF BRAIN INJURED CHILDREN (ACT) INC – PROFILE

Friends of Brain Injured Children is a not-for-profit organisation, which has operated in the ACT and local region for twenty-five years, and has been incorporated since 1988.

The organisation currently provides support to forty families who have a child with a brain injury. The families are thus able to provide an early, intensive therapy program for their children at levels far beyond that available through the general system. To this end we seek financial sponsorships for the children and engage in fund-raising to help pay for this important therapy.

Friends of Brain Injured Children also offers information about a wide range of useful therapies and offers parents support and encouragement in a number of ways.

The organisation strongly promotes its philosophy of providing early, intensive therapy for babies and young children who have suffered a brain injury, in order to reduce future physical disability.

Our office is in the SHOUT office, Collett Place, Pearce, 2607. The phone is (02) 6290 1984 and the website is www.fbic.org.au.

COMMITTEE

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| President | Ngairé Kinnear |
| Vice President | Libby Steeper |
| Treasurer | Terry Watson |
| Secretary | Ron Cruikshank |
| Committee | Jim Sharrock |
| | Fiona West |
| | Peter Leek |
| | Gabi Monus |

FBIC President's Annual Report

Friends of Brain Injured Children ACT Inc. has been working hard since 1988 to help families of children with brain injury to access vital early intensive therapy. Modern neuroscience now acknowledges brain plasticity and the importance of early intervention after any injury, as well as the enormous benefits of appropriate therapy on young, developing brains. With forty-one children registered with us, we have a bigger task than ever to get that transforming therapy where it is needed.

A small organisation such as ours needs to use networking to achieve as much as we do for our children. Sharing of information, methods, and ideas among the organisations is a vital source of knowledge to keep us aware of opportunities for the organisation and for our families.

For National Brain Injury Awareness Week in August this year we teamed up with Hartley LifeCare to host a breakfast, held at Canberra Southern Cross Yacht Club. Nick Rushworth, CEO of Brain Injury Australia provided an inspiring speech. It was a great event for more networking, and we received some useful media coverage.

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 all our administrative equipment, as well as vital elements like access to collective regulatory resources such as insurance. 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.

We participate in the Disability Sector Expo, the Disability Service Providers Network, National Disability Insurance Scheme meetings and Hands Across Canberra events.

Friends of Brain Injured Children continues to run workshops on children with disability for all ACTION driver recruits, and this is a small source of income, as well as socially useful.

We have links to many like-minded organisations, such as the Cerebral Palsy Alliance, The Developing Foundation, Children with Disability Australia, Hartley Life Care, 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, in many ways, 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. It is great to watch mums and dads interacting at our parties. While the children are having a good time their parents are able to get support and encouragement from each other, as well as share practical knowledge and tips. Some good friendships have resulted.

The coming year will see the introduction of the DisabilityCare scheme, and will provide a new landscape for all disability-focused organisations to operate in.

DisabilityCare has brought attention to disability and a welcome new approach to improving the lives of people with disabilities. At this stage we are not sure how helpful the Scheme will be in providing early intervention to children with brain injury. One of its principles is to reduce disability

through early intervention, but there is some uncertainty about what therapies will be regarded as acceptable. Furthermore, there is probably inadequate focus on intensity of the therapy, in the degree that successfully stimulates neuroplastic response. In our organisation's experience, many non-intensive mainstream therapies are not effective. We will be pushing for the acceptance of therapies such as Conductive Education, Bowen Therapy, acupuncture, massage, and osteopathy when offered by practitioners with proven expertise with children with brain injury.

Another concern is that the existence of DisabilityCare will make fundraising more difficult, as the community comes to expect that the levies and taxes they are paying to the Scheme should be covering the work we do, and this coming year will see FBIC reposition ourselves to this purpose. We expect there will always be a role for Friends in keeping families informed about useful therapies for their children, group workshops to learn what they can do at home, support, and no doubt, continued financial support to fill therapy gaps.

This year the ACT government has funded Enhanced Service Offers as a preliminary step to the DisabilityCare launch in July 2014. We made sure all our registered families were aware of this opportunity.

We introduced a couple of new initiatives this year, and extended and developed some of last year's.

The "Mud Map" that our administrator Mandy Hudson and Vice-President Libby Steeper had been working on, a broad and highly accessible easy-reference guide to the range of services available to families of children with a disability, and other general and useful information, was taken up by the Schools P&C Council. All the material and design that we had done so far formed the basis of their publication *WHO CAN HELP? DISABILITY RESOURCES FOR YOUNG PEOPLE*, which they published this year. It is a great resource for families.

Our first Walkathon was run last November, with brilliant expert partnership and support from the Developing Foundation in Queensland, to give our families an opportunity to raise money for their own children through sponsorships of the walk. The Walkathon was a wonderful day out and we expect the next one to be even more successful.

This year saw development of some earlier initiatives. Mengde Yu has visited Canberra from Melbourne again, providing therapy techniques and understanding of the principles of development for the families who attended his clinics.

We have gone on to broaden this initiative this year, and have sought to cast the net widely to bring in other therapists. One of the grants we won from the Commonwealth Bank Foundation was applied for expressly on the basis of sponsoring such visits, and we will certainly give consideration to routinely applying for grants for this purpose in future, and making this kind of activity a core function of the organisation. We will invite back the same therapists, and keep looking out for more.

We have provided a number of workshops to introduce parents to various therapies, with a focus on training them in particular skills and techniques that they can apply at home, so that the intensity and frequency of therapy applications can be increased for the children. Thanks to the efforts and knowledge of Gabi Monus, parents have been introduced to yoga for children with disabilities. Evonne Bennell visited us from interstate to run a BrainGym workshop, and our parents' network has yielded people who can provide lessons in swimming and hydrotherapy, and special nutrition workshops.

Yet again we have had amazing support from donors both regular and new, and we are extremely grateful to them all for the opportunities for development that their generosity extends to our kids.

The Snow Foundation renewed its grant this year to allow Mandy Hudson to spend time offering family support and information. With our numbers growing we appreciate this opportunity to help families more.

Carers ACT and Noah's Ark are great allies. Carers ACT funds our three parties, as they recognise the value of family support and linkages. And Noah's Ark offers us their rooms for parties for free. This help is very much 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. They are aware of our work and have increased their financial assistance from a small annual grant to a Contract for Service. This new status allows 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.

We also express our gratitude to the Commonwealth Bank for no less than two grants in this Committee year, to Hands Across Canberra, to the Green Shed who donated somewhat out of the blue some very substantial sums, to the Canberra Southern Cross Club for their annual Community Grant to us, to KPMG for the incredible shot-in-the-arm they gave us right at the beginning of the Committee year, and as previously mentioned, Carers ACT and Noah's Ark for their support for our parties.

And finally, we sadly report that Dick Jenkins died this year, just a few weeks ago. His wife Pat died last year in June. Dick and Pat were instrumental in establishing Friends of Brain Injured Children in 1988, and worked tirelessly to make life better for children with a brain injury. They retired from the organisation in 2003, but kept in touch to provide help and advice, and occasionally coming to the parties. Pat and Dick were life members of FBIC.

Libby Steeper and Ron Cruikshank attended the funeral. Dick requested that donations be made to Friends of Brain Injured Children in lieu of flowers.

I wish to extend my personal thanks to the Management Committee for the support I have personally had from them, and for carrying on the work of the organisation so seamlessly during the illness which took me out of the first half of the Committee year. Thank you so much Libby Steeper, in particular, for gathering up yet again to attend presidential-level duties when you thought you were getting a year's rest.

I also can extend, on my own behalf and that of the Committee, deep gratitude to Mandy Hudson for the incredible quality of the work she produces for this organisation. Mandy your commitment and competence are second to none, and we are just so lucky to have you.