



Welcome to the Kids Plus Winter

newsletter, & the start of the third year of the Kids Plus Therapy Program!

We have been very busy with thirty six children in the Kids Plus Therapy Program, & five therapists working hard together with their families.

Thanks to The Costa Family Foundation & CFK, Kids Plus has been able to purchase a pool of equipment for trials & short term use, reducing wait times for equipment & enabling everyone to concentrate on the goals at hand.

Welcome to all the new families, congratulations to the children & families who have achieved all their goals & have moved on from Kids Plus, & "keep up the good work" to all our other families.

The Kids Plus Team

About Kids Plus

Kids Plus Foundation is a parent driven, charitable organisation, based in Geelong, which provides paediatric therapy programs for children (0-18 years) in the wider Barwon Region, since 2003.

Each Program is one term of weekly, one:one therapy, for children with physical disabilities including neuro development difficulties, cerebral palsy, brain injury, stroke & related problems.

For eligible babies, children & teenagers, Kids Plus provides 36 places each term, of occupational therapy, physiotherapy & speech pathology. The Therapy Program is conducted by experienced paediatric therapists using the NDT/Bobath model of therapy.

Each place is funded by generous donations from philanthropic & community groups; & there is no cost to children & their families.

For more information, please talk to your paediatrician or Contact the Kids Plus Coordinator, Sarah Olliff on 1300 305 881 or 0412 489 752. Email info@kidsplus.org.au

Postal Address: 32 Myers Street,
Geelong, VIC 3220

Art & Photo Competition...

This year, Kids Plus is producing an Annual Report. & the design & layout theme will center around the children & their siblings from Kids Plus Therapy Program.

We would like to invite families to send in any artwork by your child & photos of your child with their siblings. (All photos & artwork returned, maximum size A4 please). The Design team will judge the best art or photos for the front cover, & the rest will be used in the middle of the Annual Report.

Please drop in contributions of artwork & photos at your next therapy session.

Mobility Goals...



Joey, Liam, Jemma, Alana & George on the move...

"You can discover more about a person in an hour of play than in a year of conversation"

Plato



In this Newsletter...

- **Kicking goals—insights from some of our families**
- **The Geelong Special Play Space is open**
- **Noah's Ark Geelong, Programs & Toy Library**
- **An External Evaluation of Kids Plus Therapy**
- **News & articles for families**

Our Goal Kickers

Tatum, age 3 years

Firstly I would like to thank everybody involved with the Kids Plus Foundation, without the help of those who fund the program & the wonderful therapists our children wouldn't have the opportunity to become what they are today.

Tatum has a rare genetic disorder, her main problems are balance, coordination, low muscle tone & ataxia (Loss of the ability to coordinate muscular movement). My husband Aaron & I were initially told that Tatum may never walk or talk. Since Tatum has been attending Kids Plus she has surprised us amazingly. Tatum has gone from not being able to sit unaided to now sitting & commando crawling, Tatum's communication is improving all the time. She is now using some sign language & has a bunch of clear words. Aaron & I are ecstatic to say that our gorgeous girl is now taking steps & walking in her miniwalker with the help of us slightly pushing it. We are looking forward to the day hopefully very soon when she walks in the walker without assistance.

Once again, thank you to all the people who donate their time & funds. **Melissa**

Cooper & Declan, Age 16 months

Twins, Cooper & Declan started Kids Plus in term 1 this year. In brief, Declan has achieved his goals of touching textured toys & objects, & holding food & putting it in his mouth.

Cooper is transitioning from sitting to crawling & back again, has learnt to crawl & is starting to confidently stand more. We have also been working with Cooper to tolerate more textured foods in his mouth without vomiting or gagging too. **Kylie**



Rhys, age 2 ¾ years

This is Rhys' first term. Rhys has achieved free standing (with light support) for 30 seconds, feeding himself 6 spoonfuls of sticky food & commencing early construction play.

He has also progressed with walking with support. Rhys can now walk at least 20-30 steps holding on hand at waist level. He is also standing on his own for 1-2 seconds.

The Therapy program has helped my husband & I to learn play techniques that will assist Rhys & Rhys has learnt better communication skills as well as having more confidence in his walking.

Our next goals for Rhys are to walk independently, to drink from an open cup & to hold a crayon or texta & draw.

Thank you to all involved in such a wonderful program. **Melissa**

Jemma, age 1 ¾ years

Update: Jemma can now weight bear a bit without full support. Leaning against the couch or exercise ball, still a long way to go but it is a start.

Jemma has been lucky enough to see Melissa, our new Speech Pathologist, for 3 sessions this term. We are very slowly but surely trying to teach her a few signs & using the communication book.



The next set of goals will include Jemma standing fully, unassisted & walking. & being able to have her communicate with us by using the communication book or with signs or even talking.

Jemma is slowly beginning to show some big improvements. She stood independently for a short period only with her back against the coach. Just long enough to get some photos... It is so exciting to see her finally up on those legs. Jemma still has a long way to go but it's a start. A very big thank you to Kelly (PT) who has worked so hard with Jemma this term, yet

again. Your support & encouragement with Jemma & her physio is very much appreciated. We don't think she would be doing some of the things she is starting to do if it were not for Kelly & the Kids Plus Program. You all do a fantastic job. Looking forward to working with you in the future. **Jodie**

Joey, age 3 ½ years

This term Joey has stood unsupported for a minute & a half

STOP PRESS he has taken three steps! He has achieved all his goals. I can't say how good it is to get help, support & new ideas each week in getting Joey to achieve greater mobility. It can be a sad time when your child appears not to be progressing - thank you! Joey enjoys the sessions & gets more adventurous seeking out familiar tasks & wanting to explore life more. **Sue**



Our Goal Kickers

Liam, age 3 ½ years

Over the last 6 weeks, Liam has again been surprising us with some achievements. While to some they may seem quite small or even trivial, anyone who has a child with special needs would know how these achievements are “minor miracles”. Liam is a lot more alert, responsive to people & aware of what is going on around him. He will pull himself onto his knees in an attempt to pull himself up at the coffee table or couch (he still needs assistance with transition from kneeling to standing.) Liam will now bring himself up to a standing position from sitting (and is very proud of himself for doing so!) Because of this he wants to be standing more & more, & doesn't want to just sit on the floor. He will do his sit to stand for hours! Liam now has his own Miniwalk & is enjoying himself in this also. While he doesn't do a lot of forward stepping, he covers a lot of ground either going backwards or round in circles. And, to manoeuvre the Miniwalk from left to right to keep me in his sight. This is still movement & great improvement. These are the more significant achievements of Liam's. He seems a much happier boy lately, with lots of energy, lots of smiles & laughs & definitely proud of himself. **Michelle**



Sean, age 5 years

Over the last year the family decided, along with our therapists, as Sean was nearing school age, that Sean needed to start to communicate in a sociable way. No more mummy spending hours trying to guess what Sean wanted, he needed to be able to tell us. So in stepped Melissa, the Speech Pathologist from Kids Plus, with a blue communications book. (Mum was a bit scared at first) Melissa showed Sean & Mum how the book worked & how Sean could communicate his needs. First he had to learn to show everyone how he said Yes (nodding his head). & No (shaking his head), in a consistent way so we would know what he wanted. After a lot of singing the yes & no song, Sean caught on quite quickly. Mummy however was a bit slow on the uptake, which caused Sean a bit of frustration. Let me just say that Sean got very grumpy when mum didn't get it if he nodded yes to a question & asked him again. Or when Mum didn't find the right page fast enough. Sean is typical of most 5 year olds who have no patience, & told Melissa that Mummy should just know what he wants!

So now Mum, Dad & all those who work with Sean are making a big effort to use the book to communicate consistently to get him to used to telling us what he wants. As we are all hoping Sean will be able to attend school next year, this will be a big step forward for him. Our baby boy no more, our little man is growing up fast. **Liza**

Alana, age 2 ¾ years

There's no stopping her now! Alana took her first 4 independent steps on the very first day of Term 1, during her therapy session with Sarah (PT). Amazed, I fought back tears, but was boasting about it for weeks. All Alana seemed to need now to get her on her feet was some improved balance & self confidence.

On 25 April, ANZAC Day, therapy & perseverance paid off. Alana decided she was tired of waiting for her big brother James to take her outside for a walk (usually having to hold her hand before even taking a step). So Alana, let go of her brother's hand & off she went, heading for the back door to go outside. Well. Myself, her father & brother in tears & total amazement, we just stood there in the kitchen looking at each other & thinking who should we phone first!! Alana continued to walk around the house all that day & she hasn't stopped since!! **Rebecca**



Sophie, age 1 ¾ years

We honestly though Sophie would never crawl & at time when it was hard in therapy sessions, Kate (OT) stayed so positive. Her commitment to improve Sophie's strength in her arm ultimately leading to Sophie taking weight on her arms & being on all fours. Then with Sarah's (PT) help, Sophie has begun to move along the floor a short distance. The positive experiences Sophie has had with both Sarah & Kate has led to huge improvements in her mobility. Which for us as parents has been fantastic. We look forward to the next term when we aim for Sophie to get up on her feet & perhaps take her first steps! **Claire**

Taylah, age 17 months

Taylah was diagnosed at 5 months with a rear brain disorder “Lissencephaly” which means ‘smooth brain’. Taylah has had two short stays in hospital due to seizures, which are now controlled by medication. Taylah commenced Kids Plus in Term 1 2006 starting with physiotherapy. In this short period of time Taylah has achieved most of her goals. Together with seeing Sarah and the ‘home work’ that she gave



me has given me confidence to work with Taylah's goals at home also. Taylah is now rolling onto both sides and reaching for her toys. She tends to favour her right side, so rolling to her left is a bit difficult at times. She rolls over onto her stomach, which she doesn't like much, but her head control is improving. Thank you to Sarah and Kelly for their time and support and we are looking forward to Term 3, which will involve OT and Speech Therapy. Thanks to all involved with Kids Plus. **Michele & Craig**

Evaluation of the Kids Plus Therapy Program

Kids Plus Foundation has begun a three stage evaluation of the Kids Plus Therapy Program. The outcomes of which are to be used to measure, monitor, maintain, sustain, grow & improve the Kids Plus Therapy Program.

1 Internal Kids Plus Family Survey

The first Stage was an internal survey developed by Kids Plus, asking families about the therapy program, & family centered practice that families received from Kids Plus. This survey included the MPOC survey (Measure Of Process of Care for Family Centered Practice, an international benchmark tool developed by CanChild (<http://www.canchild.ca>))



at McMaster University in Canada).

36 surveys were distributed & 26 surveys were returned. The results provide a bench mark for future surveys, & showed a high or very high level of satisfaction of the services provided.

The MPOC results indicated very high degrees of family centered practice for all areas of service that the program provides.

Of the families who returned the surveys:

- For 100% of families, weekly therapy is a priority for their children, and they are happy to travel to the therapy center for the Kids Plus Therapy Program
- The most important factor for families choosing Kids Plus is the therapists skills & qualifications, followed by the weekly therapy sessions.
- 100% of children receive therapy for mobility problems & 62% receive therapy for communication
- 73% of families believe they cannot access individual therapy session from suitably skilled therapists for their children anywhere else
- 92% of families receive disability services with other organisations and 8% are on waiting lists

Thank you to everyone who participated.

2 Deakin University

Deakin University has an independent Honours Project looking at “*Family Perspective of a Neurodevelopment Program for Children with Cerebral Palsy & Developmental Disabilities* “. Families have been invited to join in focus groups or to be involved with a telephone interview in Term 3. This project will also include a literature review. The project will be completed at the end of 2006.

3 External Evaluation

The Helen Macpherson Smith Trust as part of the long term sustainability planning for the Kid Plus Therapy Program have generously funded an independent evaluation of the Therapy Program.



The objective of this project is an independent evaluation of the Kids Plus service, process & outcomes as a means of describing, understanding & validating the therapy model, in order to:

- Facilitate ongoing sustainable funding & expansion of the Kids Plus Therapy Program
- Provide a discussion paper for the Kids Plus Therapy Program
- To assist families to make informed choices
- For discussion with other agencies, health providers & government to find opportunities to enhance or improve service & choice to children & their families
- For parent groups in other regions interested in adopting the Therapy Program model

Currently, the tender process is underway, with the project starting in August 2006 & completion due in August 2007.

Thank you to Dr. Erin Wilson of SCOPE (Vic) and Dr. Helen Larkin of Deakin University for their professional assistance in developing the proposal for this project.

Geelong Play Space Now Open for All Abilities & All Ages

The Geelong Play Space is now open & is designed to integrate children with disabilities in a unique play environment. It is located in the heart of the Geelong's Eastern Park - adjacent to the Geelong Botanic Gardens.

The Play Space provides a facility enabling social interaction between all children including, but not limited to, those with special needs, their peers, carers & family members. It is an attractive natural space for everyone to use & is unique in design, considering different ability levels & providing an activity space for a wide age range.

The Play Space is an initiative of the Committee for Geelong & has been funded by community, business & government groups.

The Play Space covers approximately 3000 square metres & houses over 3000 plants. The Play Space ensures there is a diversity of accessible play opportunities & experiences for all ages. Different play areas include Gondwanaland, The Dreaming, Entry On, Pioneer Homestead, The Bridge & the Built Form Area. One piece of equipment is the Liberty swing designed specifically for use with a wheelchair.

Facilities include:

Parking:

Disabled and general parking spaces available.

Public Toilets: Disabled and public toilets available.

Facilities:

The park has BBQs, picnic tables and shade structures adjacent to the Play Space.



Liberty Swing Key Access Swing for Wheelchairs

The key to use the Liberty Swing can be obtained from the National Wool Museum, 26 Moorabool Street, Geelong.

- Drivers Licence ID required to borrow a key
- Or \$16.50 to purchase your own key.

The Museum is open 9:30am – 5:00pm daily, except Christmas Day & Good Friday.

Kids Plus Foundation

would like to thank the families, trusts and foundations for their generous support for 2006



THE JACK BROCKHOFF FOUNDATION



THE MARIAN & E.H. FLACK TRUST

Cecilia Kilkeary Foundation



the **costa**
family foundation





How to be Your Own Best Advocate

Our approach to parent support is to provide information & advice to help you be your own best advocate. It's not easy being an advocate for your child. It's often a case of constantly battling & wondering 'why does it have to be this difficult?' However, we also see many 'success stories' - parents armed with information & some tips on how to negotiate, are able to go ahead & organise the services they need for their child. Some tips for how to be your own best advocate include:

- Be positive & be clear on what you want.
- Be honest!
- Plan/list what issues are the most important to you.
- Gather any relevant facts, figures or documents to take to the meeting.
- Know the rules of 'the game' (eg policy, guidelines).
- If you are unsure of 'the rules' try & check them out first.
- Understand all the issues involved as best you can.
- Know what options are available to resolve the situation.
- If necessary, have a strategy, eg an ideal outcome & a compromise outcome.
- If a meeting is involved, ensure that your items are put onto the Agenda.
- Never enter a meeting angry - let off steam beforehand.
- Don't always expect to strike conflict. Others might agree with you, but also be prepared for conflict.
- Have your documentation sorted so it's easy to find if needed.
- If you are negotiating on the phone, always make sure you know the name & position of the person you are speaking to so you can follow up with them next time if needed.
- Be assertive, not passive or aggressive, in a meeting situation.
- Don't try to talk in the 'jargon' - be yourself.
- Don't allow others to intimidate you.
- Listen carefully.
- Don't get into personal attacks on individuals.
- If you need to draw on strong emotion, confine it to the issues not at someone.
- Be prepared to compromise and/or to concede unimportant points.
- Select the most 'winnable' points to begin with.
- Ask for important issues, decisions etc. to be formally noted in writing.
- Don't accept 'cop-out' excuses for indecision or lack of action (politely).
- If applicable, another meeting date should be made that suits everyone before you finish.
- Be prepared to follow up to ensure that the things which are agreed on are done.

For more tips & advice call 03 9500 1232 or visit:

http://www.acd.org.au/support/best_advocate.htm

Noah's Ark Geelong



Noah's Ark is a not-for-profit statewide organization assisting children with disabilities & their families, & is the largest Early Childhood Intervention & Inclusion Support provider in Victoria.

OUR VISION is a society where families & children are valued in their diversity & respected & included within the community.

NOAH'S ARK GEELONG is one of the largest regional services & has been supporting families in the Barwon district for 30 years.

Support is provided through Early Childhood Intervention programs, Parent Support groups & an extensive Resource & Equipment Library.

The Early Intervention Program offers families playgroups, parent support, Family Service Coordination, support with inclusion into community programs, support with transition to Kinder & School, Occupational Therapy, Speech pathology, & assistance with borrowing equipment from the Resource Library. Referrals for programs are made through the Barwon Regional Central Intake system.

The Equipment & Resource Library is the largest of its type outside Melbourne. An extensive range of toys & specialized equipment is available for borrowing by any family who has a child with additional needs aged from 0-18 years.

With the emphasis on learning through play, equipment is available to assist in all areas of development, & professional advice is available in the selection of appropriate items.

Families are asked to bring reports or suggestions for borrowing from their Therapists or other service providers. The Library also has a large selection of books & other information resources.

Noah's Ark also organises parent discussion groups, social events such as "Parent Pampering" and other family events. contact them for details.

For further information phone 03 5229 5327 or email : geelong@noahsarkinc.org.au

Noah's Ark Toy Library

is open for borrowing on:

Tuesday 10am -12.00 noon

Wednesday & Thursday 10am - 4.00pm

Address: 37 Fenwick Street Geelong.
P.O. Box 1663, Geelong 3220

DEAF BOY WINS SCHOOL INTERPRETING DISCRIMINATION CASE

A 14 year old Melbourne Deaf boy has won the right to a full time Auslan interpreter after a discrimination case against the state government. The court found the boy could not participate fully in class while there was Sign Supported English provided to him, or no interpreting support at all, when he needed Auslan.

In 2003, Robyn & Kim Beasley decided to lodge a complaint of discrimination against the Victorian Dept of Education, on behalf of their son, Dylan. Mr & Mrs Beasley and Dylan are deaf and use Auslan (Australian Sign Language). Dylan is a native Auslan user, and relies totally on sign language to understand what is being communicated to him.

Dylan was attending Pearcedale Primary School, who have a philosophy of not using Auslan to communicate in the classroom. They were using a sign system called Sign Supported English, which is not an accredited sign language. In addition, sometimes Dylan had no one at all interpreting for him, and sometimes other students had to sign to him. Some of the teachers could only fingerspell or write on a white board what was happening in the class.

The Department of Education refused to provide Dylan with a full time Auslan interpreter, and despite the stress of Dylan and Robyn appearing as witnesses, they decided to take the discrimination case, under the *Equal Opportunity Act 1995*, to the Victorian Civil & Administrative Tribunal. The case was heard in late 2005. A decision was handed down by Deputy President McKenzie on 3 February 2006. DP McKenzie found that the Dept of Education had discriminated against Dylan directly and indirectly by not providing him with a full time Auslan interpreter. The Tribunal found that Dylan was not able to fully participate in the classroom, and he was therefore denied a benefit provided by the Dept of Education.

While this case centered on a deaf child, the principles of participation apply to all children with disabilities who are not getting their individual needs met and are therefore unable to get the same access to education that children without disabilities are getting. Some information critical of the Program for Students with Disabilities came out during the trial, including the Dept's strategy for limited the funding to children with disabilities.

If any parents have questions about the decision and how it may benefit their child, they are welcome to contact:

Julie Phillips

Anti-Discrimination Consultant

Phone: (03) 9481-0999 or
email2jphillips@yahoo.com.au.



Medicare Rebate for Allied Health Services

Medicare rebates are available to patients that have a chronic condition and complex care needs being managed by their GP under an Enhanced Primary Care (EPC) plan. Patients need to be referred by their GP who needs to use an *EPC Program referral form for allied health services under Medicare*. You will need to book in to see your GP and say you are wanting a 721 item assessment completed for your child- it means the GP will allow more time with you for this to be done. A separate referral form needs to be completed for each allied health professional and a new referral needs to be obtained each calendar year. A maximum of 5 allied health services per patient in a calendar year.

Eligible services include those provided by Aboriginal health workers, audiologist, chiropractors, chiropodist, diabetes educators, exercise physiologists, dietitians, mental health workers, occupational therapists, osteopaths, physiotherapists, podiatrists, psychologists and speech pathologists.

The Allied health professionals need to be registered with Medicare Australia. They may set their own fees, however the Medicare rebate is \$45.85, so there will be a small gap depending on how the account is settled. For more detailed information speak to your GP, Allied Health Professional or therapist.

Call Medicare Australia on 132150

or go to www.medicareaustralia.gov.au

Parent to Parent Guide

Real-life advice, information & strategies from parents , to parents.

This book has been developed by Deakin University—information for parents, by parents. Ask for a copy from your therapist or contact DHS Barwon on for a free copy to be sent to you.

Source: http://www.deakin.edu.au/dhs/parent_to_parent/



Structure of the guide

Chapter 1: The early days describes some of the feelings & events that you may experience during the early days & weeks following your child's diagnosis.

Chapter 2: Behaviour & your special needs child looks at some of the strategies that you can use when you are working with the behaviour of your child, such as social stories, time-out, progressive exposure, reinforcement, explaining why & routines.

Chapter 3: Dealing with specific behaviours gives examples of the way the strategies described in chapter 2 can be used to manage specific behaviours. Parents offer advice on dealing with aggression, bedtime, escaping, fear of specialists, bath time, mealtimes, tantrums, showing affection & toileting issues.

Chapter 4: Getting social with your child explores some of the more social parts of your child's life. Parents provide practical tips on dealing with comments from the public; preparing your child for group social activities; dealing with loneliness & bullying; & managing school holidays. There are also some hints on how to manage day-to-day tasks such as shopping & banking.

Chapter 5: When your child asks 'Why am I different?' provides some ideas for answering your child's questions about their disability.

Chapter 6: Your family explores some of the issues that can arise within families when raising a child with special needs. Attention is given to the issues & needs of parenting partnerships, single parents, fathers & brothers & sisters.

Chapter 7: Friends & extended family discusses the response of family & friends to a child's diagnosis. It looks at some of the feelings & beliefs that can influence their behaviour, & provides some suggestions for creating & keeping positive relationships with them.

Chapter 8: Dealing with specialists provides practical tips for getting the most out of your meetings with the specialists who are involved with your child.

Chapter 9: Looking after yourself provides information about the things that you can do to keep yourself energised & healthy. This chapter also addresses issues related to respite care & looks at the pros & cons of support groups. At the end of this chapter you will find '10 hot tips for staying cool', for quick action when you reach boiling point.

Chapter 10: Getting organised describes a variety of activities that can help you to get organised. These include goal setting & planning, time management tips, & help with setting up an information file for your child.

Chapter 11: The things that make us strong presents parents' beliefs about

Resources: Resources contains up-to-date information about agencies, services & websites that may be relevant to you while raising your child.

Attending Kids Plus?

Starting On Time

We recommend that families arrive 10 minutes early, leaving time for trips to the bathroom or other needs.

It is very important to ensure that families arrive on time, & be ready to commence their therapy session to make the most of the scheduled space available, for each child. And, yes sometimes sessions may run late, apologies & patience please.

Parking

Parking is limited around the area, so leave extra time to find a park. Kings Funerals opposite have invited families to park opposite in their car park. Please check in with Kings Reception in case they have big funeral attendance expected.

Brothers & Sisters

Siblings are welcome to visit a therapy session, with a toy area set up especially for them. Parents are asked to pack up these toys at the end of each session, ready for the next children.

Parent Support

Donna Shaw

Donna is our Parent Support Person. If families would like to talk to Donna about any concerns or ideas they have, or improvements in the service the Kids Plus Foundation provides, please call Donna on

0402 757 987

AH 5282 1991

Thought for the day

"Be like a duck. Calm on the surface, but always paddling like the dickens underneath."

Michael Caine