

Torque

magazine

ISSUE 1 2008

 northcott
spina bifida group

2007

International Day
Of People With
A Disability

Feature

Spina Bifida
Awareness Week
2007

Could you be the next
Spina Bifida Awareness
Week Ambassador?

Win a
Holiday!

The Magazine of The Northcott Spina Bifida Group

Comfort. Independence. Freedom.



At Northcott Equipment Solutions, sales, expert advice and service of products which allow people with disabilities to achieve greater mobility, independence and freedom, are all in one organisation. This provides an efficient and complete customer service - second to no other mobility equipment outlet.

We specialise in:

- Wheelchair sales, repair and maintenance
- Seating and orthotics
- Assistive technology
- Independent living aids and appliances

Call us now on (02) 9890 0950
or www.northcottes.com.au


northcott
equipment solutions

Showroom at: No. 1 Fennell St,
North Parramatta NSW 2151

WORD FROM THE EDITOR

WELCOME to a new year and our first colour edition of *Torque!*

We have a number of special features, including some great photos from Northcott's International Day of People with a Disability (page 14) and Spina Bifida Awareness Week celebrations (pages 12-13). Thank you to Julie and Jane Charlton, who did a wonderful job as our Northcott Awareness Week Ambassadors (page 11)!

2007 was also a year of change for Northcott as we bade a sad farewell to our CEO, Glenn Gardner, who has overseen the development of our organisation over the past 20 years (page 5). We now welcome Kerry Stubbs to the role of CEO; a feature story for our next edition.

Enjoy!



Anita Fisher



Cover photo: Julie Charlton in the cockpit en route to Dubbo during Spina Bifida Awareness Week 2007

Meet our 2007 Spina Bifida Awareness Week Ambassador – page 11

THE PUBLISHERS OF THIS MAGAZINE HAVE MADE EVERY EFFORT TO ENSURE THE ACCURACY OF INFORMATION, BUT NO RESPONSIBILITY WILL BE TAKEN FOR ERRORS OR OMISSIONS. NO ENDORSEMENT OF ANY PRODUCTS OR PROCEDURES WHICH APPEAR IN THE PUBLICATION IS GIVEN OR IMPLIED BY THE NORTHCOTT SPINA BIFIDA GROUP. THE OPINIONS EXPRESSED BY WRITERS ARE NOT NECESSARILY THE VIEWS OF THE NORTHCOTT SPINA BIFIDA GROUP. TO SUBMIT ARTICLES, LETTERS OR PHOTOGRAPHS, WRITE TO: TORQUE MAGAZINE, PO BOX 4055, PARRAMATTA NSW 2124.

CONTENTS

Letter to the editor	4
Win a holiday	4
The end of an era	5
A bright blue beginning	5
Scaling the stairs of independence	6
A step toward success	7
Speak out	8
Find your voice online	9
Smooth sailing	9
Fitness for all	10
Interschool sports carnivals	10
Meet our 2007 Ambassador	11
Spina Bifida Awareness Week 2007	12-13
International Day Of People With A Disability	14
60 Seconds with Amanda Loughman	15
Practical parenting	16
Strategies for successful students	16
Sports ability	18
IN THE LIBRARY	19
KIDS CORNER	20
Changes to Independence Solutions	21
ORDERING PADS AND NAPPIES	22
TELEPHONE DIRECTORY	23



A division of Northcott Disability Services
(Established in 1929 as The NSW Society
for Crippled Children)

1 Fennell Street, North Parramatta NSW 2151

PO Box 4055 Parramatta NSW 2124

TEL: (02) 9890 0990 FAX: (02) 9683 2827

TOLL FREE: 1800 506 071

E-mail: sbgroup@northcott.com.au

Manager, Northcott Spina Bifida Group:
Anita Fisher (02) 9890 0160

Administration Support:
Kayleen Flood (02) 9890 0990

Torque Magazine Editorial Team:
Anita Fisher, Kayleen Flood, Jean Pitkin,
Judi Lipp, Tereza Culina, Roxanne Martinenko

Design & Layout:
Michael Lakin, Northcott Publications

Printed by: Phillip Daines Productions

Editorial contributions to: Roxanne Martinenko
(02) 9890 0170 or roxanne.martinenko@northcott.com.au

CONGRATULATIONS TO BRIDGET VIRGONA, WHO HAS WON A HOLIDAY TO THE CENTRAL COAST

Dear Editor,

My name is Bridget Virgona and I am a 23-year-old woman who lives with Spina Bifida.

Earlier in the year I approached *Torque* and Northcott Disability Services about starting up a support group for young adults with spina bifida.

We have now had a couple of meetings and things are starting to get underway with the group. We are planning lots of social functions this year and we also hope to go on a holiday as a group.

I couldn't have got this group up and running without the help and support of Beth Horton, Robyn Cathers, Mary Louise Cuy and Dr West and Anita Fisher.

Thank you all for believing in me and helping me fulfil my dream of starting this group.

Yours sincerely,
Bridget Virgona

See page 6 for Bridget's profile.

WIN A HOLIDAY!

YOU too could win a holiday to the Central Coast. As always, we are keen to receive your feedback about *Torque*. We encourage you to comment on the articles and stories that appear in the current edition. The person who submits the best letter to the editor will have a chance to win a week away at our Budgewoi cabin!



A dream becomes reality... Bridget Virgona at home in Mosman

NEED A HOLIDAY...

THE Northcott Spina Bifida Group owns a fully accessible holiday cabin at Budgewoi, on the Central Coast, located on the foreshores of Lake Munmorah.

The cabin has been specifically designed and constructed for use by people with a physical disability. The cabin can sleep five people, has modern amenities, laundry facilities and a barbecue. A Northcott Freewheeler is also available for use.

For bookings, call The Northcott Spina Bifida Group on (02) 9890 0990, fax (02) 9683 2827 or email sbgroup@northcott.com.au



THE END OF AN ERA

AFTER 19 years of service, Northcott's Chief Executive Officer Glenn Gardner is saying farewell to an organisation of which he has been so much a part.

Glenn Gardner recently announced his resignation as CEO of Northcott Disability Services, which took effect in December 2007.

Glenn began his journey with Northcott, which was then the NSW Society for Crippled Children, in 1988.

"I've always tried to ensure that whatever Northcott does, it provides opportunities and choices that people with disabilities may not otherwise have."

When Glenn started work at Northcott in 1988 there were 26 client programs supporting 2,500 clients and their families (now there are over 6000). In 1988 there were four regional offices, now there are ten.

Glenn will not be far away, having accepted the role of CEO of Ability First Australia, of which

Northcott is a founding member.

The Board has appointed Ms Kerry Stubbs as Northcott's next CEO. For the past five years Kerry has been the Executive Director of St Vincent's Hospital and Sacred Heart Hospice. Kerry begins her appointment with Northcott in February 2008 and will be featured in the next edition of *Torque*.

During his years at Northcott, Glenn has shown great commitment and the success of the organisation is a compliment to him. Goodbye Glenn.



Farewell Glenn... (L to R) Northcott CEO Glenn Gardner, Wagga Wagga's Jack Tori and Wagga fundraising committee president Lyndall Watts

A BRIGHT BLUE BEGINNING

SPINASAURUS, our friendly blue mascot, brightened up Port Kembla Hospital for the official launch of the Spina Bifida Health Checklist and Emergency Contacts card, an initiative between the Northcott Spina Bifida Group and the Greater Metropolitan Clinical Taskforce and South East Sydney Illawarra Area Health Service (SESAHS).

The launch was attended by Shalna Ward, a Northcott client who has spina bifida and played a significant role in the design of the cards.

Joanne Morrell, Shalna's physiotherapist, recognised the significance of the cards in the spina bifida community.

"This is a huge achievement for our area, there is nothing like it in NSW," Joanne said.

If you would like to receive a card, please contact Kayleen Flood, Administrative Assistant to the Spina Bifida Group on (02) 9890 0990. There is no cost for the card.



A step forward in health management... (L to R) Shalna Ward, Spinaurus and Joanne Morrell at Port Kembla Hospital

SCALING THE STAIRS OF INDEPENDENCE

"SOME people tell me that I am only capable of doing certain things, but I want to do what I enjoy, not live under restraints set by other people."

These are the words of Bridget Virgona, 23-year-old Mosman resident who was born with spina bifida.

Bridget used a wheelchair for mobility when she was young, but now walks without the use of walking aids or artificial foot orthoses.

"Some doctors told me I would never walk. I proved them wrong," Bridget said.

Bridget attributes this to the 115 steps that she walks each day to get to and from her house. It is certainly a hike as the steps go up a steep incline.

It is Bridget's optimism in the face of perceived inability that allows her to overcome the challenges she meets.

Bridget is using this optimism to approach her newest challenge of establishing a social support group for people between the ages of 18-30 with spina bifida. The group is modelled on the Girls' Nights In that Northcott Disability Services Recreation Service run for children under 18.

"I loved attending Northcott's Girls' Nights In, we all had so much fun, but once I turned 18 I was no longer eligible to attend them," Bridget said.

Support services for adults of all ages who have disabilities are rare. To try and counteract this, Bridget, with the help of staff from Northcott's Spina Bifida Group and Adult Outreach Team, formed her own social support group. Bridget has big plans for the group, with inspirational speakers and medical practitioners to advise members on current medical issues, as well as fun social activities all in the pipeline.

"The group is for everyone. We all gain from it and help one another in the process," Bridget said. "I want to try and combat the isolation felt by people with spina bifida. We all share the same experiences and I want to show them that they are not alone."

Bridget's social support group has a lot of promise because it addresses an identified need.

"My long-term goal is to eventually establish funding for the group," Bridget said. "There is clearly a need for support services like this."



Outgoing... Bridget Virgona begins a new journey

WANT TO JOIN?

IF you are interested in Bridget's social support group or require further information please contact **Bridget Virgona on (02) 9969 5052 or bvirgona@lycos.com** or **Robyn Cathers, Community Worker with the Adult Outreach team on (02) 9890 0100.**

A STEP TOWARD SUCCESS

EMMA Hoad of Coffs Harbour is a determined and motivated individual. With the help of Northcott Disability Services, Emma has recently completed a three year Bachelor of Social Science degree at Southern Cross University (SCU) and is now one step closer to achieving her dream career in the disabilities field.

The 25-year-old, who has spina bifida, is a recent recipient of Northcott's Gregory and Dolores Farrell scholarship.

The scholarship, which is offered on a one year basis and covers tertiary costs up to the value of \$5000, has allowed Emma the opportunity to further pursue her academic goals.

"Receiving the scholarship has truly been a lifesaver. I would have really struggled without the funds, as the scholarship has helped pay for textbooks and transport costs to and from university," Emma said. "I previously limited my travel to uni to only when I had lectures as it would cost so much to travel there by taxi, but the scholarship means I don't have to worry about this and has allowed me to successfully concentrate on my studies, making use of the library and other facilities available to me on a more regular basis without having to worry about whether I can afford it."

In addition to her undertaking her degree, Emma is well on her way to achieving her dream career, dedicating a few days each week to both paid and unpaid work experience with three different organisations specialising in providing services to people with a disability.

"I enjoy the work experience as it allows me the opportunity to interact with a wide range of people," Emma said. "I would eventually like to work with children with disabilities, as this has always been a passion of mine."

Emma, who uses a wheelchair for mobility, is currently supported by Northcott's Community Participation Program in Coffs Harbour.

"Northcott has always provided me with the support whenever it is needed," Emma said.

Emma encourages and advises others with a disability to push their boundaries.

"If there is something you want to do, give it a go," Emma said. "Anything is possible if you put your mind to it."



Quietly confident... Emma Hoad at home in Coffs Harbour

NORTHCOTT SCHOLARSHIPS

Northcott Disability Services offer a number of scholarships. For more information on eligibility criteria and other details **please contact Elizabeth Mead on (02) 9890 0135.**

SPEAK OUT!

WE all have the power to influence decisions made by the government.

It is your right to voice your opinion on issues and to ask government ministers or local council members to take action and address your concerns.

No special knowledge is required, you just have to be willing to talk about the challenges that people with spina bifida face. This may involve talking about your healthcare, education and job.

What sort of thing should I say?

You can say anything about your local area that you think is important for your local council to know. Such as the footpath is cracked and bumpy or perhaps you have no footpath at all.

You may also want to challenge certain policies a politician holds (their official stance on healthcare, employment, etc.).

Once you have identified an issue, call the politician to action. This means asking them what they are going to do about it.

Why?

Politicians and council members need to hear from people with spina bifida in their local community so they can make informed decisions on topics such as transport, health services, architecture and events.

Keeping in contact with your local politicians will ensure they support people with spina bifida in their local community.

How do I make my opinion heard?

There are many different methods of expressing your opinion such as letters, phone calls, faxes,

emails and petitions.

You are not the only one who can use these methods. Ask your parents, children, spouses, siblings, aunts, uncles and friends who know what it is like to live with spina bifida to also express their opinions.

The more voices you have the greater your chance of being heard.

Who do I contact?

Your first point of contact is your local council member who is responsible for your area.

If you are unsure of who your local member is then look on your local council website or phone them and ask.

Remember:

- You are the experts in what it is like to live with spina bifida and members of parliament need to hear from you about the issues that affect you.
- Do not get discouraged, persistence pays off.

START HERE!

A perfect way to begin expressing your opinions is to send a letter to our editor. Tell us your thoughts on *Torque* magazine:

- Do you like our stories?
- What would you like to see included in the next edition of *Torque*?
- Are there any improvements we can make?

For the person who writes the best letter to the editor there is the chance to win a holiday to Budgewoi cabin, on the Central Coast, located on the foreshores of Lake Munmorah! **See page 4.**

FIND YOUR VOICE ONLINE

Multicultural Disability Advocacy Association of NSW (MDAA)

Promotes, protects and secures the rights of non-English speaking people with a disability and their families.

Toll free 1800 629 072

Email mdaa@mdaa.org.au

Website www.mdaa.org.au

People with Disability Australia (PWD)

A free non-legal advocacy service for individuals and groups of people with disability who have serious and urgent problems.

Toll Free: 1800 422 015

Email: pwd@pwd.org.au

Website: <http://www.pwd.org.au>

Disability Complaints Service

A free service to help people with a disability who wish to make a complaint about their rights being infringed.

Website: <http://www.post-polionetwork.org.au/dcs.html>

Toll Free: 1800 424 007

NSW Disability Discrimination Legal Centre

Assists people to understand and use disability discrimination legislation.

Website: <http://www.ddlcnsw.org.au/>

Toll Free: 1800 800 708 (NSW Only)

Justice becomes accessible

THE Diversity Services website is a recent government initiative into the fight against discrimination.

This website aims to make the justice system more accessible to people who have a disability or who are from culturally and linguistically diverse communities.

Courts provide a range of services to ensure that no-one is disadvantaged and this website explains how to request an interpreter, equipment or assistance.

"The Diversity Services website will empower members of the community who often face discrimination by informing them of their legal rights and the remedies available to them," Diversity Services Manager Julia Haraksin said.

Visit Diversity Services at www.lawlink.nsw.gov.au/diversityservices

SMOOTH SAILING

NORTHCOTT Disability Services has established a partnership with Sailors with disABILITIES (SWD), an organisation that offers programs for children, adults and their carers, providing them the opportunity to experience sailing. SWD have generously offered to continue providing further sailing opportunities for Northcott clients, carers and staff. A number of events, such as carers sailing days, recreation sailing days and the NRL Rookie Regatta will directly benefit Northcott carers by providing them with the opportunity to have time off from their support role and will also allow Northcott clients to experience the joy of sailing, through steering the boat or just taking in the feeling of freedom on the water. **Please contact Mitch Taylor on (02) 9890 0166 for more details.**



Freedom on the water... Northcott client Ralph Hasna, who has spina bifida, enjoys a sail on the harbour

FITNESS FOR ALL

THANKS to a new initiative by Northcott Disability Services in conjunction with the NSW Department of Sport and Recreation, people with a disability will now have the support they need to join or access fitness centres.

Mohamed Hussein, a 30-year-old man with cerebral palsy, is currently one of the participants involved in Fitness For All. This program aims to provide participants who have a physical disability with the opportunity to use a gym that is accessible and equipped to provide services to people with different abilities.

Staff members from the fitness centres involved in the program are trained in disability awareness and fitness for people with disabilities, and are able to assist in adapting gym equipment to suit each individual's needs and abilities.

Sarah Kowald, Northcott's Fitness For All Project Coordinator, hopes the program will generate a heightened awareness about the need to make gyms more inclusive for people with a disability.

"Many people don't realise that not all gyms are

accessible," Sarah said. "This program aims to create an inclusive environment by integrating people with disabilities in fitness centres to help them achieve their goals."

For more information contact Sarah Kowald on (02) 9890 0192.



Motivated... Mohamed Hussein at his local gym in North Parramatta

NORTHCOTT DISABILITY SERVICES INTERSCHOOL SPORTS CARNIVALS

NORTHCOTT Disability Services annual Interschool Swimming and Football Carnivals are being held in the first half of 2008.

Carnivals are open to schools and individuals with all levels of ability and experience. Come to compete and break some records:

- Junior Swimming Carnival: **March 14, 2008.**
- Senior Swimming Carnival: **March 28, 2008.**
- Senior Football Carnival: **May 27, 2008.**
- Junior Athletics Carnival: **August 12, 2008**
- Senior Athletics Carnival: **August 26, 2008**

For more information or to register please contact Claire Garside on (02) 9890 0143 or email claire.garside@northcott.com.au.



Making a splash... Northcott's Naomi Boyd and Julian Bleicher at Northcott's 2007 swimming carnival

MEET OUR 2007 AMBASSADOR!

HEAR about Spina Bifida Awareness Week 2007 first hand as we speak to Northcott's 2007 Spina Bifida Awareness Week Ambassador Julie Charlton and her mother Jane.

What did you enjoy most about SBAW 2007?

Julie: Speaking in front of all the people was fun, even though I did get a bit nervous sometimes!

Jane: Going to schools and meeting the students and teachers who do a brilliant job of looking after our special needs kids. I also enjoyed seeing Julie's sense of achievement and self-esteem grow.

Where was your favourite place that you visited during SBAW 2007?

Julie: Going to Dubbo was fun, because I travelled on a plane and I went into the cockpit and wore the pilot's hat. I also visited Western Plains Zoo which was very special.

Jane: Seeing Julie speak at her own school was very special for me, I was so proud of her!

Why do you think SBAW is important?

Julie: It is very important to spread the word

about ability, achievement and inclusion so that everyone will understand this 'different ability' (spina bifida). I hope for a time when people with 'different abilities' are not left out of anything ever again.

Jane: To abolish fear we need to educate everyone about people with 'different abilities'. Once the fear is gone then the doors to full inclusion will open. Thank you Northcott for selecting us to be part of Spina Bifida Awareness Week 2007 because it is the most wonderful experience we have had.



All smiles... Jane and Julie Charlton at Western Plains Zoo in Dubbo

COULD YOU BE THE NEXT SPINA BIFIDA AWARENESS WEEK AMBASSADOR?

WOULD you like to represent Northcott Disability Services and be involved in raising awareness of spina bifida?

Northcott's Marketing, Communication and Media Team are seeking a Northcott client with spina bifida to represent Northcott Disability Services at various media opportunities in the lead up to and during Spina Bifida Awareness Week 2008 (September 1-7).

Although based in Parramatta, the role will involve visiting schools and hospitals across NSW

to promote Spina Bifida Awareness Week during the months of August and September.

Applications for this position close June 27, 2008. **Please contact Roxanne Martinenko to obtain a copy of the job description and application details on (02) 9890 0170 or email roxanne.martinenko@northcott.com.au. A copy of the job description can also be obtained online at www.northcott.com.au.**

SPINA BIFIDA AWARENESS WEEK 2007

SPINA Bifida Awareness Week 2007 (September 1 to 7), celebrated under the tagline of promoting ability, achievement and inclusion, was yet another busy week for our mascot Spinasaurus.

Spinasaurus, together with our first ever Spina Bifida Awareness Week Ambassadors Jane and Julie Charlton, launched the week by taking part in a parade at St Mary's Annual Spring Fair, where they received a rousing reception from the crowd and onlookers.

Several schools from across NSW also had the opportunity to meet Spinasaurus and understand more about spina bifida as our big, blue and friendly dinosaur visited Tiffanie Hill from Kuyper Christian School, Amy-Lea Attard from Werrington Public School, Chloe Kite from Richmond North Public School, Bradley Pemberton from Tacoma Public School and Dale Johnson from Dubbo South Public School. Spinasaurus also made

a special appearance at a playgroup run by Northcott's Early Childhood Support Service in Windsor.

The Northcott Spina Bifida Group hosted a lunch at the end of the week, with the evening concluding with a forum held by Dr Angela Wilson on Learning Issues for Children and Adults with Spina Bifida and Hydrocephalus.

The week also celebrated a number of exciting and new initiatives, with the Spina Bifida Health Checklist and Emergency Contacts Card officially launched at Port Kembla Hospital. Also, as reported in the last edition of *Torque* magazine, the cute and cuddly Spinasaurus toys were launched for sale through Northcott during Spina Bifida Awareness Week 2007, raising almost \$1000.00.

EXCERPTS FROM JULIE CHARLTON'S SPEECH FROM SPINA BIFIDA AWARENESS WEEK 2007

MY name is Julie Charlton and I am eight years old. I have spina bifida and hydrocephalus.

I am very honoured to have been selected as the Ambassador for Spina Bifida Awareness Week, and I thank everyone at Northcott Disability Services for giving me this opportunity.

Spina Bifida Awareness Week is about ability, achievement and Inclusion.

'Differently abled' is a term given to my Mum by a good friend of hers. I prefer this to 'disabled' because there is nothing dis about me! I love to laugh, play and be with my friends, even if some things are trickier for me.

My spina bifida hasn't stopped me from ice-skating, even if I did have to wear the biggest boots to fit over my Ankle Foot Orthotics. My AFOs allow me to walk, run and dance. I have even

learned tap, street funk and jazz. Tap was the hardest, I kept falling into the sink (not really). I have even done rock climbing. Both ice-skating and rock climbing are some of my dreams come true. I got to do these fabulous activities at some of my friends' birthday parties. Their Mums phoned my Mum to see if I would cope. Mum always says "Well, let's give it a try and see how it goes."

I feel I have a great many abilities. My abilities may not be the same as yours but after all, we are all different.

So remember everyone, try to include everybody and that way you will achieve some great abilities: compassion and kindness.

You will make some very extraordinary friends along the way.

SPINA BIFIDA AWARENESS WEEK 2007



Spina Bifida Awareness Week 2007 launch at St Mary's Spring Fair.



Spinasaurus, Chloe Kite, Julie Charlton and her mother Jane at Richmond North Public School.



Spinasaurus embraces Bradley Pemberton at Tacoma Public School.



Tiffanie Hill and Julie Charlton show off their Spinasaurus toys at Kuyper Christian School.



Julie Charlton, Amy-Lea Attard and Spinasaurus at Werrington Public School.



Spinasaurus and children from Northcott's Early Childhood Support Service at a playgroup in Windsor.



Julie Charlton and her mother Jane with the Qantas flight crew before take off to Dubbo.



Spinasaurus greets children from Dubbo South Public School.



Stacey Baird, Dubbo Team Leader and Julie Charlton at Northcott Disability Services Dubbo office..

INTERNATIONAL DAY OF PEOPLE WITH A DISABILITY 2007

STUDENTS and adults with a disability beat to the sound of drums, competed in wheelchair sports and let their creativity run wild as part of Northcott Disability Services International Day of People with a Disability celebrations on Friday December 7, 2007.

Over 200 children and adults joined in the celebration of ability. A variety of activities were held throughout the day, including face painting, an art workshop, wheelchair basketball with paralympians and an interactive drumming session with Drum Café.

For the fourth consecutive year, Drum Café provided all students with a drum on the day,

producing a loud, energetic and inclusive performance.

Acclaimed drummer Andrew Hewitt, who has cerebral palsy, also gave an inspirational performance.

Special guests included members from the Parramatta Eels, Kylie Gauci from the Australian Wheelchair Basketball Team, Paul Nicholls from the Australian Cerebral Palsy Soccer Team and the Northcott Spina Bifida Group mascot Spinasaurus.



Brenton Smith and Nicholas Nguyen from Bossley Park High School share a joke.



Trinh Truong from Bossley Park High School takes part in Drum Café.



Joshua Zizza from Peakhurst Campus, Georges River College enjoys a beat with Drum Café.



Julie Charlton and Spinasaurus with Perfection Fresh vegetable mascots.



Rebecca Donattiello, Houda El Asmar and Dale Ryan of Northcott's Community Participation Program show their smiles.



Damien Rist and Senna Phanthavady from Airds High School show off their artistic creations.

60 SECONDS WITH AMANDA LOUGHMAN

AMANDA Loughman is a young woman brimming with enthusiasm for life. So much so, that there are few things the 22-year-old does not enjoy. Amanda has spina bifida and uses a wheelchair for mobility.

What do you enjoy?

"I have a real passion for writing and I write whenever I can. In high school I wrote a play, which was four years in the making. It sounds like a long time but when you enjoy things they become easy.

I also enjoy performing arts, which I participated in at the National Institute of Dramatic Art."

Do you play sport?

"I live in a prime position. With Centennial Park around the corner and a pool in my backyard I can remain as active as I like. I really enjoy swimming and I have a personal trainer. All my exercise has really improved my health. "

Have you ever been overseas?

"Travelling to Italy with my family would have to be one of the best experiences of my life.

Pompeii was the biggest challenge. It hasn't changed since 79AD, but then that was why it appealed to me. Without my family I could never have travelled there, they helped me so much.

My next holiday is currently in the planning process. I think I will go to America or Canada. They are accessible countries and I can be much more independent."

What are your goals?

"My goal is to have a steady part-time job and get out there and do more things.

I currently work casually at the Powerhouse Museum and I can't wait to gain more work and experience. I am very interested in the tourism and hospitality industry and I can see myself working in that area in the future.

I also have my sights set on something greater. I am writing my own book and I really want to get it out there. It indulges my passion for the world. It's all about life. I find life and people very interesting."

What would you consider your greatest achievements?

"Every step of life is a success. I consider everything I have done as a great achievement.

People with disabilities need to acknowledge their efforts. Sometimes I think we are too hard on ourselves."



Brimming with enthusiasm... Amanda Loughman at home in Randwick

PRACTICAL PARENTING PARTICIPATE!

NORTHCOTT'S Adult Outreach team is keen to hear from people with spina bifida who are interested in participating in a parenting group. Men and women who are thinking of having children or already have children are welcome to join. Dr Carolyn West will attend to provide medical and practical advice about pregnancy and parenting for people with spina bifida and a community worker and occupational therapist from the Adult Outreach team will also attend on the day.

A similar group was held in July last year and participants responded positively, finding it very useful to be able to share their stories and experiences.

Northcott's Adult Outreach team has community workers and occupational therapists who provide services to adults with physical disabilities in the Sydney metropolitan area.

To register your interest for the Spina Bifida Parenting Group or for general enquiries about the Adult Outreach team please contact Jaie Thomson, Team Leader on (02) 9890 0100.

STRATEGIES FOR SUCCESSFUL STUDENTS

ON Thursday September 6, 2007 an information session was held at Northcott's Parramatta office on the topic of Learning Issues for Children and Adults with Spina Bifida and Hydrocephalus. Angela Wilson, an experienced teacher, consultant, researcher and lecturer, presented to a number of Spina Bifida Group members and health professionals, providing useful information and tips to help parents support their children through the school years and make them aware of the obstacles that some children with spina bifida and hydrocephalus face in their daily lives.

Angela, along with Alison Jones, Occupational Therapist from the Children's Hospital at Westmead, has put together a CD called Super Strategies for Successful Students. It is a resource for parents and teachers and is available to purchase from the Children's Hospital at Westmead.

Please contact Kayleen Flood on (02) 9890 0990 if you would like to obtain an order form or you can email the hospital directly at kidsh@chw.edu.au.



Ensuring success... (L to R) Anita Fisher, Kayleen Flood and Dr Angela Wilson at the information session.

NORTHCOTT DISABILITY SERVICES NEW WEBSITE

NORTHCOTT Disability Services has launched a new website at www.northcott.com.au

It comes with a complete calendar of events and recent news stories as well as useful links.

Each service has its own section including the Northcott Spina Bifida Group which is available at this address: http://clientprograms.northcott.com.au/spina_bifida/index.html.

Here you can read about recent news on Northcott's Spina Bifida Group and updates on Spina Bifida Awareness Week 2008; you can also access resources specific to spina bifida.

Our goal is to make our website more user friendly and we are keen to know what you think. **Your comments and feedback are most welcome!** Contact Tereza Culina on (02) 9890 0113 or email pr@northcott.com.au.

RAISING CHILDREN - YOUR ONLINE RESOURCE

RAISING Children is a great online resource which addresses many questions and concerns relevant to parents of children with disabilities.

Information is available on topics including health, disability rights, services and support, siblings of children with disabilities and education. There are videos, fact sheets,

opportunities for parents to interact and share their stories as well as a disability reference guide which provides simple explanations of disability terms and definitions of industry professionals.

Visit Raising Children at <http://www.raisingchildren.net.au/disabilities>.

TRANSITIONAL ACCOMMODATION

...SERVICES AND ACCESSIBLE HOUSING FOR PEOPLE ON THE MOVE

DO you...

Dream of moving out of home?

Dream of living more independently?

Have a physical disability?

Need some time to learn new skills?

Northcott has three accommodation services offering short to medium-term housing for adults with physical disabilities. Each service is unique in the level and type of support offered.

Contact Taryn Bankier, Transitional Accommodation Services Manager for more information.

Phone 0412 436 604

P.O. Box 4055, Parramatta 2124

Email: taryn.bankier@northcott.com.au



SPORTS ABILITY

NORTHCOTT Disability Services has recently obtained the new Sports Ability kit, an initiative of the Australian Sports Commission (ASC), designed to allow people of all ages and abilities participate in sport and physical activity.

The games included in the kit are Boccia, Goalball, Sitting Volleyball, Polybat and Table Cricket.

Will DiSanto, Senior Support Worker in Northcott's Community Participation Program, believes the equipment holds great potential.

"This sporting equipment is the first of its kind and we are exploring various ways to use it," Will said. "Currently I am considering the abilities of my clients and adapting the equipment to include everybody's different abilities."

The group will shortly receive a training session from ASC in addition to the instructional DVDs.

"You can really use your imagination and a bit of improvisation to make the most of the equipment," Will said.

The sporting equipment will also be available for use by Northcott's recreation and respite clients and will gradually make its way to Northcott's Community Participation Programs in Roselands, Dubbo and Tamworth. **For more information contact Will DiSanto on (02) 9890 0984.**



Getting a competitive edge... Rebecca Donattiello and Shona McDonald playing Boccia, which is played at the Paralympics.

YOU ARE INVITED...

IF you are a young person or a parent of a young person with a chronic illness or disability and are interested in assisting to identify and address issues of importance to consumers, please **contact Lynne Brodie on (02) 9887 5578 or email lbrodie@nscchahs.health.nsw.gov.au.**

Working groups meet at Macquarie Hospital at North Ryde every two or three months for one or two hours. Teleconference facilities are available.

MOVING ON UP...

MOVING on up is a forum for sharing ideas about transition issues for young people with chronic illness or disability moving from paediatric to adult health care.

We are keen to hear from anyone interested in issues relating to transition.

Download the publication from the internet at: www.health.nsw.gov.au/gmct/transition or email Lynne Brodie at lbrodie@nscchahs.health.nsw.gov.au.

IN THE LIBRARY WITH JUDI LIPP

ADAPTIVE BABY CARE EQUIPMENT FOR PARENTS WITH PHYSICAL DISABILITIES [dvd]: 2006 and ADAPTIVE BABY CARE EQUIPMENT: Guidelines, Prototypes & Resources written by Kris Vensand: 2000, both published by Through the Looking Glass (TLG). <http://www.lookingglass.org>

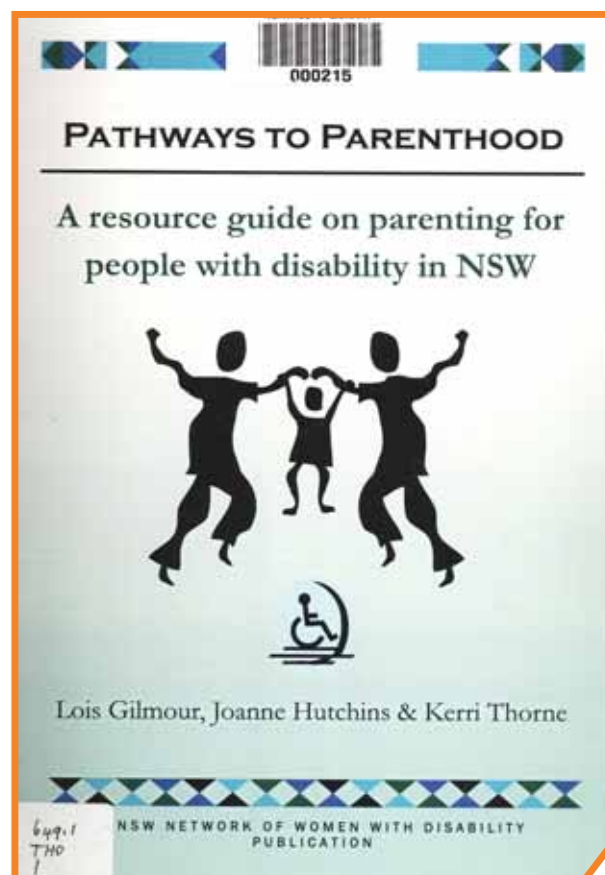
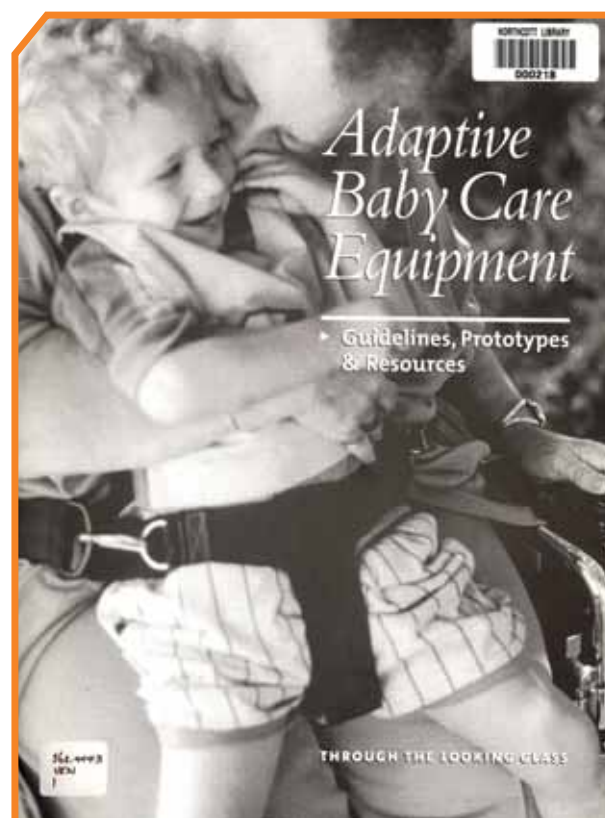
These resources present creative solutions gained through the publisher's work with parents who have physical disabilities. The twelve minute DVD demonstrates successful use of adaptive baby care equipment and adaptive techniques. The DVD does not instruct, rather it shows examples of solutions for individual circumstances. The baby trained to lift its bottom at nappy change time is remarkable. The booklet of 86 pages covers holding, carrying and moving, feeding, diapering, dressing, bedtime, bathing and safety gates. The solutions are intended to serve as catalysts for problem solving obstacles when caring for infants. Two appendices offer checklists – Safety checks for adapted baby care equipment and Tips for your baby's safety from CPSC, Consumer Product Safety Commission.

PATHWAYS TO PARENTHOOD: A resource guide on parenting for people with disability in NSW: 2007 written by Lois Gilmour, Joanne Hutchins & Kerri Thorne, published by NSW Network of Women with Disability. www.femability.org.au/parenting_with_disability.htm

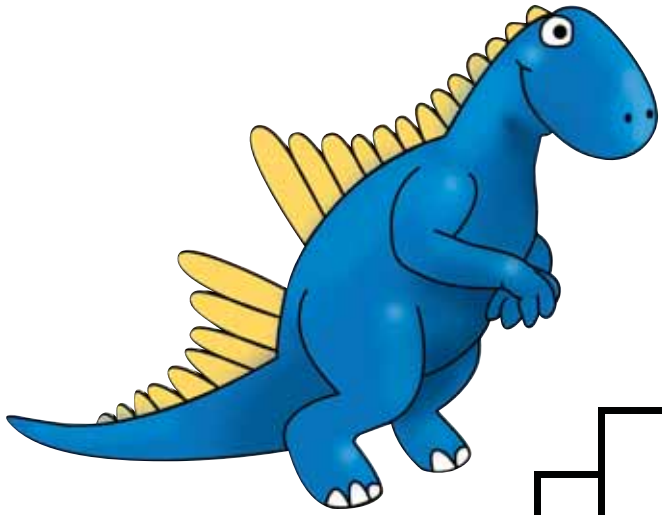
Northcott Library has added a print copy of this resource to its collection. This reference book provides information on resources, services, peer support networks, and equipment/modified aids for parents (and parents to be) with disability or chronic illness.

The online format has the capacity to be added to and updated on a regular basis.

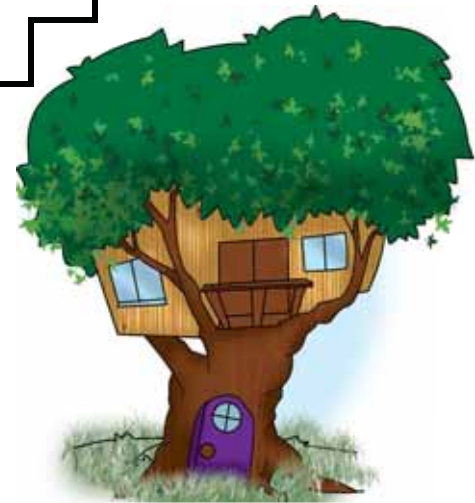
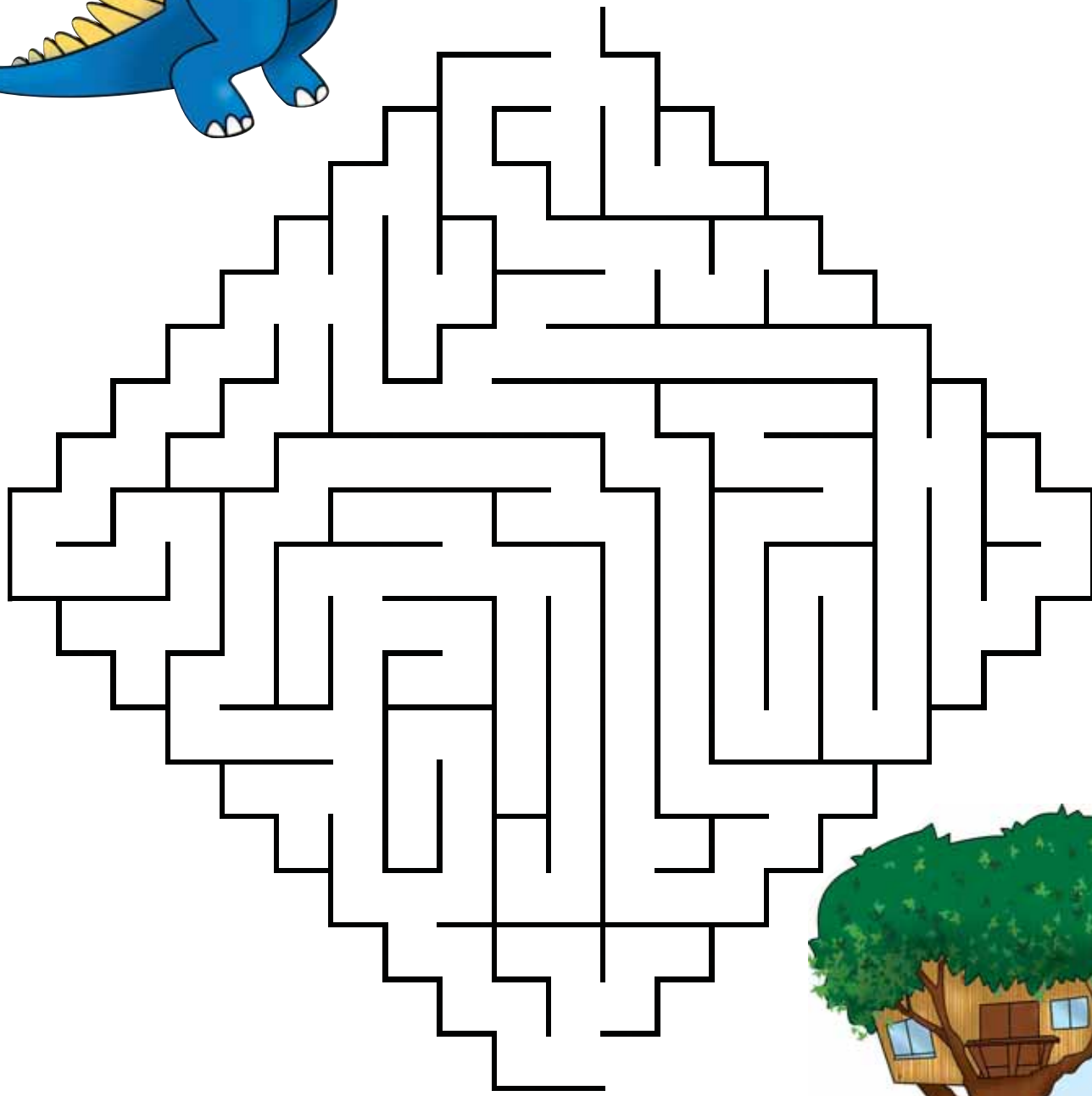
The books and DVD are among the wide range of resources available from the Northcott Library in central office at North Parramatta. Contact Judi Lipp, Librarian on (02) 9890 0161 or judil@northcott.com.au



KIDS CORNER



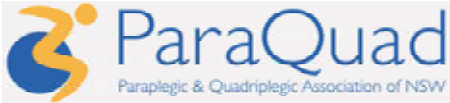
HELP SPINASAURUS
GET HOME!



CHANGES TO INDEPENDENCE SOLUTIONS

ONCE again there has been a name change. Independence Solutions has now been changed back to Paraquad. There have also been changes to delivery fees, with a slight increase on price and a merge for some regions, please refer to the table below to see

how the price change may affect you. These changes came into effect from November 1, 2007. **Please call Kayleen Flood on (02) 9890 0990 if you have any questions or need help working out your new delivery fees.**

Freight Charges and Delivery Zones Valid from 1st November 2007			
			
Regular Customers - NSW and ACT			
Charge per parcel OR per strapped parcel (where applicable)			
Code	Metro	Rural	Remote
Cost including gst	FL1	FR1	FD1
	\$6.80	\$8.80	\$13.05
NSW	Metro	Rural	Remote
	1215 - 2082	2083	2311
	2084 - 2234	2250 - 2310	2328 - 2421
		2312 - 2327	
		2422 - 2551	
	2558 - 2567	2568 - 2647	2648
		2649 - 2714	2715
		2716	2717
		2720 - 2737	2738 - 2739
	2745 - 2751	2752	
	2753 - 2756	2757 - 2758	
	2759 - 2770	2773 - 2831	2832 - 2880
ACT		2600 - 2620	
		2900 - 2914	



ORDER FORM FOR PADS & NAPPIES

Please return your order with a cheque or money order (**NO CASH PLEASE**)
Cheques/money orders are to be made out to: **Northcott**

Northcott Spina Bifida Group
PO Box 4055 PARRAMATTA NSW 2124

Name: _____ Phone: _____

Delivery Address: _____

Post Code: _____

Amount Enclosed: \$ _____

- **Products are supplied by Paraquad NSW**
- **Please indicate in the box how many of each product you would like.**
- **Please note the delivery fees.**
- **A sampling service is available if required.**

Abriform Small Super
\$17.25 (1pkt x 28) 15000005

Abriform Medium Plus
\$19.55 (1pkt x 26) 15000015

Abrisan Mono Elasti Cuffs
\$3.80 (1pkt x 28) 15000100

Abriform Medium Super
\$19.10 (1pkt x 24) 15000020

Cello Anaform Midi Inserts
\$33.35 (8pkts x 20) 15130080

Cello Insert Boost Pad 400ml
\$4.30 (1pkt x 20) 15130141

Depend Normal Brief Large
\$45.10 (3pkts x 20) 15230125

Depend Shields
\$3.60 (1pkt x 10) 15230020

Huggies Dry Nights 34230391
Size 5: 27-57kg - BOY
\$11.40 (1pkt x 13)

Huggies Dry Nights 34230392
Size 5: 27-57kg - GIRL
\$11.40 (1pkt x 13)

Tena Flex Super Medium
\$26.15 (1pkt x 28) 15120470

Tena Lady Mini Plus
\$36.60 (10pkts x 16) 15120005

Tena Lady Mini Ultra Thin
\$36.60 (10pkts x 20) 15120001

Tena Lady Normal
\$21.95 (6pkts x 12) 15120010

Tena Lady Extra
\$21.95 (6pkts x 10) 15120020

Tena Lady Super
\$21.95 (6pkts x 8) 15120030

Tena Slip Extra Small
\$22.50 (1pkt x 30) 15120151

Tena Slip Plus Small
\$20.05 (1pkt x 30) 15120156

Tena Slip Plus Medium
\$9.95 (1pkt x 12) 15120161

Tena Slip Super Small
\$18.95 (1pkt x 25) 15120171

Tena Slip Super Medium
\$9.35 (1pkt x 10) 15120176

Tena Slip Super Large
\$11.55 (1pkt of 10) 15120181

Tena Super Shields
\$5.65 (1pkt x 30) 15120050

Saniform Mini
\$3.45 (1pkt x 20) 15000400

Saniform Normal
\$3.65 (1pkt x 20) 15000200

Saniform Maxi
\$5.45 (1pkt x 20) 15000410

Paraquad Delivery Fees
Please call 9890-0990 to
discuss your delivery fee.

I give permission for the goods to be left if I am not home Yes/No

Please leave goods _____

PLEASE NOTE: Drivers will **NOT** leave the order if no-one is home, unless specifically requested.

NO RESPONSIBILITY for any loss will be taken by Northcott Spina Bifida Group, the supplier or the carrier should you choose to have the goods left unattended.



TELEPHONE DIRECTORY**Northcott Spina Bifida Group**

1 Fennell Street, North Parramatta 2151
Tel: (02) 9890 0990
sbgroup@northcott.com.au

Northcott Disability Services

1 Fennell Street, North Parramatta 2151
Tel: (02) 9890 0100

The Sydney Children's Hospital

High Street, Randwick 2031
Tel: (02) 9382 1111
Spina Bifida Clinic Tel: (02) 9382 1595

Prince of Wales - Randwick

Adult Spina Bifida Clinic
4th Wednesday of every month with Dr Engel
Make appointments through "Adult Outpatients" on 9382 0400

Westmead Hospital (Adults)

Sister June Kelly
Wednesdays:
Tel: (02) 9845 5555 page 12545
Other Days: leave a message with Ward A4C or if more urgent please phone Medical Rehabilitation on (02) 9845 7800

The Children's Hospital at Westmead

Cnr Hawkesbury Road & Hainsworth Street
Westmead 2145
Sister Julie Dicker
Tel: (02) 9845 2802

Spina Bifida Unit Secretary - Westmead

Pamela LARBALSTIER
Tuesday to Friday 8am to 4pm.
Call Pamela to make appointments for the Spina Bifida Clinic which occurs every Friday on 9845 2769

John Hunter Children's Hospital

Lookout Road
New Lambton Heights
Spina Bifida Clinic
Contact: Clinic Co-ordinator Dr John Stuart on (02) 4921 3750

Central Coast Spina Bifida Nurse

Mrs Mikey Oxby – Wyong Hospital
Tel: (02) 4394 8275 or 0413 482 528

JOBMATCH

(A job service for people with disabilities)
1 Fennell Street, North Parramatta 2151
Tel: (02) 9890-0970

SUPPORT GROUPS:

If you would like to attend one of the Spina Bifida Parent Support Groups in your area please contact one of the following:

Wollongong Area

Mrs Jessie Norwell Tel: (02) 4256 6484

Canberra Area

Jan Pummeroy Tel: (02) 6298 8394
Eileen Catanzariti Tel: (02) 6241 6713

Central Coast

Ann & Philip Hudson Tel: (02) 4341 7972

Newcastle Support Group

Patsy Osbourne Tel: (02) 4987 2780
Joan Gatt Tel: (02) 4948 6096
Therese Barlow Tel: (02) 4987 2161

Hydrocephalus Support Association

Mr Jun Steinfurth Tel: (02) 9586 1057

National Continence Helpline

Freecall: 1800 330 066
Monday – Friday 8am – 8pm

Paraquad – Tel: (02) 8741 5600**Sanicare – Tel: (02) 9437 9611**



Northcott's FAMILY FUN OPEN DAY

Sunday March 16, 2008

08



The Parramatta Eels
Face painting
Family entertainment
Showbags

WSFM live cross overs
Free BBQ
Prize Wheel
Seminars

Northcott's Family Fun Open Day
10:00am - 3:00pm
The Northcott Building
1 Fennell Street, North Parramatta

Media Sponsor



The Northcott Building - 1 Fennell Street, North Parramatta 2151
Phone: (02) 9890 0100 Fax: (02) 9683 2827 Web: www.northcott.com.au