

Spina Bifida Awareness Week 2008

A healthy, folate rich breakfast at the Northcott Building in North Parramatta marked the beginning of Spina Bifida Awareness Week on Monday, 1 September 2008.

Spina Bifida Awareness Week is held across NSW each year from September 1-7 and raises awareness of spina bifida within the Australian community. The Northcott Spina Bifida Group uses the week to highlight the ability and achievements of people living with spina bifida and to remind the community about the importance of taking folate before and during pregnancy.

The official 2008 Spina Bifida Awareness Week Ambassadors, Linda Thomson and Emilie Lacoba, and the Northcott Spina Bifida Group mascot Spinasaurus travelled across NSW to educate the community about the condition.

The week included visits to John Hunter Hospital, Sydney Children's Hospital, Castle Hill Library, Camden Play Links, The American International School, Fairfield Public School and a regional visit to Kurrajong Early Intervention Service and Tarcutta Public School in Wagga Wagga.

The week also introduced the newly developed "Moving On" Spina Bifida Transition Resource, a resource that will provide information and contacts to support young adults with spina bifida who are leaving paediatric services and will now need to negotiate the adult world.

The resource, which has been developed by Northcott in conjunction with the Spina Bifida Clinic at The Children's Hospital at Westmead, will initially be trialled by young people and adults with spina bifida who are transitioning from paediatric services

and clients with spina bifida who access Northcott's Adult Outreach Team.

Spina bifida is the second most common childhood physical disability in Australia. In Australia each year, one in 1,000 pregnancies are affected by a neural tube defect such as spina bifida (The Australian Spina Bifida and Hydrocephalus Association).



Fun in the park... Linda Thomson (left), Emilie Lacoba (right) and Spinasaurus with children from Northcott's Camden Play Links group.

Message from the CEO

Dear Friends,

2008 is, in many ways, proving to be a positive year for people with disabilities and their families in New South Wales and the ACT and I am very excited that Northcott will be able to offer services to more clients and carers as the year unfolds.



The NSW budget in May 2008 confirmed the Government's support of increased services for people with disabilities through the 'Stronger Together' program, and Northcott has already begun working on submissions to offer new programs in metropolitan, rural and regional areas of the state. We will keep you informed of these as they develop.

In addition, and even more exciting in many ways, on 17 July 2008 the Australian Government ratified the United Nations Convention on the Rights of Persons with Disabilities, which has the aim of promoting, protecting and ensuring the human rights and fundamental freedoms of people with disabilities. Northcott, which has always worked with the purpose of building an inclusive society, fully supports this move, and we hope it will mean much greater recognition of the rights of our clients and

more opportunities for them to participate as fully as they wish in society.

I would also like to offer my special thanks in this edition of Northcott News to the many people who work tirelessly to raise funds for Northcott so that we can continue our work. I have been fortunate to meet many of the active fundraising groups which support us, and to attend some of the wonderful events they organise. I expect to meet all fundraising groups as time goes on. These people are motivated by passion for their local communities and for the services offered by Northcott to those who need them. I thank them whole heartedly.

As you may know, some 60% of Northcott's funding comes from Government contracts, while the rest needs to be raised in a variety of ways. Many of the services we offer would not exist, or would be much more spartan, without the support of the fundraising groups.

Please don't hesitate to contact me if there is any issue you wish to raise with me.

A handwritten signature in black ink, which appears to read 'Kerry Stubbs'. The signature is fluid and cursive, with a large, sweeping flourish at the end.

Kerry Stubbs
Chief Executive Officer

New services

Northcott has been successful in securing funding from the NSW Department of Ageing, Disability and Home Care to begin five new services:

Tamworth Comprehensive Support Networks Program

Northcott will establish support networks for children, young adults, parents and siblings. Support groups, family days, camps and communication forums will be held, with the aim of linking people and developing supportive networks.

Younger People in Residential Aged Care Program

This new service supports people with disabilities under 50 years old who are living in a residential aged care facility in the Riverina and Orana Far West.

Macarthur Wingecarribee Therapy Transition Project

This new service provides an occupational therapist, speech therapist and physiotherapist to assist children with disabilities and their families in their transition to mainstream school.

Aboriginal Intensive Family Support

In the coming months Northcott will be setting up an office in Moree, from which the new Aboriginal Intensive Family Support service will operate, providing short-term and intensive support to families who are experiencing crises.

Leisure Links - Cumberland Prospect and Orana Far West Program

This new initiative will support people with disabilities to access the community and pursue hobbies, sports and other leisure and recreational activities.

Relax and retreat

Girls with disabilities in Coffs Harbour enjoyed four fun-filled days during 7-10 July 2008 as they retreated to Korora as part of the Coffs Harbour Girls' Respite Camp 'Banana Coast Breakaway', funded by Newcastle Permanent Charitable Foundation.

Four girls attended the camp, taking part in many enjoyable activities including bowling, trips to the movies, shopping, swimming, cooking, make-up and facials, and jewellery making.

Liz Forsyth, Acting Regional Team Leader, said the respite camps are important in providing independence to children with a disability as well as time out for their parents.

"Respite camps provide the children with some time out from their families, as well as some valuable respite for their parents," Liz said. "It allows the children to have some fun socialising among other children with similar abilities."

Coffs Harbour runs boys' and girls' respite camps several times a year and mothers' and fathers' retreats annually. For further information please contact Liz Forsyth on (02) 6651 2366.

Northcott opens its doors in Queanbeyan

Children and adults with disabilities and their families in the Queanbeyan area now have access to dedicated disability services with the launch of Northcott Disability Services' new office in Queanbeyan on 30 June 2008.

CEO of Northcott Disability Services, Kerry Stubbs, officially opened the Monaro Street premises, which will house three Northcott Disability Services programs, including the National Disability Coordination Officer (NDCO) program, Support Coordination for Older Parent Carers and the Respite for Older Carers program.

Northcott Disability Services Queanbeyan office will provide up to one million dollars in direct support to people with a disability and their families in the Southern Highland region over the next two years.

For more information on any of these programs, please contact Paul Norris on (02) 6279 6899.

ECAT: Focus on the regions

Children aged 0-6 years with disabilities and their families, carers, teachers and therapists who live in regional areas of NSW will receive information, support and training regarding assistive technology options thanks to the Early Childhood Assistive Technology (ECAT) Project.

Assistive technology options for young children can range from augmentative and alternative communication systems such as symbol based communication books or voice output devices, to alternate computer mice and keyboards, switches and early learning software.

Debbie Fraser, Director and Early Special Educator of the Kempsey Early Intervention Program, knows the difficulty children and families in regional areas face when accessing assistive technology and is pleased that the ECAT Project addresses these concerns.

"Children and their families will normally have to travel to Sydney to access training and assistive technology options such as the ECAT Project," Debbie said. "Having a speech pathologist and occupational therapist conduct free screening assessments and training on-site provides families with the opportunity to reduce the time and cost involved in travelling to metropolitan areas."

ECAT will be visiting Wagga Wagga, Albury, Dubbo, Mudgee, Newcastle, Armidale, Glen Innes, Inverell and Nowra later this year.



Assisting communication... Northcott client Holly Sultana explores her communication options.

2008 Spina Bifida Awareness Week Ambassadors

Northcott Disability Services selects a client with spina bifida to be an Ambassador for Spina Bifida Awareness Week each year. This year Northcott has selected two Ambassadors, Emilie Lacoba and Linda Thomson.

Emilie Lacoba

What do you do?

"I am 20 years old and I am a social work student at the University of New South Wales. However, I have just taken a year off to work, travel, enjoy life and search for opportunities to further my career as a social worker."

How has Northcott Disability Services helped you?

"Most recently Northcott helped me by funding a mini computer for me to take to university. My spina bifida means that I live with chronic pain. This becomes worse when carrying heavy books, so the mini computer helped greatly. My grades have improved and it has made attending university a much more enjoyable experience."

Linda Thomson

What do you do?

"I am 26 years old and I am a full-time mum. I live in Dapto, Illawarra.

I deferred my study of a Bachelor of Psychology at Wollongong University when my son Reilly arrived in October 2007 so I could focus on caring for him."

How has Northcott Disability Services helped you?

"Northcott helped me most recently when I was pregnant with Reilly. Northcott's Illawarra Case Management service linked me to services I really needed such as housecleaning, transportation and the temporary use of a wheelchair. These services helped me remain independent and meant I was not constantly relying on my family and friends to support me."



Spreading the word... [L to R] 2008 Spina Bifida Awareness Week Ambassadors Linda Thomson with her son Reilly and Emilie Lacoba.

United in fun

A day of fun, food and friendship was held on Friday, 18 July 2008, attended by 18 children from kindergarten to year six who have brothers and sisters with disabilities, as part of Northcott's annual Siblings Fun Day.

An Olympic theme resonated on the day, with the children divided into countries to compete in shot put (with bean bags), javelin (with paper planes) and tug-of-war. Craft activities including mask making and flag making were also undertaken and lunch was a banquet of international food, which the children helped to prepare.

Peter Garran, Team Leader of Northcott's Early Childhood Support Service, said that Siblings Fun Day supports siblings of children with disabilities.

"Siblings Fun Day acknowledges the importance of these children in their own right and in their families and reassures them that they are not alone; there are other children with a brother or sister with a disability," Peter said. "Through fun and games the children were able to understand that there are

other children who share similar experiences and feelings."

For further information on Siblings Fun Day please contact Peter Garran on (02) 9890 0929.



A day of fun... Children from Northcott's Siblings Fun Day show off their artistic creations.

Northcott hits the slopes

Children with disabilities who use Northcott's Recreation service hit the slopes at Thredbo during 6-11 July 2008, as part of Northcott's annual Ski Camp.

Northcott's affiliation with Disabled Wintersport Australia ensured that professional instructors and lessons were provided for the week, with support and adaptive ski equipment provided to cater for all levels of ability.

Mitch Taylor, Team Leader of Northcott's Recreation Service, said that the ski camp is a unique opportunity for children to take part in a sport that they are often unable to participate in because of their disability.

"There are not many opportunities for children with disabilities to access sports such as snow skiing," Mitch said. "Northcott's Recreation Service often provides the only opportunity for many children to take part in sports like this."

Northcott's Recreation Service runs camps for children and adults with a physical disability throughout the year.



Taking the plunge ... Madison Marsh hits the slopes with her instructor.

Karingal Respite celebrates 20 years

Karingal Respite House, Northcott's centre-based respite service at North Rocks, celebrated its 20 year anniversary on Saturday, 12 July 2008 by hosting an open day to introduce children with disabilities to the experience of respite.

Karingal Respite House first opened on 6 August 1988 as a children's respite house and continues to provide families and carers with a break, as well as an opportunity for children with disabilities to meet friends and experience social activities.

Adel Ayad, Karingal House Manager, said that for many children, leaving the family home to attend respite is an overwhelming thought.

"It is important that children are gradually introduced to the experience of respite, so they feel comfortable in a new house with different people," Mr Ayad said. "Leaving their families for the first time can be intimidating for some children."

Karingal Respite House is open for respite on weekends during the school term and 24 hours a day during school holidays.



Open house... Brad Seymour gets a creepy crawly painted on his hand.

Beverly Park Residential Service celebrates 20 years

Northcott Disability Services' Beverly Park Residential Service celebrated 20 years of the established community house on Wednesday, 17 September 2008.

The doors to the current residential service were officially opened in 1988 by the Minister for Health, Peter John Collins AM. Today, Beverly Park Residential Service comprises five villas that have

been designed to provide maximum independence for people with a range of disabilities.

Dignitaries who joined the residents and staff in the celebrations were the Minister for Ageing, Disability Services and Aboriginal Affairs, the Hon. Paul Lynch MP and the Minister for Juvenile Justice, Volunteering and Youth and Member for Campbelltown, The Hon. Graham West, MP.

Help us celebrate Northcott's 80th birthday

Northcott Disability Services is celebrating its 80th Birthday in 2009 and we are looking for people who are interested in joining a client committee to plan events in the Sydney Metropolitan area. We would love the involvement of a range of clients of different ages and nationalities, including parents and carers. **Please contact Roxanne on (02) 9890 0170 to express your interest.**

Northcott's International Day of People with Disability celebrations

Northcott will be hosting International Day of People with a Disability celebrations in partnership with Parramatta City Council at Parramatta Town Hall on Tuesday, 2 December 2008. **For further information on events planned for the day please visit our website: www.northcott.com.au.**

Newcastle Permanent Charitable Foundation supports children with disabilities

Northcott Disability Services has recently benefited from a \$35,000 grant from Newcastle Permanent Charitable Foundation, with the funds used to run respite camps organised for children with a disability from the Mid North Coast region.

Northcott's General Manager, Client Programs, David Bate, welcomed the much needed grant, acknowledging the need for respite and the support

provided by the Newcastle Permanent Charitable Foundation.

"Respite is very important to both the children with a disability and their carers," Mr Bate said. "It is very pleasing to know Northcott clients and their families in the Mid North Coast community will continue to have access to respite thanks to the Charitable Foundation."

Women in sport inspire

Some of Australia's most influential sportswomen gathered over breakfast on Wednesday, 8 October 2008 at Rosehill Gardens Race Course to help support children and adults with a disability, as part of Northcott's Women in Sport breakfast, sponsored by GHD.

130 guests were captivated as an expert panel of influential female sporting legends, including softball player and four-time Olympic medallist Natalie Ward, cyclist and Beijing Paralympics bronze medallist Jayme Paris and three-time Paralympian and runner Amy Winters OAM discussed 'The Business of Sport' under the experienced direction of Australian swimming champion Nicole Livingstone OAM, Master of Ceremonies.

The goal of the event was to raise money to purchase four children's wheelchairs for Northcott's Equipment Loan Pool, a service that provides a range of wheelchairs and equipment available for loan to children and adults with disabilities across NSW.

Northcott currently has enough funds to purchase one wheelchair and is working towards a goal of

purchasing the four children's wheelchairs required.

Northcott Disability Services Women in Sport Breakfast raised \$7,166 and was proudly sponsored by GHD, Rosehill Gardens Event Centre and Roses Only.

To help support this wheelchair campaign, please donate online by visiting www.northcott.com.au or contact Michael Johnson on (02) 9890 0100.



Inspirational... [L to R] Jayme Paris, Julie Charlton and Nicole Livingstone OAM.

FEEDBACK To share your opinions or suggestions for improvement, or if you no longer wish to receive this newsletter, please contact Roxanne Martinenko on (02) 9890 0170 or email pr@northcott.com.au.