



THE SCENE - No. 12 – 7 August 2006

Welcome to The Scene - the eNewsletter from The Spastic Centre.

The Scene features news, events, issues, links and contacts of interest to people living with cerebral palsy, their families and service providers.

Your feedback and suggestions are welcome. Email rcummins@tscnsw.org.au at The Spastic Centre.

FEATURES

CP Awareness Week 2006



We hope you're enjoying some of the activities during CP Awareness Week 2006. People in Sydney will notice banners along roadways across the city and flags flying around the CBD. View the entire calendar of exciting events at www.thespasticcentre.org.au/news/cpweek_06.htm

Presentation by Dr Stephen Back

On 7 August 2006, Dr Stephen Back from the Oregon Health and Sciences University spoke at The Spastic Centre about his pioneering research into the causes of brain injury in premature infants. Dr Back's informative presentation provides fresh thinking for research into cerebral palsy and the hope that in the future some brain injury may be at least partially reversible. You can download slides and an audiocast of his presentation from The Spastic Centre's podcasts page at www.thespasticcentre.org.au/about_cp/podcasts.htm

CP Register

13,300 people with CP are missing! The NSW CP Register is a confidential database of information about people with cerebral palsy. At the moment, we only have 700 registrations and yet we estimate that there are 14,000 people with CP in NSW.



Piecing together the facts on Cerebral Palsy

It's absolutely vital that everyone with CP is counted, as information from the register will be used to support vital research into the causes and prevention of cerebral palsy. It will also be used to determine the types of services that are needed across the state.

Please help! All details are strictly confidential. You can register online at www.cpreregister-aus.com.au or phone Sarah McIntyre on 02 9975 8239.

More details at <http://www.thespasticcentre.org.au/services/cpreregister/index.htm>

PARENTS

Free Information Session on Family Care

A parent's journey of providing lifelong care for a son or daughter with a disability is often a rollercoaster ride of joys and challenges. Terry Ryan, parent, author and presenter, offers a framework and practical information on

decisions to be made and strategies for reaching peace of mind, in free information sessions to be held throughout September.

The series is hosted by The Spastic Centre and are all parents with concerns about the future for family relationships, supported care arrangements, and short and long-term planning.

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Locations: The Spastic Centre

Ryde Monday 11 September - 10am to 12 noon - 3a Smalls Road

Allambie Hts Thursday 14 September - 10am to 12 noon - 189 Allambie Road
(Head Office Boardroom)

Prairiewood Wednesday 27 September- 7pm to 9pm- 224-244 Restwell Road



Refreshments will be available. Childcare is available only on request – minimum five days notice please. Bookings are essential. RSVP to Penny Clarke, Community Development Unit, Phone 02 9975 8227 or email pclarke@tscnsw.org.au. (Please advise Penny if you would like your name on the mailing list for future flyers).

OUT & ABOUT

Wheelpower – How One Man’s Vision Became Reality



Woollahra Council's Access Committee invites you to Wheelpower – how one man’s vision became reality. Listen to motivational speaker, Brett Falkner and enjoy a drumming workshop by Andrew Hewitt.

The workshop will be held at Woollahra Council Chambers on 23 August 2006 from 4.30 to 6pm and is free.

Light refreshments will be provided. For more information or to RSVP, contact the Council’s Aged and Disability Officer by 18 August on 02 9391 7957.

For further information on the Access Committee, contact the Aged and Disability Development Officer on 02 9391 7957 or email naomi.polivis@woollahra.nsw.gov.au

Ku-ring-gai Wildflower Garden

The picturesque Ku-ring-gai Wildflower Garden is a bushland haven on the outskirts of St Ives on Sydney’s North Shore.

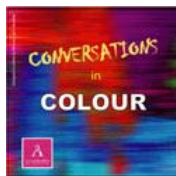


A new, large undercover shelter is now available for family and groups at ‘Dampier’s Clearing’ within the garden. It has a southern side panel (to protect against cold winter winds) and 40 high backed movable chairs with arm support. The new development also includes barbeque facilities (with a sink and outdoor power point), accessible toilet facilities and the ‘Senses Track’ - a level 260-metre wander through tall open woodland. The Senses Track is a unique bushland experience, specially designed for use by wheelchairs and strollers.

The Ku-ring-gai Wildflower garden is at 420 Mona vale Rd, St Ives (entrance on left as you head out of St Ives towards the St Ives Showground). Entry is free and opening hours are from 8am-4pm 7 days a week. For more information, phone the Ranger on 02 9440 8609.

For further information visit <http://www.kmc.nsw.gov.au/go/facilities/ku-ring-gai-wildflower-garden>

ARTS



Conversations in Colour Exhibition - Miroma Paddington - September

Miroma's annual art exhibition, Conversations in Colour, is coming your way this September so there is loads of time to organise yourself, your friends or a group to attend! This year it will be held at The Stone Gallery Paddington (Paddington Markets, Oxford Street) to be opened on Saturday 2 September at 6pm.

Conversations in Colour will encompass a broad range of abilities in two-dimensional form and most of the works will be for sale. The exhibition will also be open for viewing all Saturdays in September from 10am to 3pm and on Thursday 14 and 28 September between 10am and 2pm. The venue is wheelchair accessible and has accessible toilets.

For further information contact Miroma on 9337 5167 or email enquiries@miroma.org

Signature of Sydney - Call for Artists with Disabilities!

The Signature of Sydney is offering free entry to the 2006 competition for artists with disabilities. The Signature of Sydney is Australia's largest art prize with 1st prize of \$150,000. This is your chance to show what you can do and reflect who you are. They are looking for the artwork that captures Sydney in 2006 - its lifestyle, diversity and magic attractions, and creates a moment in time.



When making enquiries/submission, please quote that you were invited through Accessible Arts. Deadlines are 4 September 2006 for registration and 16 September 2006 for concept submission.

For more information and to obtain an application form email arthur.chan@project005.com.au or phone 02 90061104.

RESEARCH AND INTERVENTIONS



Neurotoxins and CP Online Seminar

The most recent EP LiveOnline seminar, 'The Team Approach to Assessment and Treatment of Spasticity Including Surgical Interventions' is now available to view on the EP website. This seminar was the fourth in a series on the effective treatment of spasticity using neurotoxins, as well other treatment interventions - including surgery - for conditions including cerebral palsy.

Guest presenters included Drs Tom Novacheck and Hank Chambers on surgical interventions for the treatment of spasticity such as Intrathecal Baclofen (ITB Therapy), Selected Dorsal Rhizotomy (SDR); orthopedic surgery and others. Dr Chambers presented a case study that led to a roundtable discussion that included Drs Marc DiFazio and Barry Russman.

The recording of Session 4 and associated documents are now available at <https://services.choruscall.com/links/ep060726.html>.

The next EP LiveOnline Seminar: The Efficacy and Safety of Hyperbaric Oxygen Therapy in the Treatment of Cerebral Palsy, Traumatic Brain Injury and Autism Spectrum Disorders will be held on 13 September 2006 at 7pm US EDT (Australian Eastern Time - Thursday 14 September 2006 at 9am). Register at <http://www.vemics.com/eplo2/eplive-program4.html>

HEALTH & WELLBEING

Osteoporosis

People with a developmental disability such as CP are at increased risk of osteoporosis and it occurs at a much earlier age than in the general population. The reported prevalence varies, but one study of adults aged between 40 and 60 years who are living in the community, found that 21% have osteoporosis and 34% have osteopenia. The risk factors increase with age and include impaired weight bearing, impaired mobility, small body weight and impaired nutritional intake. These are all risk factors associated with CP. ⁽¹⁾ Screening is very important, so please remind your GP that it can be an issue.

There are many preventative steps that can be taken. Find out more about Osteoporosis and Osteopenia on the Healthinsite website at <http://www.healthinsite.gov.au/topics/Osteoporosis>

The Disability Health Institute Clearinghouse has information about Osteoporosis in multiple languages. Find it at <http://www.dhi.gov.au/clearinghouse/Resources.htm> .

⁽¹⁾ 'Management Guidelines: developmental disabilities', version 2, 2005, Therapeutic Guidelines, Melbourne, Vic

CONFERENCES .. WORKSHOPS .. FORUMS People with Disabilities/Families/Carers

A Carers Forum and Sibling Workshop - Caring for the Carer

Lismore - 19 August 2006

Lorraine Hodgeson, Genetic Counsellor Intake Manager, Dept of Ageing, Disability & Home Care is holding a workshop on Caring for the Carer on 19 August 2006 from 10am to 4pm at Invercauld House, 161 Invercauld Rd, Goonellabah (near Lismore).

Topics include:-

- Panel of services; to be confirmed but may include Centrelink, Department of Education, Post School Options
- Local carer issues and support networks
- Personal experiences of carers
- Looking after yourself as a carer

For more information contact Rachel Spencer on 02 9697 9111 or email carers@mdansw.org

Sibs Workshop

Lismore - 19 August 2006

A workshop for siblings (brothers and sisters) of people with disabilities, genetic conditions or special needs. The workshop will give siblings an opportunity to meet other young people in similar situations in a relaxed and fun setting, talk about the positives and negatives of living with someone with special needs and a chance to share stories, strategies and ideas with others who understand.

The workshop will be held on 19 August 2006 from 10am to 4pm at Invercauld House, Goonellabah (near Lismore) and runs in conjunction with a carers forum. Lunch, drinks and snacks will be provided.

For more information contact Rachel Spencer on 02 9697 9111 or email carers@mdansw.org.

The First Richard Lavoie National Australian Tour

From 23 August 2006

Australian Federation of SPELD Associations is sponsoring Richard Lavoie, recognised expert on learning difficulties and popular international speaker on a tour in NSW throughout August/September.

- Liverpool, 23 August - one session 4pm to 6.30pm at the Catholic Club, Hoxten Park
- Chatswood, 26 August - two sessions, 9am to 12.30pm and/or 2pm-4.30 at the Willoughby Civic Centre
- Wagga Wagga, 29 August - one session, 4pm to 6.30pm at the Charles Sturt University
- Newcastle, 2 September - one session, 10am to 12.30pm at the University of Newcastle
- Wollongong, 4 September - one session, 4.30pm to 7pm at the University of Wollongong

Registration includes arrival refreshment and certificate of attendance as required. SPELD NSW member/nonmember: single session \$70/\$80, full day (2 sessions) \$125/\$145; Student/conc/senior (validation required) single \$60, two sessions \$100; group (of 10+) \$60pp one session / \$100pp for full day.

For further information visit or www.auspeld.org.au/2006_lavoie_tour.html or email enquiries@speldnsw.org.au.

Forum on Employment Rights Sydney CBD - 21 September 2006

A forum hosted by the City and Inner West Disability Advocacy Service will discuss how the Workchoices law may affect you, what you can do if your employer discriminates against you at work and whether you may be affected by the new Welfare to Work legislation. Guest speaker Ben Fogarty is Principal Solicitor, Disability Discrimination Legal Centre. The forum will be held on 21 September 2006 from 5pm to 7pm at Sydney Mechanics School of Arts, 280 Pitt Street, Sydney (venue is wheelchair accessible). Refreshments will be provided and the forum is free of charge.

For further information and to RSVP contact Elizabeth or Sophia on 02 9212 2048 or 02 9212 2020. Please RSVP by 15 September 2006.

SERVICE PROVIDERS

25th Anniversary International Day of People With a Disability (IDPWD)

Be involved in the 25th Anniversary of IDPWD by increasing access for people with a disability to your arts program or event on or around the 3 December 2006.

Accessible Arts coordinates the arts program for IDPWD each year and are inviting arts and disability organisations to offer further access for people with a disability to the arts and creative opportunities. By becoming involved your event will be included in the statewide program of over 110 events.

For an Expression of Interest Form or to find out more, contact Alison by phoning 02 9251 6499, faxing 02 9251 6422 or emailing amclaren@aarts.net.au

Supporting Communication Through AAC (Alternative and Augmentative Communication)

Communication is a basic human right, a need and a critical part of learning. For some people, communicating through speech is difficult, or slow to develop. Many people now use Alternative and Augmentative Communication (AAC) systems. These systems supplement or support the spoken element in communication. There are different vocabularies and languages from which to choose, so the individual can use the most appropriate system.

'Supporting Communication Through AAC' from Scope (UK) aims to help parents, teachers and professionals to support individuals who may benefit from using AAC. Each of its 12 modules stands alone and addresses a specific topic or a particular group of users.

Download this package at www.scope.org.uk/education/aac.shtml

A Lot to Say

'A Lot to Say' from Scope (UK) is a guide for social workers, personal advisors and others working with children and young people with communication impairments. It will be of use in a number of settings – health, social services, education, and private and NGO sector agencies. It is aimed at professionals who are not specialists in communication impairments, but who have responsibilities to assess the needs, and seek the views, of this important group of children and young people.

Download it in PDF format at www.scope.org.uk/downloads/action/publications/lotsay.pdf

The Good Practice Guide

'The Good Practice Guide' is another Scope (UK) publication for support workers and personal assistants working with disabled people with communication impairments.

Download it in pdf format at www.scope.org.uk/downloads/action/publications/goodpractice.pdf

NSW Multicultural Health Communication Service

NSW Multicultural Health Communication Service (MHCS) provides information and services to assist health professionals to communicate with non English speaking communities throughout NSW. The NSW Department of Health funds the Service, and endorses the multilingual health information published on the website. MCHS has a new website with over 450 publications on health in a wide range of languages.

Find it at www.mhcs.health.nsw.gov.au

Teaching Children with Sensory Impairments Strategies for Mainstream Teachers

Dolly Bhargava and Ylana Bloom, Speech Pathologists (AAC Consultants) with Innovative Communication Programming have co-authored two handbooks on inclusion of students with vision or hearing impairments in mainstream classrooms. It is now available online for free.

To download the handbooks visit <http://www.trinity.edu/org/sensoryimpairments/>

CONFERENCES .. WORKSHOPS .. FORUMS - Service Providers

Dystonia Management in Cerebral Palsy

10 August 2006

The Rehabilitation Department of the Children's Hospital at Westmead invites you to attend a workshop on dystonia management in CP, presented by Dr Mary-Clare Waugh (Staff Specialist) and Ruth Evans (Senior Occupational Therapist).

The workshop will be held on 10 August 2006 from 2.30pm to 4.30pm at Lorimer Dodds Lecture Theatre, Level 4, Children's Hospital at Westmead, Cnr Hawkesbury Road and Hainsworth St, Westmead. Entry is free. Target audience is hospital medical staff, occupational therapists, orthotists, paediatricians and physiotherapists working with children with cerebral palsy.

Please note this workshop is a repeat presentation from the Australasian ACPDM meeting in Adelaide in March 2006. No handouts will be available on the day. Presentation will be emailed prior (without videos). For further information and to RSVP Ruth Evans phone 02 9845 2854 or email ruthe2@chw.edu.au.

ACROD NSW Annual Conference 2007: Disability Services - What's Next?? - Call for Papers

19-20 February 2006

ACROD NSW's annual conference in 2007 will examine short to medium-term current issues across the sector, within the framework of initiatives such as DADHC's 10-Year Plan; the Productivity Commission's Report on Government Service Delivery; the NSW Ombudsman's Disability Monitoring; and the Commonwealth/State/Territory Disability Agreement (CSTDA). The conference will be held at Novotel Brighton-Le Sands, Sydney on 19 and 20 February 2007.

ACROD NSW invites presentations that focus on at least one of the following topics and address the question 'What's Next?' | Access | Accommodation support | Advocacy | Ageing and disability | Children and family | Community Participation & other day programs | Diversity | Employment & Transition | Equipment | Information | Respite

ACROD NSW is calling for abstracts from those wishing to present papers on conference themes. Abstracts, up to 500 words in length and in the approved format, must be submitted by 12 September 2006

For submissions queries and conference enquiries contact Damien Anderson, Deputy Executive Officer, ACROD NSW Division on 02 9503 1602 or email damien@acrodsw.net or visit <http://www.acrodsw.net/Resources/ACROD%20Seminars.html>

NovitaTech Tour 2006 – Sydney

19 September 2006

This day will introduce the range of assistive technology products from NovitaTech, including many new products. The venue is The Northcott Society, 1 Fennell Street, Parramatta on 19 September 2006 from 9am to 4.30pm.

RSVP to Glad Greco on 1300 85 55 85 or assistanvetech@notita.org.au by 8 September. For more information visit <http://www.novitatech.org.au/content.asp?p=537#sydney>

2006 Feeding Conference – Feeding through Life’s Stages

6 October 2006

The Paediatric Feeding Interest Group together with the Dysphagia Clinic at The Children’s and Adult’s Hospitals at Westmead is hosting the 2006 Feeding Conference – Feeding through Life’s Stages. The will be presented by a number of specialists in the area of dysphagia & nutrition. There will also be trade displays and plenty of networking opportunities on the day! Register early as numbers are limited.

The workshop will be held St George Hospital, Research and Education Building, Belgrave Street Kogarah from 8.30am to 4.30pm on 6 October 2006. The cost is \$50. A raffle will also be held on the day with great prizes. Snacks, drinks, tea, coffee, and lunch will be provided on the day.

For further information contact Lenore Scali on 02 9350 1779 or email lenore.scali@sesiahs.health.nsw.gov.au

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FOR SALE

Shoprider

Shoprider 4 wheel scooter, approx 4 yrs old, charger, front carrier basket and shopping carrier at rear, swivel adjustable seat, grey upholstery, full dust cover, excellent condition. \$2000 (new price \$5000 +).

For further information contact Margaret 0402 461 248 or email mayesfam@swiftdsl.com.

Wheelchair Accessible 1994 Ford Falcon



This wheelchair accessible Ford Falcon 1994 LPG is automatic and has air conditioning, reconditioned engine 6700kms, registration until December 2006. Rego number AB-16-QL.

Asking price is \$10,000 or reasonable offer is negotiable.

For further information contact Lubica on 02 9546 1752 or mobile 0400 883739. The car is currently garaged in Blakehurst.



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Disclaimer

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take no responsibility for the information published in this newsletter or any person's actions in reliance on that information.

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What would you like to see in "The Scene"? Contact Robyn, Phone 02 9975 8251 Fax 02 9451 4877, Email rcummins@tscnsw.org.au if you would like to contribute any ideas, advise of any future events or know of any websites that might be of interest to others.

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