



what's

the buzz

NEWSLETTER



APRIL 2010 Edition No.16



CEREBRAL PALSY
SUPPORT NETWORK
strength through connection

&



my
connected
community

mc2.vicnet.net.au

The CPSN has many and varied requests for information and service. Although we spend extensive time on every request for answers we receive, often we find it difficult to provide all the answers. Thankfully we know two very important pieces of information 1) We have an abundance of knowledge on all things Cerebral Palsy across our member database, and 2) when people who have information, can share, they usually do.

With these two important pieces of information in mind and the support of My Connected Community (mc2), the Cerebral Palsy Support Network now has a blog, forum, chat page. We would like to invite all our members', friends and families to join our site. Unlike social networking sites, this is a members' only, secure site where families and individuals are encouraged to ask questions and discuss all facets of life. The Cerebral Palsy Support Network feels members' services that utilise technology are a vital link to not only those families that are comfortable with asking the questions, but also those families who are not quite at that stage of the experience but require valuable first hand information.

Here is a little information on what the mc2 is all about

The main objective of mc2 is to encourage community groups located in Victoria (Australia) to create their own online communities. mc2 offers participating groups a variety of free, easy to use Web-based services which they can use to communicate with existing members & like-minded communities across the world. Online groups created at this site must be community

based groups. Community based groups include special interest groups such as sporting clubs or hobby groups, support groups, not-for-profit organisations, local government entities, state government agencies and peak bodies.

At mc2 you can...

- join an online community of your choice
<http://mc2.vicnet.net.au/help/join.html>
- create your own online community
- interact with others of similar interests
 - have your say in a live chat room
 - make your mark in a guestbook
- participate in forum discussion with other members
- check out the calendar of community events
 - make your voice heard by voting in an online poll
- visit recommended sites on your favourite topic - just follow the links

We will be contacting members in the next few weeks to personally invite them to join this site but if you're interested, now go to <http://mc2.vicnet.net.au> and register, then search Cerebral Palsy Support Network. We will be adding some genuine member's questions in the forum section for you to comment and assist if possible.

CALENDAR OF EVENTS

APRIL / MAY 2010

(School Holidays 27/3-11/4)

APRIL

Wed 14th - Parent Support Group, Broadmeadows
(Note change of address - now no longer in school holidays)

Wed 21st - Parent Support Group, Sandringham

Wed 28th - Parent Support Group, Greensborough

MAY

Tues 4th - PARENT/CARER INFO SESSIONS

**Topic: "DEVELOPMENTAL DELAY -
What does this mean for our child and family?"**

Speaker: Dr Bronwyn Cathels, Consultant Paediatrician, RCH

Time: 7.15pm - 9.30pm

Location: The Department of Developmental Medicine,
Royal Children's Hospital

Tues 11th - RCH SEMINARS (2 TOPICS)

**Topic 1: "Cerebral Palsy -
Early Intervention Techniques to Maximise Ability"**

Speakers: Ms Lucy Lorifice, Physiotherapist; Ms Kathy
Newton, Occupational Therapist, RCH

Topic 2: "Supporting Families With Cerebral Palsy"

Speaker: Ms Di Cunningham, Cerebral Palsy Support Network

Time: 7.15pm - 9.30pm

Location: Ella Latham Theatre, 1st Floor Main Building,
Royal Children's Hospital, Flemington Rd, Parkville.

Cost: \$15 per head per session or \$25 for 2 family members
attending same session together.

Queries: Phone 03 9345 5898/5692 or email:
education.seminars@rch.org.au

Wednesday 12th - INFORMATION FORUM

(Note change of date and time)

**Topic: "16+ WHAT NOW - As a parent, how do you
support your child to fit the pieces of the puzzle of the
adult disability service system together?"**

Time: 6pm - 9pm

Location: Northcote Town Hall, 189 High St, Northcote

Speakers: We are excited to have secured speakers from
Northern Support Services for information on Transition to Work
and Centrelink. We are finalising a speaker on Futures For Young
Adults Transition from the Department of Human Services.

Queries: For further information, contact Kim or Di at the
CPSN office on 1300 277 600.

We will still look for
your answers too!!

KIMBERLEY'S STORY



At the CPSN, we are always more than happy to be the personal voice on the end of the phone and we have had some very exciting outcomes for our members. Here is Kimberly's journey with us.

Hi, my name is Kimberly and I am 21 years old. The Cerebral Palsy Support Network has helped me get my life back on track. When I met Kim from the CPSN, I was in unsuitable accommodation and she helped me find a better place to live. When I was knocked back by numerous housing organisations she was a great emotional support. When the house I eventually got wasn't ready in time she raised the roof to make it happen! The help she provided so I could pay for a removalist meant I had money to eat on the fortnight I moved in. Now that I have settled in my new house and I've got confidence in my ability to maintain a reasonable standard of living, I have gone back to study and am currently enrolled in year 11 VCE at Adult Education... and I am loving the challenge! This would not be possible without the support of CPSN as they worked to help me organise funding for school books and with costs of repairs to my wheelchair. I can't thank Kim and the other staff for the support I've received and I hope they are able to continue their great work so that other people can have the same opportunities as me.

Kimberly Christie-Henderson

BONE MARROW DONOR INSTITUTE CORD BLOOD BANK



The current use of Cord Blood

Umbilical cord blood (CB) is the blood that can be obtained from the placenta and the umbilical cord following the birth of a baby. It is traditionally discarded as a waste product; however it can be easily collected and banked for later use, with no risk to the mother or baby. A CB unit is the term used to describe all of the CB that is obtained from one donor. CB is very rich in blood stem cells and is used instead of bone marrow to treat diseases such as leukaemia, lymphoma, other blood disorders, metabolic disorders and congenital illnesses involving the immune system. CB has the major advantage over bone marrow where, unlike with bone marrow, the tissue typing of the CB cells does not need to be an exact match with the patient. This means that it is usually much easier to find a CB donor than a bone marrow donor. Nearly every person who requires a bone marrow transplant is now able to find a suitable CB donor in one of the many public cord blood banks around the world. There are now more than 400,000 CB units stored in public banks, and more than 20,000 unrelated CB transplants have been performed.

The Bone Marrow Donor Institute (BMDI) Cord Blood Bank operates as a partnership between the Murdoch Childrens Research Institute, The Royal Children's Hospital and the Bone Marrow Donor Institute and is located at The Royal Children's Hospital, Melbourne. It is one of three public cord blood banks in Australia, the others being in Sydney and Brisbane, and is part of the AusCord network of cord blood banks. The AusCord CB banks have released more than 750 CB units for transplant, with one third of them used in Australia and the rest sent to patients overseas. There are many children and adults who are alive today thanks to cord blood provided by the AusCord CB banks.

The potential use of Cord Blood

In addition to the blood stem cells within CB, we know that CB also contains stem cells that can give rise to other tissues in the body, such as bone, muscle and nerves. These other types of stem cells are very rare, and it is not yet known how to reproducibly grow the different types of cells, but it is for this reason that CB is being investigated for use in regenerative medicines. Laboratory studies have shown that CB stem cells injected into animal models are able to migrate to the brain and improve neurological function. A clinical trial by Dr Joanne Kurtzberg at

Duke University in the USA has been investigating the use of autologous (patient's own) CB for the treatment of about 100 children with Cerebral Palsy. The results from this study are so far anecdotal, where parents have reported improvements in movement and speech following intravenous infusion of CB. No clinical or scientific data has yet been published, but reports at medical conferences indicate this approach is safe and feasible. Dr Kurtzberg cautions that there are "some hints that there may be some benefits" but that "it's very, very difficult to successfully assess efficacy."

Based on this preliminary work of Dr Kurtzberg, the Medical College of Georgia, USA is now conducting the first FDA-approved controlled clinical trial to determine whether an infusion of CB can improve the quality of life for children with cerebral palsy. This study will examine 40 children aged 2 – 12 whose parents have stored CB. Children fitting the specified criteria (ie. children unable to sit independently by 12 months of age or unable to walk independently by 18 months of age) will begin the study with a neurological exam. Then, half of the study recipients will receive an infusion of their own CB, while the other half receives a placebo (ie. no CB). Three months later, the children will be evaluated without doctors knowing which group is which. Afterwards, CB will then be given to those who did not initially receive an infusion. Children will be evaluated three and six months later. This study commenced in January 2010 and is expected to be completed by February 2013. The prime aim of the study is to confirm the safety of autologous CB infusion in children with Cerebral Palsy. The secondary aim of the study is to determine if there is any benefit.

A study such as this is currently not available in Australia. However, a group of clinical and scientific research personnel at The Royal Children's Hospital and Murdoch Childrens Research Institute in Melbourne are watching carefully and, through attendance at overseas conferences and maintaining dialogue with international colleagues, are remaining informed as to the progress of these studies. While there is no solid or published evidence yet that infusion of CB really will make a difference to children with Cerebral Palsy, this is clearly an approach worth monitoring.

Dr Ngaire Elwood, PhD - Director, BMDI Cord Blood Bank and Head, Cord Blood Stem Cell Research Program, Murdoch Children's Research Institute, Parkville, Victoria 3052

The Cerebral Palsy Support Network in the Community

Would you like CPSN to come and speak to your friends, school, work mates or peers on what we do as an organisation? The CPSN offers a number of programs to our members including our Teenage Social Group, Parent Support Groups and The Respite Brokerage Program. We would love the opportunity to come and speak to the other important groups in our members' lives. Kim and Di have both presented information sessions on Cerebral Palsy to carers and families in the community and can provide an information package suitable to the needs of your group. This, then, provides the opportunity for those who don't realise what we do the opportunity to ask questions and be involved in the services we provide. Please contact us at the office on 1300 277 600 or email cpsn@cpsn.info if you are interested in having a member of our team come and speak.



DiVine

A community for and by people with a disability

www.divine.vic.gov.au/main-site

DiVine - A Community for and by People with a Disability?

DiVine is an exciting, fun and innovative website written by and for people with a disability.

The site is published by the Victorian Government's Office for Disability in the Department of Planning and Community Development.

DiVine aims to inform, engage and entertain. It is a vibrant, inclusive community that encourages participation. We can all learn from each other, and have a laugh, too.

The website provides the opportunity for you to share your passion and unique perspective with thousands of other Victorians.

One in five Australians have a disability and the wide range of topics covered on DiVine reflects the wide range of interests of people with a disability.

We encourage you to join in the discussion, generate ideas and submit your own articles for publication on the site.

The DiVine website has been designed to meet the "WCAG 1.0 AAA" standard of the W3C (World-Wide Web Consortium).



PREPARE YOUR HOUSEHOLD FOR AN EMERGENCY

The Australian Red Cross has prepared a booklet for people with a disability, their families and carers that recommends four steps to prepare households for an emergency. There are ideas in the booklet to discuss with your family, friends, carers, neighbours and others in your support network to help integrate emergency planning into your lives.

There is a workbook section, ready to fill in with your household's emergency plan details. The booklet also contains assessment sheets and checklists for all steps of the process.

1. BE INFORMED - A household emergency plan lets everyone in your household know what to do in an emergency. Think about where you might go if you weren't able to go home, or had to leave home because of an emergency.

2. MAKE A PLAN - Being prepared in advance can make emergencies less stressful and save precious time. Should you or your household be affected by an emergency, a household emergency plan helps you to be more resilient and can reduce disruption. Establish an out-of-town contact for members of your household to phone if you are separated and record their number in your plan.

3. GET AN EMERGENCY KIT

- Put together an emergency kit with items you may need if you have to evacuate your home in an emergency, or if you have to stay in your home when essential services have been cut off. You can also make up a smaller bag to keep in your car or office. Consider splitting your emergency kit in two - one part with the things to take if you need to leave, and the other with the things that you need to stay in your home. Keep your emergency kit somewhere easily accessible - close to an escape route in your house, or in a shed. Mark your emergency kit clearly, and put some reflective tape on it so it can be seen easily in darkness.

4. KNOW YOUR NEIGHBOURS - Getting to know your neighbours is an important part of preparing your household. People who know each other in their community are more likely to turn to each other for help, and in the long term cope better with crises and emergencies. The best part is that taking time to get to know your neighbours has a range of other benefits too.

For the full Australian Red Cross booklet go to www.redcross.org.au/ourservices_acrossaustralia_emergencyservices_prepare.htm

HEATING & COOLING

concessions

OFF PEAK ELECTRICITY CONCESSION

The off peak concession provides a 13% reduction on the off-peak tariff rates on all quarterly electricity bills.

Eligibility

You must hold at least one of the following concession cards:

- Pensioner Concession Card
- Health Care Card
- DVA Gold Card

Holders of a Health Care Card for Child Disability and Foster Care issued in the name of the child are not eligible.

How to apply

Present your card when paying your account or contact your electricity retailer.

More information

For information contact the Concessions Information Line on **1800 658 521**

FAQ's:

How do I get the concession on my electricity bill?

If you have a concession card (Pensioner Concession Card, Health Care Card or Gold Card) you should contact your electricity retailer or present your concession card when paying your bill.

How much of a discount am I entitled to?

The off peak concession provides a 13% reduction on the off-peak tariff rates on all quarterly electricity bills.

MEDICAL COOLING

The medical cooling concession (formerly the summer multiple sclerosis concession) provides a 17.5% discount off electricity costs over a six month period from 1 November to 30 April for concession cardholders with multiple sclerosis and other qualifying medical conditions such as Parkinson's, motor neurone disease, scleroderma, lupus and Cerebral Palsy.

If you or a member of the household has a condition that impacts on the body's ability to regulate temperature and it's not one of the automatically eligible conditions, please contact the Concessions Information Line on 1800 658 521.

Eligibility

You must hold at least one of the following concession cards:

- Pensioner Concession Card
- Health Care Card
- DVA Gold Card

Holders of a Health Care Card for Child Disability and Foster Care issued in the name of the child are not eligible.

How to apply

An application form must be completed. Forms are available from your electricity retailer, CPSN, MS SOCIETY office (www.mssociety.com.au) or by contacting the Concessions Information Line.

FAQ's:

I suffer from a condition which affects my ability to regulate my temperature. What are my entitlements?

If you have a condition that impairs the body's ability to regulate its own temperature, you may be eligible for the medical cooling concession. Apart from Cerebral Palsy, other qualifying conditions include: Motor Neurone Disease, Muscular Dystrophy, Quadriplegia, Scleroderma, Systemic Lupus Erythematosus (SLE)

How much is the concession?

The concession provides a discount of 17.5% off your electricity costs between 1 November and 30 April each year.

For further information on either of these concessions go to: <http://www.dhs.vic.gov.au/concessions/entitlements/view-all/energy/medical-cooling>

Application for the Medical Cooling Concession

Account holder details: Name, Date of birth, Address, Telephone, Email.

Person with qualifying condition: Name, Date of birth, Address, Telephone, Email.

Doctor's statement: I certify that [] Multiple Sclerosis, [] Parkinson's disease, [] Motor Neurone Disease, [] Muscular Dystrophy, [] Quadriplegia, [] Scleroderma, [] Systemic Lupus Erythematosus (SLE), [] Cerebral Palsy, [] other qualifying condition please specify: _____

Concession card details: I hold an eligible concession card: [] Pensioner Concession Card, [] Health Care Card, [] DVA Gold Card.

Department of Human Services Concessions Unit: GPO Box 4057, MELBOURNE VIC 3001. www.dhs.vic.gov.au/concessions

free e-reader software

Blio is FREE eReader software that presents eBooks like you've never seen them before!



The **FREE Blio eReader software** is the new touchstone for the presentation of electronic books & magazines. Stunning, full-color pages come alive in brilliant 3D. Even image-rich books are now at your digital fingertips — because Blio preserves a book's original layout, fonts, and graphics.

Enjoy a vast selection of cookbooks, travel guides, how-to books, schoolbooks, art books, children's stories, and magazines. Relax, learn, work, or play! The smart display lets you insert highlights, notes, videos, and even webpages. Selected books also go hands-free with Blio's read-aloud feature.

Flexible & accessible. Shop endless titles, right from the Blio Bookstore, with access to over one million free books and a huge library of today's bestsellers. Then, take your library on the road by syncing to your favorite on-the-go mobile device.

Blio, which is due out next month, is software that combines a full-color digital book with the ability to add Web content, video, and professionally narrated audiobooks.

The inventor Ray Kurzweil said that kind of reading experience just isn't possible on current e-readers like the Kindle. Plus, he said, most people don't want to carry a separate device just for reading.

"People want to do everything - they want to watch their movies, they want to do all their computing, their e-mail on one platform" he said in an interview... "They don't want to take another device."

The application differs from other e-readers in that it uses both speech and a visual representation of a book, highlighting the text as the narrator reads through it. Based on PDF files, the voice is either pre-recorded and read out with the story, or the application uses high quality text-to-speech to deliver the audio content.

The Blio was demonstrated at the Consumer Electronics Show (CES) in Las Vegas, where it displayed a virtual hardcover copy of the Three Little Pigs children's book, with pictures and animations being highlighted as the pre-recorded narrator read out the story.

By making the experience both audio and visual based, the Blio is accessible to a variety of disabilities as the text can be visually read on the screen, read out by pre-recorded narration or as computerised text-to-speech software. The highlighting of the text as the book is read out is also designed to assist people with learning disabilities, and improve learning outcomes of children. A million books will be available free with the initial release of the application, with additional books available for purchase. Users will be able to register up to five different devices on which they can read their content, although some textbooks will be limited to just three devices to limit piracy.

Further information: www.blioreader.com



YOUR PROTECTION IN BED

Does your loved one sleep on plastic or remove mattress covers?

Does your loved one remove clothing or nappies during the night?

Does your loved one enjoy trashing the mattress?

Does your loved one's bedroom have an 'unpleasant smell'?

DO YOU NEED TO REDUCE YOUR STRESS LEVELS?

So many questions, ONE answer - BEDGUARD, your protection in bed!

BEDGUARD mattress protection is formulated to water/spill proof your mattress. The hydrophobic nature of BEDGUARD makes your mattress healthier by beading fluid on the surface of the mattress, any spill, body fluid; liquid is trapped by BEDGUARD and can be easily removed from the mattress surface. Simply blot/wipe the mattress surface with a clean white cloth or paper towels leaving it stain free and totally dry.

No more need for old fashion uncomfortable mattress protectors. BEDGUARD provides ease of clean-up after those accidents in the middle of the night, a quick blot/wipe, and back to sleep. No more removing and waiting hours drying the mattress or the inevitable odours associated with the accident. BEDGUARD is guaranteed for the life of the mattress and requires no maintenance or care. It is your protection against unwanted spills.

For further information go to: **www.bedguard.com.au**



Ambleside Tours

Ambleside Tours offer fully escorted and aided theatre parties, day trips and trips within Australia for persons with a wide range of disabilities.

They also offer tours, within Australia, for people with disabilities from overseas countries. Depending on the need, they can provide carers and plan the trip according to the interests of clients.

Upcoming events include:

APRIL

**Tuesday 6th to
Friday 9th April -**

Portarlington:
\$990

- Early booking essential

Saturday 24th -
Como Gardens, The Basin:
\$132

JUNE

Sunday 13th -
Football at Etihad Stadium:
Western Bulldogs vs.
Brisbane Lions
\$135



**Saturday 26th to
Wednesday 30th -**

Gold Coast:
\$3,000

- Early booking essential

JULY

Saturday 17th -
Cuckoo Restaurant:
\$160

AUGUST

Saturday 21st -
Theatre Party-Mary Poppins:
\$205
- Early booking essential/
limited places

(All prices inclusive of GST)



CPSN COFFEE SESSIONS APRIL - MAY 2010

CPSN Information and Support Coordinator Di Cunningham will meet you at the venues. Come along and have a chat, share your ideas and ask questions.

Running late on the day? Give Di a call on **0431 181 313**.

APRIL 2010

(Please note change of dates due to school holidays)

**Wed 14th April
GLORIA JEAN'S COFFEE**
Broadmeadows Shopping
Centre (opp. Coles)
Broadmeadows
10am-12pm

**Wed 21st April
LIMONCELLO**
54 Station Street
Sandringham
10.30am-12.30pm

**Wed 28th April
GLORIA JEAN'S COFFEE**
Greensborough Plaza
Greensborough
10am-12pm

MAY 2010

**Wed 5th May
DAL GOURMET CAFE
& CATERING**
214 Pakington St
Geelong West

**Wed 12th May
STUZZI**
319-325 High St
Northcote

**Wed 19th May
RETRO CAFE**
413 Brunswick St
Fitzroy

**Wed 26th May
MAMBOURIN SENSORY
GARDENS**
1 Recreation Cl.
(off Ballan Rd)
Werribee



ACCESS ALL AREAS
TEENAGE SOCIAL GROUP

An initiative of the Cerebral Palsy Support Network

UPCOMING EVENTS

**Sun 18th April - Beachcombers Cafe
at St Kilda Baths**

Sun 16th May - Shopping at DFO South Wharf

**Sun 10th June - Ten Pin Bowling at Galactic Circus,
Crown Casino**

Remember to register your interest and book attendance with Kim or Di at the CPSN office on **(03) 9445 7488**.