

# what's the buzz

NEWSLETTER



DECEMBER 2009 Edition No.14



## SEASONS GREETINGS!

The Board of Management and the staff of the Cerebral Palsy Support Network would like to wish all our members the best for the Festive Season and a safe and happy 2010.

Looking forward to

# 2010



The Cerebral Palsy Support Network is excited to present our Calendar of Events for 2010. We will be presenting two mini conferences in 2010 - "16+ What Now?" in May, and "Respite Funding" in September. The Board of Management felt these topics are poignant and relevant to the members of our organisation. We will be securing speakers for the day and inviting other organisations to provide information. Keep an eye on the upcoming "Buzz" Newsletters for further information on these conferences and speakers. The calendar below also includes information on upcoming support groups and activities.

### CPSN CALENDAR OF EVENTS FOR 2010

#### JANUARY

**1st - 4th:** Office closed for seasonal holiday break

**Fri 29th:** "Shape AAA 2010": 6 - 8pm at the CPSN office Northcote

**Fri 29th:** "The Buzz" Newsletter mail out (submissions and stories welcome)

#### FEBRUARY

**Wed 3rd:** Parent Support Group, Mt Waverly

**Wed 10th:** Parent Support Group, Croyden

**Wed 17th:** Parent Support Group, Newport

**Wed 24th:** Parent Support Group, Berwick

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## MARCH

**Wed 3rd:** Parent Support Group, Sunshine

**Fri 5th:** "The Buzz" Newsletter mail out (submissions and stories welcome)

**Wed 10th:** Parent Support Group, Upper Ferntree Gully

**Wed 17th:** Parent Support Group, Melton

**Sun 21st:** AAA Teenage Social Group Activity (TBA)

**Wed 24th:** Parent Support Group, Bentleigh

**27th March - 11th April** (School Holidays)

## APRIL

**Wed 14th:** Parent Support Group, Broadmeadows

**Wed 21st:** Parent Support Group, Sandringham

**Sun 18th:** AAA Teenage Social Group Activity (TBA)

**Wed 28th:** Parent Support Group, Greensborough

**Fri 30th:** "The Buzz" Newsletter mail out (submissions and stories welcome)

## MAY

Parent Support Group (TBA)

**Sat 15th:** Mini Conference - "16+ What Now?"  
- Centrelink Education Day services:  
Supported employment  
- As a parent, "what am I supposed to do?"

**Sun 23rd:** AAA Teenage Social Group Activity (TBA)

## JUNE

Parent Support Group (TBA)

**Sun 20th:** AAA Teenage Social Group Activity (TBA)

**26th June - 11th July** (School Holidays)

## JULY

Parent Support Group (TBA)

**Fri 16th:** "The Buzz" Newsletter mail out (submissions and stories welcome)

**Sun 18th:** AAA Teenage Social Group Activity (TBA)

## AUGUST

Parent Support Group (TBA)

**Sun 1st - Saturday 7th:** Cerebral Palsy Awareness Week

**Thu 5th:** Cocktail Party for Cerebral Palsy Awareness Week

**Sun 15th:** AAA Teenage Social Group Activity (TBA)

## SEPTEMBER

Parent Support Group (TBA)

**Fri 3rd:** "The Buzz" Newsletter mail out (submissions and stories welcome)

**Sat 11th:** Mini Conference - Funding and Respite DHS discussion regarding ISP:  
"What can go in them, how are they prepared, by whom are they prepared?"

CPSN Brokerage program presentation:

- Where can I find funding options?
- Who provides, what?
- How to get financial assistance?

**Sun 12th:** AAA Teenage Social Group Activity (TBA)

**18th September - 3rd October**  
(School Holidays)

## OCTOBER

Parent Support Group (TBA)

**Sat 23rd:** Annual General Meeting 1-3pm  
- Presentation on update in Stem Cell Therapy by Stem Cell Research Monash University  
- 3.00 - 4.00pm: CPSN BOM and election of office bearers

**Sun 24th:** AAA Teenage Social Group Activity (TBA)

**Sun 31st:** Members Trust Fund applications close

## NOVEMBER

Parent Support Group (TBA)

**Fri 5th:** "The Buzz" Newsletter mail out (submissions and stories welcome)

**Sat 13th:** End of Year Members Picnic

**Sun 21st:** AAA Teenage Social Group Activity (TBA)

## DECEMBER

Parent Support Group (TBA)

**Fri 17th:** "The Buzz" Newsletter mail out (submissions and stories welcome)



# AUSTRALIAN STEM CELL CENTRE PUBLISHES PATIENT HANDBOOK

Overseas Stem Cell Therapies -  
Are they safe and how do you know?

What are the risks of these treatments?

What do I need to know to evaluate these treatments?

In response to increasing concerns surrounding the marketing to patients of unregulated and unproven stem cell therapies overseas, the ASCC has published a Patient Information Handbook. The ASCC has identified a clear need to assist individuals in understanding what is involved and to guide them on how to fully investigate these treatments before travelling or participating.

The marketing of overseas stem cell therapies via the internet has been around for some years and there is increasing interest from Australians in accessing these therapies. Often these clinics use the testimonials of patients as a marketing technique hiding the fact that much of what they offer is not supported by peer review and has not been proved safe and effective.

The Patient Handbook is designed to help individuals understand what stem cells are, which stem cell treatments are considered safe and

effective by specialists, which are considered experimental and which are unproven and possibly unsafe. The Handbook does not seek to advise or evaluate the treatments, or an individual's reasons for travelling for treatment, but aims to provide the patient with the necessary information prior to considering any therapy.

Stem cell science continues to offer much promise for the treatment of a wide range of conditions and Australia maintains and supports efforts in this field. While great strides are being made in research, many important questions remain unanswered. Bringing new treatments to the public takes considerable time and investment to ensure that such treatments are both safe and effective. Until this research is completed the utmost caution must be used in order to prevent possible harm to patients.

[http://www.stemcellcentre.edu.au/For\\_the\\_Public/Patient/Handbook.aspx](http://www.stemcellcentre.edu.au/For_the_Public/Patient/Handbook.aspx)

## Members Trust Fund

We had an overwhelming response to this year's funding round. The panel has attempted to support as many members through this distribution.

Congratulations to all the successful recipients of this year's members trust fund. We received 44 applications with 22 successful recipients receiving between \$200 and \$500. Successful recipients have been notified and will soon be published on the CPSN website.



The Cerebral Palsy Support Network (CPSN) is an incorporated statewide, self-help public benevolent institution. A board of management administers the Cerebral Palsy Support Network Inc. Board members are volunteers who have Cerebral Palsy. Following the success of successful fundraising events, CPSN is able to offer its members the opportunity to apply for grants of up to \$500. The purpose of the grants are to directly support an individual with cerebral palsy. Members are encouraged to apply for something that would enhance their life. The CPSN would like their members to be creative with this funding. Requests could include for example, drama lessons, sporting equipment, musical instruments- the possibilities are endless.

The CPSN would like to extend the opportunities to our members to benefit from these grants. To encourage sponsorship and further grant opportunities, successful grant recipients must be willing to have their story used in promotional material, sponsorship proposals etc.

#### 2009 GRANT APPLICATION GUIDELINES

Five round Grant applications open on the 1st September and close on 31st October 2009.

Decisions will be made by 30 November 2009.

All applicants will be notified of the outcome of their application by 15th December 2009.

Applications to the Cerebral Palsy Support Network (CPSN) should meet the following criteria:

• Applicants must be an individual with, or parent/guardian applying on behalf of, an individual with cerebral palsy.

• Applicants must be a member of the Cerebral Palsy Support Network.

• Grants from the Cerebral Palsy Support Network (CPSN) must be spent in Australia.

• All grant recipients must be Australian citizens or have permanent residency.

• Funds eligible to be funded under the Victorian Ash and Equipment Program are not eligible for this grant.

• Payments by the CPSN will be only made directly to the supplier/service provider.

• The grant process does not require documentation from professionals such as doctors or therapists.

• Funding will be provided to individuals only.

• No funding will be provided to groups, charities or Associations.

• The Cerebral Palsy Support Network (CPSN) will require brief report on the use of these funds. This may include a photo and a paragraph on the benefits to the applicant.

• All applicants will be informed of their success or otherwise, and the timing of grants is completely at Network (CPSN).

• Lobbying of Committee members and/or panel members will result in automatic disqualification of the application.

• All decisions are final and no correspondence will be entered into regarding the status of applicants during and after the application process.

• Applications may be submitted by mail or email.

# SOCIAL IMPACT

providing people with disabilities, the social skills to build and maintain personal relationships.

**SOCIAL IMPACT** is a unique 12-month pilot dating service, teaching people with disability really useful relationship skills then providing opportunities to put stuff into practice at supportive social events. It will see them have a great time, develop relationships and new friendships towards building happier and fuller lives.

Tens of thousands of people with a disability live in Melbourne; many are lonely. Through **SOCIAL IMPACT**, people with disability who seek the companionship of a boyfriend or girlfriend, now have the opportunity to learn the relevant skills to achieve this.

## **SOCIAL IMPACT provides:**

- An ongoing dating service that can refine and develop as it goes
- Support and/or skills to make the primary objective, finding a partner, possible
- Happier people with:
  - Increased social and communication skills
  - Greater assertiveness and emotional independence
  - Awareness of the risks of unsafe sex and sexual abuse
  - Better understanding of relationships overall and how they work
  - The knowledge of how to feel good and look good
  - Respect for others

## **Who can get involved?**

- 160 - 200 people aged 20 - 45years old, with an intellectual disability, and:
  - A willingness to become involved in **SOCIAL IMPACT**
  - The capacity to contribute financially to some of the event costs
  - Availability from February – December 2010 for at least:
    - 8 x 2-hour training sessions
    - 6 x 3-hour events, April-December 2010

8-10 Practical Training Sessions led by experts in their field, deliver supportive, appropriate, reliable information in a safe environment. Groups of 16-20 people with a disability can share, discuss and role-play to gain new relationship skills and knowledge, such as:

- Let's Begin with Me
- Meeting New People
- Conversation and Communication
- Look Good Feel Good
- Chatting up
- Relationships
- Sex
- The New Me into the Future

## **New skills are practised with targeted events such as:**

- Karaoke
- Dinners
- Bowling and Supper
- Picnics (at venues such as the Botanical Gardens and the Zoo)
- Progressive dance
- Culminating in a Formal Graduation at Melbourne Town Hall, 3 December 2010

Interested? Please print out, complete and return the application form at:

<http://www.impact.vic.edu.au/images/impact-website-info.pdf> by Wednesday 23 December 2009

**Post to:**  
**SOCIAL IMPACT APPLICATIONS**  
**59 Warrigal Road**  
**Oakleigh VIC 3166**  
**or Fax to: (03) 9568 6044**

**Agencies involved:**  
**IMPACT Support Services:**  
**[www.impact.vic.edu.au](http://www.impact.vic.edu.au)**  
**EACH: [www.each.com.au](http://www.each.com.au)**  
**UCCO: [www.ucco.org.au](http://www.ucco.org.au)**



## PEDIASUIT PROTOCOL SEMINAR

**Sue David is the mother of a 10 year old with Muscular Dystrophy, and is participating in a non profitable program involving Intensive Therapy that includes a special suit called a PediaSuit, in conjunction with Hyperbaric Oxygen Therapy. This therapy has also been used in many different Neurological Disorders including Cerebral Palsy, and a Clinic in the USA has pioneered the use of the combined therapies involved.**

Susan is hoping to present a seminar in Melbourne with the American founder of the Clinic, who's son has Cerebral Palsy. If you are interested in attending the upcoming seminar to be held at the beginning of 2010, please contact Sue David on **0148 347 632** or email her on **david.susan5@bigpond.com.au**

You will be advised of the seminar location and date once we have an estimate of how many will be attending. In the meantime, here is the Clinic founder's story:

Hello, my name is Eileen and I want to tell you why this clinic and the special exercise program we have exists today.

I came upon PediaSuit Protocol Therapy & intensive pediatric exercise while researching cutting edge therapy for my son, Lucas, who has Cerebral Palsy.

I enrolled Lucas in a 3 week (60 hour) program using the PediaSuit Protocol Therapy when he was 18 months and not yet able to crawl. Lucas was barely able to combat crawl when he started this program. He was extremely weak due to right side hemiparesis brought on by a grade III & IV brain bleed and hydrocephalus caused by his premature birth at 27 weeks. Lucas has also been diagnosed with PVL.

On day 4 of this intensive suit therapy Lucas was able to crawl on his hands and knees and by the end of the 2nd week he was able to walk unassisted to the count of 7 steps. When Lucas finished the program it was clear that something joyful had happened. It was also clear that I wanted him to have more, much more, of this Intensive PediaSuit Protocol Therapy. When I made the call the following week to explore this possibility, the clinic I had sent him to had closed its doors suddenly. It was at that instant I knew that I had to bring PediaSuit Protocol Therapy and Intensive Pediatric Exercise back to South Florida, so that not only Lucas but all children with neurological damage could realize their rightful potential.

It was at this time I knew I had to open up a PediaSuit Protocol Therapy exercise facility, build a world class team and "get the word out".

I recruited and hired qualified, experienced, and gifted people for this specialized and personalized exercise treatment. I expanded the offerings to include adults and reopened the facility in February of 2004. The treatment is safe, without surgery or drugs, utilizing natural movements, combined with unique high tech equipment such as the Spider Cage, Universal Exercise Unit and Suit Therapy. Please visit our website **<http://www.therapies4kids.com>**

**For more information visit: [pediasuit.com](http://pediasuit.com)**

# A *real* HOLIDAY

**Thank you to Cindy Turkovic for providing information to us after her recent family holiday experience at "The Alvina" special needs holiday accommodation facility. Situated in Cowes on Phillip Island, these great, accessible cottages have been purpose built for wheelchair access and are the perfect holiday retreat, and provide the following features:**

**KITCHEN:** Work benches at 850mm with clearance space underneath, side opening oven, 4 hotplates, fridge with separate freezer (1350 high).

**BATHROOM:** Spacious, stepless shower base, hand held or fixed shower, accessible toilet, grabrails (shower & toilet), mobile shower/commode chair, over toilet seat raiser, lever taps, hair dryer, non slip tiles. 3 bedroom cottages have 2nd bathroom.

**BEDROOMS:** Bed arrangements can be changed around to suit requirements.

**LOUNGE:** Recliner chair & divan.

Doorways are wide (1020) with lever door handles.

Large switches and power points at 1 meter high (useable from a seated position).

**AVAILABLE FOR USE IN ALL COTTAGES:**

Freestanding self-help pole, bedstick. Dropside bedrail, single concave mattress, slide sheets, 2 mobile sling lifters/hoists (150 kg. capacity) with slings, stand-up lifter, 4 hospital beds with bed rails, 4 porta cots, 3 high chairs, folding manual wheelchair, shower seat, kylies, 3 shower/commode chairs, beach wheel chair, portable IV pole, walking frames, commodes, 3 over-bed tables. Toyota Hiace Van with wheelchair hoist available for transport if required.

Personal care or any assistance required (R.N experienced with disabilities).

Inspection welcome (by appointment please).



For more information visit: [alvina.com.au](http://alvina.com.au)



## FOLLOW UP LA TROBE UNI STUDY

### Over 200 more participants across Victoria still wanted!

What activities do children and young people with a disability living in Victoria take part in?

La Trobe University would like to learn more about the out-of-school activities of children with a disability aged 6-18 years. Children will be asked to fill out a child-friendly questionnaire about the activities they do, how often they do them, where they do them, and if they enjoy them. This can be completed by post with supervision from parents/guardians or in person with the help of a research assistant.

To find out more, please contact Annie Synnot at La Trobe University on **9479 5789** or email **A.Synnot@latrobe.edu.au**

## OWN A COMPUTER FROM \$5 WEEKLY!



**computers FOR all**

Supplying computers to those who need them

Do you receive any of the following benefits from Centrelink?

- Parenting Payment
- Family Tax Benefit
- Disability Support Pension
- Aged Pension
- Carers Allowance

Then from just \$5 a week, you can rent a PC - which you will own after just 12 months!

Contact via the website:  
**computersforall.com.au**  
or call: **(03) 9012 8492**



## HUME CITY COUNCIL presents CIRCUS OZ WORKSHOPS

As part of the Summer Season of Learning

Enjoy learning a range of circus, dance, character and drama skills from professional circus performers. These workshops are accessible to children with disabilities aged 6 - 12.

**THURSDAY 28 JANUARY 2010**

**Venue: Hume Global Learning Centre  
1093 Pascoe Vale Rd,  
Broadmeadows**

Session 1: 10am – 12noon

Session 2: 1pm – 3pm

Cost \$10. Bookings Essential  
Ph: (03) 9356 6999

**hume.vic.gov.au**



# CPSN COFFEE SESSIONS FEBRUARY - APRIL 2010

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 0422 259 447.

## **FEBRUARY 2010**

### **WED 3RD FEBRUARY**

#### **The Sweet Bakery Café**

25 Hamilton Place  
MOUNT WAVERLEY  
10am - 12pm

### **WED 10th FEBRUARY**

#### **Kofi Beans**

137 Main Street  
Croydon  
10am - 12pm

### **WED 17th FEBRUARY**

#### **Nosh at Newport Cafe**

24 Hall Street  
NEWPORT  
10am - 12pm

### **WED 24th FEBRUARY**

#### **Primary Pioneer Park Café**

Cnr Peels & Lyalls Road  
BERWICK  
10.30am - 12.30pm

## **MARCH 2010**

### **WED 3rd MARCH**

#### **Mambo**

Harvester Road  
SUNSHINE  
11am - 1.00pm

### **WED 10th MARCH**

#### **Blue Mountains Cafe**

Ferntree Plaza  
1194 Burwood Hwy  
UPPER FERNTREE GULLY  
10.30am - 12.30pm

### **WED 17th MARCH**

#### **La Porchetta Family Restaurant**

Shop 171, Woodgrove  
Shopping Centre

533 High Street  
MELTON  
12pm - 2pm

### **WED 24th MARCH**

#### **The Spotted Dog**

260 Centre Road  
BENTLEIGH  
10am - 12pm

## **APRIL 2010**

### **WED 14th APRIL**

#### **Gloria Jeans Coffee**

Broadmeadows Shopping  
Centre (opposite Coles)  
BROADMEADOWS  
10am-12pm

### **WED 21st APRIL**

#### **Limoncello**

54 Station Street  
SANDRINGHAM  
10.30am - 12.30pm

### **WED 28th APRIL**

#### **Gloria Jeans Coffee**

Greensborough Plaza,  
GREENSBOROUGH  
10am - 12pm



**ACCESS ALL AREAS**  
TEENAGE SOCIAL GROUP

An initiative of the Cerebral Palsy Support Network

In January we are going to have a casual get-together at the CPSN office for pizza and a chat to establish what everyone is interested in and what exciting activities the group are interested in pursuing for 2010. This is a great opportunity for past participants to catch up after the Christmas cheer and new participants to come along and meet everyone and get a feel for the program in a safe environment.

**So come along to:**  
**"Shape AAA 2010"**  
**Friday 29th January to 6 - 8pm**  
**at the CPSN office**  
**86 Herbert Street, Northcote**

**From February, the AAA**  
**will be scheduled for the**  
**3rd Sunday each month**  
**starting with:**

**SUNDAY 21st FEBRUARY**  
**Village Cinema**  
**Gold Class @ Crown**

**Places will be limited so get**  
**your interest in early**

**Contact Us: [aaa@cpsn.info](mailto:aaa@cpsn.info)**

