

# The Review

November 2010



The Official Magazine of the Cerebral Palsy Society of NZ Inc

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# The time to 'get rolling' is now.

Over the past 10 weeks, Boccia in New Zealand has been given its' first taste of focused attention from the Cerebral Palsy Society. I have been a part of the Cerebral Palsy Society team since the beginning of September to help develop and increase the number of people playing Boccia throughout the country and this has seen me reviewing some of the current structures in place, as well as implementing some new



ideas. For those of you not familiar with Boccia, it is a sport that was originally created for people with Cerebral Palsy and is likened to a combination of lawn bowls and petanque. It requires accuracy, patience, and problem solving...among other skills - all of which can be gained from experiencing the many joys of this wonderful sport.

The following is the first update on what things have been happening and where they have happened within the last 10 weeks...

## **Within the Auckland region:**

On the schools scene: I have worked with some secondary schools in running coaching workshops and sessions. This has led to the setup of an inter-schools competition which will be run on Friday November 12<sup>th</sup>. This term 5 schools will take part: Mt Roskill Grammar, Papatoetoe High School, Waitakere College, Takapuna Grammar and Selwyn College. Undoubtedly this will be a fun and exciting day of Boccia competition with at least 30 keen students taking part.

On the Boccia clubs scene: Auckland has been the first recipient of support with assistance being given to the existing clubs both out West and down South. This has led to events such as the Boccia evenings out in West Auckland and in Central Auckland where we are looking to establish a new more-Centrally located club. Both days gathered a lot of positive interest, attracted fresh new faces to the game... and even got some of those more-mature players back out of semi-retirement!

## **Within the Waikato region:**

On the club scene: I have been helping ParaFed Waikato to re-establish the Boccia club and get it back up and running again with the aim to have the club re-operating from early 2011 at the latest. The first event for the Waikato region will be a 'Have-a-go-day' on Thursday December 2<sup>nd</sup>.

## **On the equipment scene:**

Following some conversations with members who have somewhat fallen



away from the game in recent years, I discovered that many were unable to regularly play, whether it be socially or competitively, as they do not have the appropriate assistive ramp equipment. Therefore, construction is well under way on the first batch of brand-new 'state-of-the-art' ramps which will be available to rent from the Cerebral Palsy Society shortly.

#### Events that are coming up:

- ◆ Beginners Boccia Day – Saturday 11<sup>th</sup> December at the Ellerslie YMCA Recreation Centre.
- ◆ Cerebral Palsy Society Holiday Tournament - Saturday 15<sup>th</sup> - Sunday 16<sup>th</sup> January at the Alan Brewster Centre
- ◆ More event club-days - TBA
- ◆ The second instalment of the inter-schools competition day – TBA

#### In other news:

If you would like any assistance to start a new club, or rejuvenate an existing club. To get it up and running - whether it be Boccia resources, contacts, professional development or coaching, equipment, information or anything else - please feel free to contact me and I would be happy to help in whatever way I can.

I am also on the lookout for interested people to act as key contacts for their

local areas to update me on the progress of Boccia at their existing clubs. If this sounds like you then please contact me for further information.

Ultimately we would like to see the world of Boccia in New Zealand a thriving sport scene for everyone involved and provide all members with ample social and/or competitive opportunities. Avenues to participate and enjoy this great game. If you have any ideas on what else I can do, just let me know...J

Until the next end...keep rolling everyone!

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## CP Society Holiday Boccia Tournament

15-16th January 2011

Open Tournament, Everyone can play!

It will be a pairs competition..... with handicapping.

Entry forms will be available on our website in December.



A photograph of the Villa Maria Winery building, a modern structure with a prominent wooden slat facade and large glass windows. The building is surrounded by lush greenery and a garden area with several patio umbrellas.

**Auckland Xmas Brunch, 10am, Sunday 5th Dec**

**Villa Maria Winery, Mangere**

**Adults \$20, children \$10**

ticket request form enclosed  
or downloadable from  
our website

A photograph of the Chateau on the Park, featuring a large swimming pool in the foreground, lounge chairs, and a prominent tower structure in the background surrounded by trees.

**Christchurch Xmas Lunch**

**Chateau on the Park,**

The Great Hall,

**12th December 2010, Noon**

*Adults \$20*

*Children \$10*

Application form for tickets enclosed and it is also available from  
the Society's website at [www.cpsociety.org.nz](http://www.cpsociety.org.nz)



# AGM 2010 – 17<sup>th</sup> Oct



Thirty two members attended in person and a further 19 were represented by a proxy. The new Board members of Peter Fergusson (VP), Anthony Smith, Ira Turvey, Redmond Nicholson and Michael Turner were ratified by the meeting. (See article on pages 7 & 8 ). The Life Memberships were approved for Margaret Thomson and Glenis Lobb, their gold Life Membership cards and flowers being presented.

The Resolutions were then put to the meeting. Special Resolution 2 (if a Board member has a conflict of interest they

cannot vote or take part in discussions) was approved by 34 to 2.

Special resolution 1 (where members who contracted to the Board could be nominated for the Board) was defeated by 21 to 23 against. Resolution 5, to appoint a Welfare/Information Officer was approved by 30 to 4 against. It was an excellent meeting with healthy debate. (The draft minutes of the meeting are now on our website).



## Welfare and Information Officer

We are in the process of appointing a Welfare Officer and defining the functions they will perform.

One of the functions will be visiting members with cerebral palsy who require visits to their home to discuss their lives and issues they are facing, especially those who are elderly or with a limited support network.

We will be starting a register for members who require visits from this new service (initially in Auckland).

If you wish to be on this register please contact Harvey Brunt on 0800 503603 or email [harvey@cpsociety.org.nz](mailto:harvey@cpsociety.org.nz).



# New Board Members

## Anthony Smith



I have been closely involved with Conductive Education in Canterbury for 15 years and over that time I have also been actively involved with the New Zealand Foundation for Conductive Education. Due to the many ongoing changes to education policy for our young people with disabilities I have ardently lobbied at a national level over the years. I have also being part of a number of Ministry of Education projects ensuring that, as parents, we are heard and that our children are at the fore front of policy makers minds. Anthony's

daughter Danielle, now 18 years old, has CP and like so many parents he became involved to ensure she had a life of quality

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## Michael Turner



What I have accomplished in the past three years I still can't believe. I received a Canterbury Volunteer Award and was runner up in the New Zealand Volunteer of the Year last year. I helped put together some Cerebral Palsy events in Canterbury, organised 3 mystery outings for Avebury House and arranged two Xmas breakups for Burwood Hospital Volunteers (where I work) and the Diabetes centre. I'm also on a couple of committees at CCS Disability Action including the Access committee. I became very lonely and depressed when mum died in 1997, However about 10 years ago I had

an accident and got nudged into joining groups which boosted my confidence and I haven't looked back since. Fortunately I have two great lady friends whom give me advice and keep me on the straight and narrow.

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## Ira Turvey



I've spent most of my working life as a software developer for an insurance company. I was made redundant about ten years ago and found it impossible to get another job because of my age and disability. Fortunately for me, I had a couple of years at university doing mathematics and accountancy and I'm now involved in keeping accounts for different clubs and societies. The one that takes up most of my time during the week is my local church which involves about ten hours and running a small payroll system.

I'm keen on taking part in sports. I joined a Petanque club ten years ago mainly for a bit of physical exercise which is important for CP's especially as they age. But I really enjoy the social part of it as well, they are a mad lot. I play a game called Go Go (a thinking game, much like chess) and Bridge twice a week.



## Red Nicholson



Hi folks!

I'm absolutely thrilled to have been elected to the CP Society Board. I'm a Communications graduate from AUT and have big dreams in the pipeline. I'm excited by the direction of the Society, and look forward to being a part of future plans. The Society has been very good to me over the years, and I look forward to giving something back.

See you all soon!

(NB Red featured in the last issue of the Review writing about his big "Overseas Experience" when he travelled around Europe and he is also the master mind behind the excellent website [walkingisoverrated.com](http://walkingisoverrated.com))

## Fire Ambassador Appointed

My name is Torrin Hona, I am 33 years old and I have Cerebral Palsy and ME/CFS. In my volunteer role as the Community Ambassador – Disabilities Strategy for the Auckland Fire Region I promote fire safety to disabled people. As part of the Fire Risk Management team, I liaise with community groups through presentations and forums to identify problem areas and develop disability strategy. During a recent forum in Papatoetoe, participants built a list of specific challenges facing disabled people along with possible solutions. We are now working through the recommendations to assess how to best proceed with implementation.

In this role, I am able to be the conduit between the client and the Fire Service. This is a strategy the Fire Service are very appreciative of, as I am able to talk to both parties and through personal experience, give the Fire Service the appropriate advice to assist in making the lives of "disability" members of the Community, safer from fire.

I am available to meet with you and discuss my approach to fire safety and



your issues or concerns. I work in tandem alongside a fire fighter to consider how best you might be able to implement a practical and effective plan in your residence or work place. I am also available to come and present a fire safety message to your group. Please do not hesitate to contact me on the details below to talk about this work.

**Torrin Hona**  
**Community Ambassador**  
**Disabilities Strategy**  
**Auckland fire region**

Ph 09 8159994

mob 0212177681

Email [torrin.batman@ihug.co.nz](mailto:torrin.batman@ihug.co.nz)



# DS Consumer Consortium



The Ministry of Health (MoH) convenes a consortium of people from disability organizations to provide feedback to them on their policies and future direction. It's a diverse group consisting of sensory, intellectual, behavioral and physically disabled people/parents. There are 19 organisations represented. The Cerebral Palsy Society is one of those. We have two places on the Consortium. One place is for a parent of a person with CP, that's the role I presently represent. The other is for a person with lived experience. The late Todd Fernie fulfilled this role in the past.

The Consortium is a very valuable Forum with Minister Tariana Turia and top managers from MoH, attending and presenting. It's a chance for the MoH to gauge how they are doing and to test new ideas on consumers. It's also a great opportunity to network with other organizations in the sector that we normally have little to do with but often share similar issues.

The last 3 day meeting was in Wellington in early October. The main item that was of significance for me, (and could affect you in the future) was the New Model. MoH Disability Services Strategy revolves around introducing a new model that incorporates Individualised Funding (IF) and Local Area Coordination

(LAC) and designed to give choice/control/flexibility and budget management to the end user. This is quite exciting. Trials are going to be conducted in Tauranga over the next two years. Other trials are also planned. One of the interesting things that came from the discussion was that 15-30% of eligible users would take up IF, and in countries where LAC's are in operation, only 40% use them. That is to say the old systems will be operating but additional choice will be there for the end user.... this has got to be good!

An abbreviated summary of the following topics from the October meeting can be seen on our website: Leadership Grants, Pacific Update, Maori Update, Individualised Funding Progress, Tariana Turia's address, Respite Care Study, The New Model, Residential Review Project, Contract Board (similar to boarding with someone) and the coming Consumer Forums around NZ.

## **CP Society Vacancy on DS Consortium**

A vacancy exists on the Consortium for a member of the Society with CP, who is receiving services from the MoH. The Society is calling for expressions of interest in this position.



The terms of reference for the Consortium are available on our website. Members who are interested, should read this document before expressing an interest. The MoH pays for all costs of attending and there is also a daily payment.

If a support person is required, this is also covered by the MoH. Expressions of interest indicating your suitability for the role should be sent to me prior to 11<sup>th</sup> December 2010. (The next 3 day meeting will be in Wellington in April 2011) - Harvey Brunt

## Great participation, including players from Oz

The 2010 Boccia Nationals made for an ideal backdrop for the exciting new directions for the sport, clarified by our Director of Boccia, Luke Morriss, in the Review's feature article on pages three and four.

Once again the South Auckland Boccia club hosted a very successful tournament with forty-two player participating. The event was held at Papatoetoe's Allen Brewster centre on Saturday 6<sup>th</sup> and Sunday 7<sup>th</sup> of November.

The tournament was enhanced by the participation of two Australian players, BC2 player Scott Elsworth and BC3 player Terry Cooper. Other out of towners were Reece Bycroft from Manawatu, Kerri Bonner and Jeremy Morriss from Canterbury and a nine strong contingent from Northland, including Scott Burdett and Kim McLean, who fought out the Kiwi class final, with Scott the eventual winner.

However it was Aucklander Leonie Brunt who came away with the most trophies. Leonie won the title of the most improved player of the tournament and the Fay Goodall memorial trophy for the BC1 class.

Michael Bull, another BC1 player, starred over the weekend as he won the title for the very first time. This statistic came from a most reliable source. From



**"Leonie Brunt receiving the Most Improved Trophy"**

the man himself in fact who proudly lay claim to this piece of information.

Other features of the tournament were the very attractive Iris uniform worn by its members and the fact that Anthea Hurst went through her pool games without conceding a point. However she was eventually defeated by the internationally experienced Mandy Slade who took the gold.

In the BC2 class the old rivalry of Liam Sanders and Maurice Toon continued with Sanders the victor.

Wayne Barnhill won the Referee's choice Janet McVeigh trophy and the player's choice referee trophy went to Luke Morriss.



# Insights Revealed via Research

*Cerebral Palsy Through the Lifespan* is continuing to evolve. Information has been gathered through a variety of mediums: in person interviews, online questionnaires, phone interviews and interviews making use of an interpreter. It has been a challenge (notwithstanding a rewarding one) to make CPTTL accessible to everyone. By utilising the net it has been possible to widen the research outside Auckland and start gathering regional variations. I would like to thank everybody who contributed to this development, particularly those who reviewed and commented on multiple rewrites at all hours of the day and night.



As the project moves through its first round of analysis I can't help but reflect back on what journey it has been. When I began this process, I assumed, naively, (arrogantly?) that it would be a relatively simple and forthright process. How hard could it be I thought? Wrong. The carefully balanced questions would be addressed, the answers collated and neat statistical profiles would be produced (complete with snazzy by lines and logos). To certain extent this is exactly what has happened. The statistics are slowly being compiled and the graphic design has only been mildly hampered by my complete lack of artistic/creative skill.

However, what I didn't anticipate was how much insightful information can be gathered simply from offering an open forum under the umbrella of lifespan research. I am increasingly excited by the in depth knowledge of the reality of living with CP in an everyday context. This includes bringing forward a possible vocabulary around largely hidden

aspects of CP and its impact on important life events such as employment and childbirth. For example, how do people living with CP fair in manual trade apprenticeships? How about the circus then?

As always please free to contact me if you would be interested in volunteering for the research or if you have any questions or comments. I am also on the hunt for anybody with a working knowledge of Excel and the graphic design programs. If you have talents in those areas please feel free to drop me a line.

Just as a side note: I am not in the office very often so the best way to contact me is either by email [amy@cpsociety.org.nz](mailto:amy@cpsociety.org.nz) or my cell phone 027 359 1117.

Amy Hogan.



# Manual or Automatic?

Sometime back I read an article in the CP "Review" about Braun Oral B electric toothbrushes. Years and years ago (I am now over 60!) I purchased one of the first automatic toothbrushes available in NZ – it was made by Ralga and had a simple "back and forth" motion and absolutely no "guts." It had an effective life of about a week and was very limited.

In contrast, the Braun Oral B toothbrushes I have used have been both fantastic. I began with the "Advanced Power" model and have recently upgraded to a "Professional Care 5000." The "5000" not only rotates, but also oscillates vertically in a short range. Since using these tooth brushes, the amount of dental work I have needed, has been almost reduced to zero.

I conceded that when I used to brush manually, I had very few fillings other than the replacement of old amalgum that had cracked with time. However there has been an immense improvement for me in the reduction of the time taken to have a "scale and clean" at the dentist. Obviously the use of Oral B toothbrushes has resulted in virtually a "zero" build up tartar.

Gone are the days when I would frantically grip the dentist's chair as if trying to break the arms in two; as my "scale and clean" now takes about five minutes, rather than the seemingly slow and tortuous three-quarters of an hour it used to take.



"Ivan's daily routine"

Be warned though that the "Oral B's" do have at least one pitfall. For instance, when using them, be certain to put the brush and the tooth-paste on it, actually in your mouth before turning it on. To do otherwise, will mean that you will not only have your teeth to clean, but also most of your bathroom as well! The toothbrushes rotate extremely fast, (several thousand r.p.m.), so fast the toothpaste initially will fling itself off the brush and all over the nearby surroundings. However after the toothpaste becomes emulsified in the mouth, this ceases to become a problem at all.

Happy and effortless brushing and cleaning everyone

Ivan Ford



## Jess medals at Com. Games

If shot putting silver medallist, Jess Hamill had to choose the best moment of her Commonwealth Games adventure, it would have been a tossup between taking her rightful place on the podium and her fantastic arrival back home, proudly displaying her hard earned treasure around her neck

"One of the biggest highlights was when I touched New Zealand soil after a long trip home. It was 11.30pm when the plane landed. Despite the late hour my family and friends were there displaying banners and giving me an awesome welcome home" said Jess Southlander and CP member



**"Jess with proud parents"**

Jessie's parents, Peter Hamill and Isabel Hamill, were at the front of the welcoming home party with flowers. Jess spotted them instantly and felt compelled to take her medal off her own neck and put it around her mums. Naturally more than a few tears flowed. This was not the end of the celebrations as a wee surprise party was organised and Jess had a great time catching up with friends and family.

Of course Jess has settled back into her regular routine in her home town of Invercargill. But life is not the same due to her local celebrity status.

"I am recognised in the street now and people come up to congratulate me on my effort, which is cool. The winning of my medal has also given me the opportunity to speak at schools which I really enjoy," said Jess

Jess provided an unexpected but understandable response when asked of her initial feelings of winning silver.

"To be honest initially I was a bit disappointed because I didn't get a personal best. However at the actual medal ceremony I felt completely different. I was on top of the world, extremely happy. I was coming home with a medal around my neck," confessed Jess.

She still vividly remembers the build up to her parasport shot putting event.

"It was a long day as I was competing at 5.30pm. I woke up at 8.30am, had a late breakfast and late lunch. I didn't eat much but drunk heaps of water throughout the day. I played cards to pass the time and as the day wore on I was ready to go," reflects Jess.

There were few words as her coach and Jess parted to prepare for the event. They both knew what she had to do. Her coach simply said "Go for it". And she did. The rest is history with London 2012 Paralympics firmly in her sights.



# CP Grant Recipient Rebecca Moulton

My name is Rebecca Moulton and I live in Palmerston North with my daughter Brittani. I have Cerebral Palsy, have limited use of my hands and use a motorised chair for mobility. I am studying towards a post graduate diploma in Counselling. This year with financial support from the CP Society, I completed a paper towards my post graduate degree in Counselling through Massey University.



I found the paper extremely valuable as I learnt different approaches in Counselling. I have identified which approaches I am drawn to. One of these is the solution focused approach which is client driven and accentuates the clients own ability strengths and resourcefulness to find solutions to problems. The counsellor walks alongside their clients as they discover their own solution, giving them a sense of hope and empowerment. As a person living with CP I believe that no matter what the circumstances are, how we choose to overcome them is most important, something which the Cerebral Palsy society also values.

This is the very mantra I have adopted throughout my life as I have encountered some incredible highs and some challenging lows - some of which I will not repeat but on reflection, have learnt lessons from. With this philosophy I have completed two degrees, brought my house, travelled overseas and given birth to my daughter Brittani, now 11. She will always be my greatest

achievement and no doubt my greatest challenge as she continues to grow into the wonderful young person that she is.

My goals are to finish this diploma within the next three years and to establish my own practice. I am about to enter the next phase of my training and I have found myself a placement for the next two years. I'm looking forward to the challenge that lies ahead and the people I will meet.

## Paint the Town Blue?

Perhaps Gisborne's solution to deter illegal parking in disabled spaces should go nation wide?

Since Gisborne has painted all their mobility parks, they have noticed a substantial drop in illegal use of the parks by around fifty per cent.



# Leonie Brunt tells her own story of having Cassie in her life....

30<sup>th</sup> May 2008 might just seem like another day to you, but not to me. On this day my world changed. Why you might ask? Well, this was the day *Cassie* (my mobility dog) and I became one. Since *Cassie* came into my life it has been enriched: e.g, when I come home from university, I no longer have to wait out in all weathers to be let in to my house, one command of 'tug' and ...open slides the door. Before I got *Cassie* and I was at home with my sister, and I needed assistance I would scream and hope like heck that she'd hear over raging music. These days it's *Cassie* to the rescue - one command of 'speak', *Cassie* barks, and my sister comes to my aid.

Best of all, in stressful situations such as exams, having *Cassie* is like having 'rescue remedy' because I know that I need to be calm so that she won't pick up on my nervousness. I believe that *Cassie* has made a huge impact on my life especially by helping me conquer many physical challenges. *Cassie* is so in tune with following my wheelchair, I wouldn't be without her. Thanks to her I feel more human because when in public,



people actually talk to me. Having *Cassie* in my life has increased my sense of responsibility. Having her has made my confidence increase tenfold.

*Leonie Brunt October 2010*

## **Mobility dogs like Cassie are trained by the Mobility Assistance Dogs Trust (Mobility Dogs).**

The Trust is an Auckland based not-for-profit organisation which aims to: "enhance the lives of people living with long term physical disabilities by providing mobility dogs to increase independence, confidence, self-esteem and participation in New Zealand communities" The Cerebral Palsy Society has been a long-time supporter of the Trust ensuring that their members are able to receive dogs should they be considered appropriate candidates.



## The dogs are primarily trained to:

- ◆ Activate pedestrian crossing and elevator buttons
- ◆ Assist with transfers to/from a wheelchair
- ◆ Retrieve dropped items - eg car keys, pens, credit cards
- ◆ Fetch items - eg phones, remote controls, books
- ◆ Open doors, cupboards and drawers
- ◆ Turn lights on & off
- ◆ Or as Leonie so eloquently puts it – having a dog is like having 'rescue remedy'

Working with a dog is a long term, and hugely rewarding 'partnership'. However, it takes time, energy and commitment to make it successful – Leonie and Cassie's story is testament to the potential rewards of these partnerships. Mobility Dogs is keen to hear from CP Society members interested in being considered for a dog. Ideally, potential candidates:

- ◆ Can **communicate** clearly with others
- ◆ Are able to **exercise** their dog every day
- ◆ Are able to take on the **responsibility** of a dog
- ◆ Have a home/living environment that is **suitable** for a dog
- ◆ Most of all, have the **desire** and **commitment** to lay the foundations for a Long term partnership with a dog.

If you are interested please go to our website [www.mobilitydogs.co.nz](http://www.mobilitydogs.co.nz) and read stories about our working teams. There is a DVD to view which describes what life is like with a mobility dog.

Please contact me direct on [jody.hogan@mobilitydogs.co.nz](mailto:jody.hogan@mobilitydogs.co.nz) or (027)7007017 and I would be more than happy to discuss a potential application with you.

Jody Hogan ...GM of Operations



## ACADEMIC GRANTS 2011

As in 2010, the Society is now advertising their 3 Academic Grants for the 2011 academic year. Each grant is worth \$2500. Applications can be downloaded from our website or requested from the office. Applications must be received by the 18<sup>th</sup> January 2011.

For further details re criteria and conditions, go to our website at [www.cpsociety.org.nz](http://www.cpsociety.org.nz)



# “No One Alone” Conference

Is my child, family member or friend going to be ok once I am no longer there to support them?

I am going to be able to find and sustain effective support when my primary support person is no longer able to care for me?

These questions are frequently raised by individuals with CP and their families. Family members or primary support people tend to spend countless hours over the years navigating the often labyrinth like entities, that are Ministry of Health, Ministry of Education and Ministry of Social Development. While caregiver roles inevitably change and may lessen over time, there is still no substitute for their innate and automatic knowledge and skill. No matter how fiercely independent the individual may be, support services can be crucial for a multitude of situations from a bout of the flu, to perhaps a more serious concern.

Recently I attended the *No One Alone* Conference. The three day series of seminars and workshops sought to offer practical guidelines to address these concerns from many different academic and community perspectives.

These included:

- ◆ The most effective ways to set up and maintain guardianships and trusts
- ◆ Strategies for moving into independent community living
- ◆ Outlining Micro Business: Framing a small business based on hobbies or passions such as preserve making, music composing and woodwork
- ◆ Circles of Support: A Detailed Review
- ◆ Peer Support and Technologies



- ◆ Parental Cooperatives: New Zealand, Australian and Canadian Models

While it is important to acknowledge that there is no perfect way to approach the future, the following are some common themes that emerged from the conference.

**Decide:** This is quite simply the process of deciding the fundamental aspects that will occur in the future such as education, moving from paediatric services, employment and medical operations.

**Discuss:** Discuss these plans with close friends, family and community members. There are resources available to help facilitate this process.

**Document:** Cerebral Palsy can often produce a complex series of interactions between various medical and government services. Producing a ‘CP passport’ centralising information that facilitates daily living is a great idea. This could be used for parents navigating multiple systems or for individuals with CP who are seriously unwell.

Amy Hogan



# Diversity works for Peer Support

Facilitating effective peer support has long been considered something of a holy grail within the disability sector. Literally thousands of studies, many years of research and good old plain common sense, indicate that it is strong friendships that are a crucial factor in predicting health and well-being.

I've been through most of the peer support incarnations. By in large, whilst they were well intentioned, these efforts were largely contrived and not appropriate on many levels to be relevant or constructive. I am therefore pleased to see a trend in 'peer support' movements away from forcing chemistry/'friendship' based solely on disability. I am here to profile one such programme that I have been involved in both as an advisor and active participant.

Diversityworks Trust created its Peer Support Network (DPSN) to provide a safe place for people discuss and collaborate on the unique experiences and challenges of living with a disability and other life situations. The point of difference with DPSN is its accessibility. The network is sustained by several different mediums: face to face meetings, weekly chats, discussion blogs, workshops and social events. This diversity which is offered in accessing peer support means that many of the barriers to seeking genuine assistance are lessened – that is things like transport, carer hours and time constraints.

The topics can range from the very serious 'How do people with disabilities become safer in disasters' to the not quite so deeply thought provoking 'I've



"Philip Patston & Amy Hogan communicate"

tossed my footplate up a tree' Some of the recent topics include:

- ◆ Art and Performance
- ◆ Mental Health and Labelling
- ◆ Movie Group
- ◆ Teen Space

A key factor within DPSN is that there is no fixed agenda - you can be either active or passive and commitment is entirely up to the individual. You can become closely involved or simply use it as a one-time problem solving tool.

This isn't a perfect model (but you can't please everyone) - the free style isn't for everyone. However, I have found it a valuable, friendly and largely impartial resource. DPSN has also cemented some potentially lifelong friendships for me.

If you are interested in learning more or joining the Network, visit [www.dpsn.net.nz](http://www.dpsn.net.nz) or please contact [amy@cpsociety.org.nz](mailto:amy@cpsociety.org.nz) or [anna@diversityworks.co.nz](mailto:anna@diversityworks.co.nz)



# Shaken AND Stirred

Last year Allison Franklin was commissioned by DPA Christchurch & Districts to put together a booklet to guide people with disabilities through a Civil Defence Emergency. She entitled it "Don't Be Scared, Just Be Prepared" As she wrote it she thought people could put it away safely in a draw and pull it out if a catastrophe struck. A situation she thought would never happen in her lifetime.



"How wrong can you be?" she said. "At 4.35am on September 4<sup>th</sup>, my peace of mind was shattered, possibly permanently. I was sound asleep and for the first nanosecond thought that the movement I felt was my cat PurrJo either jumping on my bed or having a scratch. Quickly I realised that this was an earthquake, and within a few seconds I had scrambled out of bed to brace myself in the doorway. As I did so, the lurching escalated, items began falling off my dressing table and I could hear glass smashing elsewhere in the house. It was the ultimate nightmare and I have truly never been more terrified in my 51 years.

Other Christchurch residents with Cerebral Palsy tell similar stories.

Kerri Bonner wrote ---"Although I suffered no damage in the quake, it affected me nonetheless, as I'm sure it did everyone. One of the main things that struck me is the lack of power we had throughout it all. Something disastrous was happening and there was nothing we could do about it. Like most of Christchurch I was in bed that morning. It was the noise that struck me. It was incredibly loud. Contrary, to what we're all taught to do in an earthquake, I

did the opposite, I stayed in bed. I didn't really like my chances of making it to a doorway or a wall (although I could have tried if I needed to) and figured since the house wasn't falling down that was probably my safest option."

Rachel Mullins wrote --- I felt the earth move and it was memorable but not for any good reason! I awoke to a vicious shaking of my bed. The violent shaking and rattling moved to a significant wave like roll and my house was plunged into pitch blackness. As the ground continued to roll I knew I could not safely transfer into my chair nor could I get on the ground beside my bed because my wheelchair was there. I grabbed My iPhone and after texting my family to ensure that everyone was ok, a friend (and carer) came by about 5.15am and helped me get up. After my experience I have come up with twelve tips Unsurprisingly quite a few of these tips are similar to what Civil Defence promote for us all to do in an emergency such as this.



1. **If you are in bed stay there,** (If you can, cover your head with a pillow if you think you might be hit by something.
2. **Have a corded phone that plugs into the wall by the bed,**
3. **Charge your cell phone by the bed.**
4. **Keep a torch by the bed.** (Light is reassuring)
5. **If you need regular assistance, have someone that lives close by on stand by** (It's not going to be too long before they can get to you)
6. **Get to know your neighbours.**
7. **Be with other people.** If there is no power its much nicer to be able to chat with other people be they family, friends or neighbours.
8. **Store some water to use.**
9. **Have some batteries in the radio by your bed**
10. **Get a flatmate**
11. **Get back to (some) normality as soon as you can.**
12. **Not all earthquakes hit during the night!** So if is during the day look for

something you can brace yourself against. A wall, cupboard or couch for example.

As mentioned by all the contributors above the old CP startle reflex worked overtime but they all coped remarkably well. They may not have had a fully developed plan but they were aware of their capabilities and stayed within these boundaries. Because the Christchurch quake was so close to home we have become more acutely aware of the distinct possibility of catastrophe. As Allison so aptly puts it "Don't Be Scared, Just Be Prepared. Start developing a plan and get in touch with civil defence to see what plans they have for you.

Ross Flood



# 60th Celebrations

## 12th March 2011

The Society will be celebrating the 60th Anniversary of the formation of the Spastic Fellowship (the organisation that was progenitor of the Society). It will be a posh affair. Member's invitations will be sent out in early December. Start planning your trip to Auckland now.

**The Auckland Museum, 4:30pm Saturday the 12th March 2011.**

