



The Review

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The Official Magazine of the Cerebral Palsy Society of NZ Inc

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Any opinions, findings, conclusions or recommendations expressed in this publication are those of the authors and do not necessarily reflect the views of the editor, Cerebral Palsy Society of NZ or Focus 2000

Cover

NZ CP Stats

Contents

◆ NZ Stats on CP	<u>Page 3</u>
◆ NZ Stats on CP continued	<u>Page 4</u>
◆ Boccia comes to Auckland	<u>Page 4</u>
◆ Winter Lunches	<u>Page 5</u>
◆ Society News	<u>Page 6</u>
◆ CP Conference Sydney-Feb 2009	<u>Page 7 & 8</u>
◆ Gob Smacked & Adult CE in CHC	<u>Page 9</u>
◆ Focus Rehab Rocks On	<u>Page 10</u>
◆ Catamaran Beckons Disabled Sailors	<u>Page 11 & 12</u>
◆ Sunset proposal goes to plan	<u>Page 13</u>
◆ Link up with Kiwichat Camp	<u>Page 14</u>
◆ Trike available for lease	<u>Page 15</u>
◆ Zsofi comes to Con ED & On Safari	<u>Page 16</u>
◆ Ak Alexandra Park Trotting Event	<u>Page 17</u>
◆ Rehab out West	<u>Page 18</u>
◆ An old friend drops in	<u>Page 19</u>
◆ Things to Explore	<u>Page 20</u>



Some NZ Statistics on Cerebral Palsy!



As the Aussies advertising campaign says 'So where the bl*%dy h#ll are ya?'. It has often run through my mind when I have wondered how many people have cerebral palsy in NZ and where they might be. It is our goal that every person with CP in NZ is aware of the Society and what it offers, and can therefore make an informed decision whether to join or not. But how big is our playing field?

In NZ there really has been little statistical data on people with Cerebral Palsy. All figures that the Society quotes are derived from the Australian CP Register, which is perhaps the most respected register in the world. We make the assumption that NZ is similar to Australia, and off we go.

A NZ Cerebral Palsy Register is being started at Starship (see previous REVIEW article) but it will be many years before useful data will be available. Most of the planning that is done by the

Society in regards to its programmes, is a bit of a licked-finger in the air exercise.

You can imagine how excited I became when attending the Ministry of Health's (MoH) Disability Services Consortium meeting in Wellington, when they mentioned their database called 'Socrates'. 'Needs Assessment and Service Co-ordination' (NASC) Agencies are contracted by the Ministry of Health to assess people with long term illness or disabilities for supports that they need. The Ministry then funds these needs. The NASCs used to report back to the Ministry in a non uniform manner. This has since changed and NASCs now report back in a standardized format, and this allows information to be captured easily and put into Socrates. One part of the data now reported is the person's disability. I was advised 12 months ago that it would be around March 2009 before data would be available from Socrates.

On the 1st March I emailed the ministry to see if they could give me data on people with CP in NZ, grouped into geographical areas and age group categories. They replied in the affirmative, and a week later I had the results. They said more work was required and the accuracy was not exact, but hey, for me this was pure gold!



	MoH	MoH	MoH	MoH	CP Society	
	0-4yrs	5-21yrs	22-65yrs	0-65yrs	0-65yrs	
Northland	3	34	31	68	19	28%
Auckland	25	140	307	472	225	48%
Waikato	10	97	56	163	8	5%
Bay of Plenty	5	10	11	26	23	88%
Hawkes Bay	3	14	51	68	4	6%
Taranaki	3	12	13	28	7	25%
Wanganui	0	10	20	30	6	20%
Palmerston Nth	2	4	21	27	6	22%
Manawatu	0	6	21	27	4	15%
Wellington/Hutt	1	14	16	31	11	35%
Nelson	3	28	55	86	8	9%
Canterbury	9	120	134	263	91	35%
Otago Sthland	9	67	103	179	8	4%
TOTAL	73	556	839	1468	420	29%

The figures in colour do not include people who are on ACC or those with mild CP who would not require MoH supports. They are only those whom the N A S C s have assessed. Along side is the number of members with CP that the Society has in those regions..... well, there's plenty of room for membership growth, but now we have data to prioritize our actions!

The age range splits relate to pre-schoolers(0-4), those probably in

school (5-21) and those who have left school (22-65). The MoH data mainly goes up to 65 years of age only.

Our sincere thanks go to the Ministry of Health for making this data available.

We now have a much better idea of the ball park we are playing in.

Harvey Brunt-GM

Boccia Comes to Auckland

South Auckland Boccia and Boccia New Zealand are hosting the North Island Champs. This is being held over Queens Birthday Weekend on Saturday & Sunday .The venue is the Otarā Recreation Centre, between the Otarā Shopping centre and MIT, just off Bairds Road, Otarā. This is your chance to come & see a Paralympic sport in action & support some of NZs best Boccia players. For more info look at the following websites www.cpsociety.org.nz or www.boccia.org.nz



WINTER LUNCHES

AUCKLAND

Where: The Sorrento, One Tree Hill, Auckland

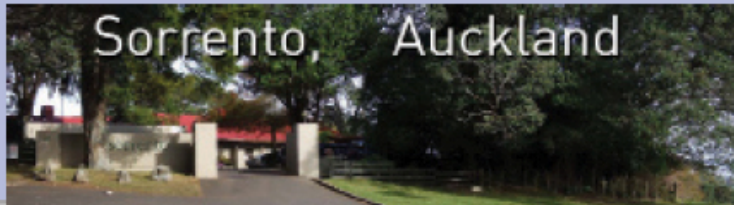
When: Sunday 12th July 09, Noon-4pm

Cost: \$15 member, \$15 carer, \$10 child, \$35 non-member,

Application form: Enclosed and on website

Forms must be received with monies by **29th Jun 09**

**This lunch is limited to 175 people only,
on a first in, first served basis**



CHRISTCHURCH

Where: Latimer Hotel, 30 Latimer Square, Christchurch

When: Sunday 19th July 2009, Noon-4pm

Cost: \$15 member, \$15 carer, \$10 child, \$35 non-member

Application form: Enclosed and on website

Forms must be received with monies by the **6th July 09**



If you wish to direct credit monies for the lunch, the Society's Bank account number is 12-3011-0809757-000, in reference specify your name and whether AKL or CHC lunch (NB: an application form is still required)

more information is on the Society's website www.cpsociety.org.nz



SOCIETY NEWS

Renewal of Membership

The Society's membership year goes from the 1st July through until the 30th June. So memberships are coming up for renewal. The cover letter sent out with this REVIEW can be used as your renewal form, and a freepost envelope is enclosed. Some of you have already renewed and some have just joined. The cover letter will advise you as to whether you need to renew.

getOutThere

For those on the getOutThere programme, the next issue of vouchers will be in June. They will be printed on blue paper. They will have an expiry date of the end of December 2009. Vouchers will only be sent out once your membership has been renewed!. Please use your yellow vouchers up first before your blue ones as yellow ones expire at the end of June 09.

The Society's Constitution

A couple of years ago a new Constitution was proposed, however it was not accepted at that time. That constitution is in the process of being modified and reviewed by the Board to take into account some shortfalls as well as ambiguity that presently exist. Over the coming months the Board expects to have a draft document to send out to members for their comments. If there is good agreement from the membership then it may be an agenda item for the AGM in October of this year.

AusACPDM (Australasian Academy of CP and Developmental Medicine.....whееееew)

This august body will be holding a conference at the Christchurch Convention Centre from the 3-6th March 2010. This conference is targeted at the medical and academic world, and showcases the latest research and finding on Cerebral Palsy. It is the first time it is being hosted in NZ. The Society is exploring the possibility of sponsoring a guest speaker on the subject of Stem Cell/Cord Blood research, a subject the Society is getting many queries about.

Conductive Education Awareness Week 25-29th May

There will be many functions and open days being run at the various Conductive Education (CE) centers throughout NZ during this week. Check with your local CE centre to see what they are doing. You can do this by going to www.conductive-education.org.nz and clicking on the links tab.



CEREBRAL PALSY CONFERENCE - FEB 2009 - SYDNEY

This conference was an international scientific/medical conference that is held every two years somewhere in the world. This was its first trip down-under.

There were 1355 delegates in attendance from 44 different countries.

The theme of the conference was **'Cerebral Palsy-Across the Life Span'**. I was to learn over the 4 days that not a great deal is known 'across the life span'. If your life span was 21 years then it would have been fine, but after 21 there is only scant knowledge/research of what happens to people with cerebral palsy, I found this very disturbing and an indictment of the research world.

Many sessions involved the presentation of research. Some research topics frustrated me as they set out to quantify what was already suspected and the subsequent affirmative finding, of what is common knowledge (certainly for anyone who has CP or a family member with CP) added little to the mix. It has emphasized to me that any support the Society gives to research must have outcomes that will make a difference.

An excellent presentation was given by Prof Karen Nelson from the USA, her work in the 90s proved that CP was there, well before the birthing process. This radically changed the thinking of the time. She gave a talk on the best chances for a break-through on preventing and minimizing CP. The following are some points she made:



- ◆ Elevated body temperature experienced by the mother prior and during delivery had a 7 fold increase of incidences of CP. Proper hydration can help with temperature control during this period as well as other techniques.
- ◆ Congenital malformations of a non-cerebral nature were also strongly linked to CP.
- ◆ A mother's long menstrual cycle of >30days was also correlated with an increase in CP.
- ◆ Of course the other factors of prematurity, multiple births, viral infections were also mentioned.
- ◆ Stressful births where CP may be likely in the child can be treated with hypothermia techniques (cooling the brain, a technique pioneered in NZ). There was a 50% efficacy with this



technique but it required skilled staff with appropriate equipment and so was not readily available in standard maternity wards.

- ◆ Of great interest is the use of magnesium sulphate (MgSO₄) taken by the mother during pregnancy. The magnesium sulphate has the effect of calming hyper activity of the growing brain (brain growth is most rapid from 20 weeks gestation through to 10 weeks after birth), relaxing muscles, acting as an anticoagulant and assisting with blood flow. It is a product that is well understood by the medical profession already, but its link in reducing CP has only recently been established.

A presentation by Prof Kerr Graham, an Australian orthopedic surgeon resulted in some interesting opinions, namely:

- ◆ That SDR (Selective Dorsal Rhizotomy) may be overused and long term outcomes need further monitoring. One problem with studies was that they were 1-3 year duration, and adverse affects often don't show up till 10 years later.
- ◆ Hip displacement was mainly due to 'activity limitation' and spasticity probably only played a small role..... use it or lose it.
- ◆ The growth spurts of adolescence would invariable adversely affect the motor function for the young adult.
- ◆ Monitoring a person with cerebral palsy all the way through to skeletal maturity was very important
- ◆ One of the general themes coming out was that when treating a child or young person, it was important to keep the eventual adult in mind. An operation in youth to enhance function in the short-term may negate the

possibility of other operations in adulthood.

A presentation by Dr Hank Chambers from San Diego (he has an adult son with CP) was the highlight.

He is a pediatric orthopedic surgeon in the USA. He has practiced for many years and now his patients are adults and return to him in adulthood as they do not know who to turn to. So although he is in pediatrics he sees many adults with CP. What disturbs him about adults he sees is a litany of issues that include:

- ◆ Lack of gynecological care or breast screening for women and osteoporosis after menopause
- ◆ Pulmonary function decrease leading to loss of speech
- ◆ Back problems and skin ulcers,
- ◆ Lack of self-esteem issues that lead on to antidepressant medication or substance abuse (mainly alcohol)
- ◆ Staying active and having a good diet are key to minimizing the effects of aging... just like the able bodied.
- ◆ Poor dental care that can lead to death.
- ◆ Having seen the adult, and considering the operations he performed on them in their youth, Hank now believes he operated far too often.

He painted a grim picture for people with CP in the US. The US medical system based on insurance companies made me feel great that I lived in NZ. We may not have the best system in the world, but most would envy us.

Harvey Brunt



Gob Smacked!

Just how important is it to keep your mouth, gums and teeth in good shape was brought home to me at the CP Conference in Sydney.

Dr Hank Chambers related how in his practice in the USA, he had witnessed a number of deaths of people with CP, the origins of which could be traced back to dental hygiene. Keeping gums and teeth in good conditions should be high in your priorities.

Electric tooth brushes have been proven to be superior to manual tooth brushes for dental hygiene. With this in mind we have requested the Disability Resource Centre (DRC) in Auckland to stock electric tooth brushes. You can visit the DRC online and purchase online at www.disabilityresource.org.nz But wait, there's more..... by joining the Society's getThis&That program you receive \$200 in vouchers to spend at such a facility..... hey presto, buy yourself an electric toothbrush.



To join the getThis&That program, download an application form from our website or call the office on 0800 503-603..... Just do it, and keep smiling!.....

Harvey Brunt



Adult CE Centre in Christchurch

A group of Christchurch parents have formed a committee to open a Conductive Education facility for adults with cerebral palsy. Their young adults are nearing secondary school leaving age. The concern of many parents is "where to next?"

The aim is to set up a facility in Christchurch that will meet the needs of the young adults. It will open on a daily basis, closing only for a break over Christmas holiday period. It is envisaged that each individual will be able to continue their established relationships with friends, gain life skills, and access recreational and work placements within the community.

Conductors would be employed to establish individual programmes both at the centre and in the community. There would be a continuing involvement with Speech Language Therapists, Physiotherapists, and Occupational Therapists.

There is a great need for a facility in Christchurch that caters for young people with physical disabilities.

Any persons interested in more information could contact

Camille Ross (Committee Member)

Email: stromboliolives@xtra.co.nz



Focus Rehab Rocks on

Sailing, Tai Chi and Physio, along with the always popular Focus Cup Boccia competition are all on the upcoming agenda, at Focus 2000's Rehabilitation Department. The vibrant and passionate Rehab team are leading the way, by introducing an array of exciting activities for everyone to enjoy. The team is made up of:

Lyn Dew (Service Manager), Margaret Moylan and Stacey Hardley (Sports Therapists), Evelyn Newell (Physiotherapist, waiting NZ registration), Sally Legg (Arts Therapist) and Paula Crimmons, (Drama Therapist).

The Rehab team has regular excursions to Westhaven to link up with the disabled sailing group "Sailability." Recently the team took five of its members to test the waters and they ended up learning to steer the yachts and rescue boats for three hours.



- ◆ The team are now qualified to teach modified Tai Chi which is an effective exercise for the body and mind. Modified Tai Chi is made up of slow gentle movements which can lessen the risk of falls by improving balance, coordination, flexibility and lower leg strength. Participants also report improvement with relaxation and sleeping, as well as other health benefits.
- ◆ Evelyn Newell has come all the way from Galway, Ireland to offer a physiotherapy service to clients. She is available to see people in the gym or at home for exercises which include stretching, strengthening and walking. She is currently waiting on her New Zealand physiotherapy

registration.

- ◆ Preparations for Boccia's Focus Cup are well on the way. It will be held at Papatoetoe's Allan Brewster Centre on the 4th and 5th of July. The Focus Cup is a well respected tournament with a great balance of fun and serious competition. Most of the past and present members of the New Zealand Boccia team started playing Boccia in this tournament, so come along and join in the excitement. You never know where your skills will take you. Registration forms are on the Focus and Boccia NZ website
- ◆ In addition to all these activities the Rehab department are completing an equipment project and have recently trialled a hoist, standing frame and tilt table
- ◆ "When I come here I feel good about myself. I need the exercise and the fantastic people here have given me a fitness program, that encourages me to get going," said Yung Chen a regular member of Focus Rehab.
- ◆ For more information about the above activities ring 846-6295 ex 831



Catamaran Beckons Disabled Sailors

Disabled Sailing Trust N Z is embarking on an exciting sea going venture for the disabled community of New Zealand.

The Trust is committed to making a significant difference to the quality of life of families and individuals affected by disability and serious long term medical conditions by promoting social, emotional and physical well-being through active participation in sailing and related activities.

The Trust's primary objective is to fundraise, build and operate a purpose built and fully adapted 16 metre catamaran that can be sailed by disabled people. Other activities will include fishing, swimming, kayaking, snorkelling or just sitting and enjoying a sail.

A feature of the catamaran will be a one level deck around the yacht and electric



access throughout the vessel. Another feature will be a platform that can be raised to deck level for wheelchair access and then lowered into the water for swimming or kayaking.

Since Roger Hill Yacht Design completed preliminary plans for the catamaran in late November 2008 the Trust's design team has consulted widely in the disabled and related communities to check that design features are as user friendly as possible. A few minor but important changes have been made particularly in relation to wheelchair users. Preliminary catamaran plans are on the website.

The Trust is now ready to move to the next stage, which is to employ a Project Manager to develop specifications, with our design team and obtain three quotes from boat builders. (Cost \$1520 +GST).





Once quotes are in and 3D visualisation graphics are created the trust will be in a position to approach potential major funders for capital to build the catamaran. To support approaches for funding the trust asks people to please visit the website.



The Trust will also have 3D plans drawn by Roger Hill Yacht Design to ensure details are right for this unique design. (Cost \$5,500 + GST) and to have 3D visualisation graphics created to assist with marketing.

The Trust has approached several parties with a view to financing this project. There have been some very enthusiastic responses from both organizations and individuals. If you know of anyone or any organization that may be able to assist please let Disabled Sailing Trust NZ know

www.disabledsailingtrust.org.nz and consider the Expression of interest on the "You Can Help page.

For further details contact trustees@disabledsailingtrust.org.nz
Postal Address Disabled Sailing Trust
PO Box 32 057, Devonport,
North Shore City, 0744
Phone Jon Kirk 09 445 2979

And for further investigation of these exciting possibilities visit the website www.disabledsailingtrust.org.nz



Sunset proposal goes to plan

Cerebral Palsy Board member, Immanuel Koks, had a predicament that needed solving. He wanted to propose to his girlfriend, Sarah, who he met early last year, at a one day conference, run by the bible college he was studying at.

Immanuel is unable to drive because his reaction speed is too slow. "That makes it kind of difficult to take your girlfriend on a surprise date, confessed Immanuel. " Anyway, what I did was give Sarah the keys and directions for driving, on a need to know basis. So I told her we needed to go over the Harbour Bridge. I then lead her up Mount Victoria, in Devonport, and waited until the sun was setting, (which we had a full view of), and then I proposed.



After that we went down to a restaurant to have dinner, where we enjoyed ringing family to break the news."

"One of his most vivid memories of the wedding day was when he was driven up to the church surrounded by the parked cars of the wedding guests. "When I entered the church I realised that all these people, had taken time out of their busy lives to spend time celebrating with us. We had 120 guests at the reception and quite a few more for the ceremony," Immanuel said.

Yes the wedding was a great occasion but "I felt that I was doing something pretty "normal" (by that I mean something many average people do in their life time.) Sometimes I feel it is more of a misperception about my CP, that it stops me being able to do normal things. Like falling in love, and choosing to spend the rest of my life with someone I love. When in fact what I am doing sounds pretty human to me. A situation that many people with CP could aspire to, if they like me chose a married lifestyle," he said.

Immanuel and Sarah value, highly, the many interests they share together. "Although I have CP and Sarah does not identify as disabled, she has a real interest in understanding the experience of disability, and shares my interest in disability studies. While the reality of my disabled body does mean we have to do things differently, I think it is also fair to say that this is a small part of our relationship," reflects Immanuel. The Society wishes to pass on its congratulations to Immanuel and Sarah who were married on 4th of April at Papanui Baptist Church, in Christchurch.



Link up with “KiwiChat” Camp

The Society has agreed to assist in sponsoring the “KiwiChat” camp, hosted by TalkLink Trust. Twelve school aged children, who use high technology communication devices as their main method of communication, will be invited, along with their families, to the Matamata camp in February 2010.

The primary aim of the camp is for the children using the devices to improve their device use and become more competent communicators. Intensive communication therapy will be provided each morning at the camp, and the afternoons will involve activities and opportunities for everyone to practice the skills they have learnt in the morning. The morning sessions will concentrate on language activities.

For example the children will be given open ended questions which will help initiate two way conversations. In the afternoons, activities which encourage communication will take place, such as treasure hunts and arts/crafts activities.

Throughout the day play money will be awarded to communication device users who “talk the talk” during activities. This money can be used at the camp’s tuck shop.



Organiser Leesa Ross, Assistive Technology Trainer, at Talklink Auckland is very pleased with the camp’s planning progress.

“Talklink’s branches in Auckland, Wellington and Christchurch have all been very supportive and there has been strong volunteer support” said Leesa.

KiwiChat camp information packs will soon be available. These packs include a detailed application form. The form is designed to give an overall sense of where the child is, regarding confidence and familiarity with the communication device. A video of the child is also requested showing him/her using their device in different situations such as school, home and community.

A separate sibling recreation program will be conducted in the mornings, and this time will provide an opportunity for parents/carers to discuss and work on issues around augmentative and alternative communication, such as how to program the device and tips on up skilling for support staff.

For further information on either applicant criteria or potential sponsorship contact leesa.ross@talklink.org.nz.



Trikes available for lease

Regular visitors of the Society's website would have read the article about 5 year old Ross Wadsworth's Round the Bays adventure. Ross was one of the recipients of the recently developed tricycle program funded by the Society. With lots of perseverance and encouragement from his parents, Tracy and Al, young Ross built up his stamina on his tricycle. Tracey read about the upcoming Round the Bays run and a family decision was made to enter their son into the event. The day was a huge success with Ross raising his arms in triumph as he crossed the finish line.



Your young Cerebral Palsy child could also greatly benefit from the tricycle program, as it will give them much needed exercise and independence.

Chris Havercort, a father of a daughter with Cerebral Palsy first approached the Society with the proposal of building a fleet of ten tricycles to lease to members. The society was supportive of this proposal and now there are 10 new trikes available in three sizes that are suitable for children from 3-14 years of age.

To become a successful applicant the user of the leased trike must have cerebral palsy or be a child attending the Auckland conductive education programme. The user must be a current financial member of the Cerebral Palsy Society of NZ and must be prepared to undergo an assessment for suitability for the special trikes. The user's family must be prepared to pay the current leasing costs. (Presently set at \$10/month (June 09))

Please note children that are capable of riding a standard tricycle will not be eligible for the special tricycles and an assessment is required before a tricycle is leased to an applicant. A tricycle may not be immediately available for lease and an applicant may have to wait for one to become available. Should the applicant be considered suitable for a special tricycle a lease agreement will be entered into.

A tricycle application form can be downloaded from the Cerebral Palsy Society website's homepage www.cpsociety.org.nz/ Click on the tricycle link in the left hand column. A copy of the leased agreement can also be viewed



Zsofi settles in at Conductive Ed

Our new Conductor, Zsofi Olah arrived in New Zealand on Saturday, 9 May and was welcomed by a Powhiri on Monday 11 May at Focus. She started work on Monday, 18 May, where a shared morning tea was provided for her. At the morning tea parents had the opportunity to officially meet her.

Zsofi is from Hungary; she has a 15 year old daughter and an American husband. Zsofi worked as a Conductor in Germany and the USA for a number of years and she is also a trained English Teacher. She has developed a special method of teaching English Language for children with learning difficulties.

Zsofi graduated in the Peto Institute, Budapest and has many years of professional experience.

She will be a great asset to our team. We all look forward to working with her at our centre.

By Barbara Csepcsenyi
Conductive Education Manager



On Safari

Mean while back at the Centre the children recently left their classes behind for a day and explored the

Auckland Zoo. By all accounts the children had a great time and were really fascinated by the variety of animals.

Rumour has it that the kids were acting out the antics of their favourite animal for weeks after the visit.



Auckland Alexandra Park Trotting



Food, Food, Glorious Food!
The seafood presentation was more like an exhibition to say the least, and there was every delectable dish imaginable - something for everybody to try. The beverage service was also excellent, such a treat to be waited on.

And! I've had feedback through the grapevine there were more than just a few lucky punters. I will definitely make sure I sit by those people next time (My life winnings - A stuffed penguin)

does not suffice .

Everyone had a great time, thank you to all who attended and made this event a memorable one.

All getTogethers are especially gratifying for the Society, knowing that we are achieving our purpose "To enhance the lives of people with Cerebral Palsy"

Cheers

Janet Chapman

Members Manager

- ◆ Fabulous night
- ◆ I'm glad I decided to come along
- ◆ So much fun
- ◆ Great to be part of a communal event
- ◆ Cool – Exciting – I get to dress up in my good gear
- ◆ WOW! I've never done this before

These are only a few of the comments from our members, who attended the big cup night at Alexandra Park in Auckland. Everyone dressed for the occasion and looked great. A glass of bubbly on arrival set the mood for some, while others opt for the juice. The venue (Top of the Park) was amazing.

With the mix of our members and the public, it was a very exciting place to be when the horses were heading down the straight towards the finishing line. The atmosphere buzzing with excitement and smiles from ear to ear, it did not take long before heads were down scanning the race books, and bets flowing at the totes.



Rehab out West



Nestled within the boundaries of Henderson's picturesque Tui Glen Reserve, is the Centre which houses the "Integrated Neurological Rehabilitation Foundation" The Centre's core service is a daily programme of Conductive Education for adults with motor disorders including Cerebral Palsy, Strokes, Parkinson's and Multiple Sclerosis.

There are currently 88 clients at the Centre who enjoy highly motivated classes overseen by two conductors. There are one or two classes per day for five days a week. The programs guide clients to discover new and different ways to overcome everyday problems, by helping to recover as much movement as possible on the affected side. The clients are encouraged to use this movement efficiently in everyday life, which gives them confidence and increased independence in everyday activities. Naturally the companionship within the classes, amongst people with similar problems, help achieve personal goals.

One of the most positive aspects of the centre is the presence of clients on the board of trustees like Kirk Wallace who has been a proactive board member for the past nine years, John Toole is the Community Support Services

Co-coordinator. John's input and personal understanding of the needs of clients who have suffered a stroke has been invaluable. Chairperson, Frank Schwanner, is the founder of the national foundation for Conductive Education in New Zealand and is an inspiration to all at the Centre

CEO Peter Coulson is justifiably proud of the progress been made.

"We appreciate the support of Waitakere Mayor Bob Harvey and his Council who gifted the original building to the Foundation, said Peter.

The official opening of the new Tui Glen Rehabilitation Centre was carried out by His Excellency, the Governor General of New Zealand, Hon Sir Anand Satyanand on the 17th September 2008.

The new building is three times as big as the original which has made future plans possible. The aim is to establish a wellness hub in the heart of Waitakere City which will include a Disability Resource Centre providing mobility equipment and resources, a tailored Community Training package focused on delivery of care and support services in partnership with WINZ and the setting up of a drop-in centre /art gallery.

For more information contact
Integrated Neurological Rehabilitation
Foundation

Tui Glen Centre

Henderson

PO Box 21 504 Henderson

Ph 09 836 6830

Fax 09 836 6832

Email: admin@inrf.org.nz



An old friend drops in

My name is Cindy Evans. I was once the manager of M E C A , (Movement Education and M o b i l i t y Rehabilitation) for the Society and Focus 2000. It was my role to get people with cerebral palsy to exercise, to teach them and their support crew how to move and relax



so as to promote long term health. We also took daring men and women out into the world of sport, recreation and adrenalin pumping experiences.

Then my dad had a stroke, I turned 40, and with my children I decided to turn my life upside down and changed it all. I studied for a couple of years in NZ for a PhD as a way to validate the training that we had been developing at Focus. During that time I also found a couple of pieces of technology – a massage unit that works(!) and an inversion swing. I have spent the years since then researching them, adapting them, teaching people with disabilities how to use them, and selling them.

When I was able to return to Australia with my children I gave my studies a miss and took up living beside the seaside surrounded by my family.

My dad is still alive and kicking and I

have felt like I have been given a gift every moment that we spend with him.

For a living, I now work as a disability consultant for local government and a movement education consultant for people with disabilities and body pain. I still volunteer as a classifier for Paralympic sport and seek out people with cerebral palsy to train and condition. This year we are starting a new bocchia club.

My daughters Brooke and River are great swimmers who play musical instruments, sing in choirs, body surf like seals and are just plain happy. This year we got two pets – a dog called Bubbles and a snake.

And that is what we are up to.

Cindy



Things to Explore

- ◆ Have you had a look at the Cerebral Palsy Website lately www.cpsociety.org.nz/? Every week a fresh article appears on the website's homepage. So far this year there has been articles covering the CP conference in Australia, accessible train rides, theatre productions with a disability theme and coverage of the new Minister for Disability Issues, the Hon. Paula Bennett. These articles can be read in the archival section which appears at the bottom of the home page. This section goes back to 2007.
- ◆ The right hand column of the home page features current and upcoming news and events and the left hand column features the five programs the Society offers. These programs include the very popular getOutThere program, which offers vouchers for total mobility users and the getThis&That program, which allows members with cerebral palsy to purchase small items that are needed to manage the affects of their cerebral palsy. There is also a link for grants for more expensive items.
- ◆ Go to www.cpsociety.org.nz/ and become more informed about your Society.
- ◆ One of our website articles featured the activities of Communicare There are twenty-two communicate centres around Auckland where disabled and elderly people gather once a week, to perfect their arts and crafts skills. There is an annual subscription of \$15 and each centre asks for a small weekly contribution to help with costs of resources. The money also goes towards supplying morning tea and lunch which includes scones, pikelets with jam and cream, sausage rolls and soup in the winter Take a look at the article entitled "Join family that Cares" in our homepage archival section and/or go to the communicate website www.communicare.co.nz , to see if this is for you.
- ◆ Another way to meet new friends and catch up with old friends is to join Facebook www.facebook.co.nz/ . It's free and anyone can join. All you have to do is sign up and you can chat to your heart's content. Try it. It's fun and thoroughly entertaining.

