

Huntington's NEWS

The quarterly newsletter of the
Huntington's Disease Associations of New Zealand

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Issue 108

Did She Fall or Was She Pushed?

The Prince Memorial Charitable Trust was pleased to be able to help a young member of an HD family achieve her dream. We were there when she was thrown out of a plane at 10,000 feet, attached to the front of the guy with the parachute! Apparently she screamed, so we know she didn't hold her breath all the way down!

The event was filmed for posterity, and a DVD will soon be arriving on her doorstep. The camera man was excellent and interesting to watch as he captured little details to make the story.

It was a beautiful day, with very little cloud. The whole jump was visible to those of us watching from the ground, including a rather exciting moment when the parachute was made to spin, or rather, those on the end of it spun!

It seemed to be over all too soon, with a very happy young lady waving madly as they came in to land right in front of us. We all enjoyed the event – even those of us who kept our feet firmly on the ground!

Jan Pickering
Prince Memorial Charitable Trust

Chevana writes: "I want to thank the Prince Memorial Charitable Trust for making my dream of skydiving come true. It is something I have wanted to do since I was little. It was crazy and I loved it. It was wonderful to have my family there watching and to have the DVD so I can always remember this day"

Thank you
Chevana



South Island Region Annual Camp/Retreat for Young People

The Christchurch Huntington's Disease Association is asking for expressions of interest of young people in the South Island Region who would be interested in attending a Young People's Camp/Retreat, later in the year.

Please contact Dianne Collins on 03 9605913 evenings or email ddc2@clear.net.nz by the *30th April 2010*.



Annual Camp for Young People for those 12 - 18 years old September School Holidays

The proposed Camp for young people will be held in the September School holidays.

We welcome all young people from Huntington's families from throughout New Zealand between the ages of 12 -18 years.

As with past Camps, there will be a mixture of outdoor activities and time to discuss and share knowledge on Huntington's Disease.

All interested participants should indicate their interest *as soon as possible*, and once we have expressions of interest, we can advise details.

It is important that you email, text, ring or contact your local Huntington's Advisor or email Jeanette Wiggins, Huntington's Advisor,

Wellington Huntington's Disease Association
jwiggins.wellingtonhda@hotmail.com by *9th April 2010*.

Brain Day 2010: Unlock the secrets of your brain!

The Centre for Brain Research and Neurological Foundation will host a free public open day and science lab on March 20th as part of International Brain Awareness Week

www.cbr.auckland.ac.nz

Join neuroscientists, clinicians and community groups to learn more about our greatest asset – our brain.

- Lectures from clinical and scientific experts on the latest research and treatment trials
- Science Lab area with hands-on experiments and fun brain teasers
- Kids area with fun tests you can do at home, along with a gigantic brain art area!
- Community Expo with information on support options

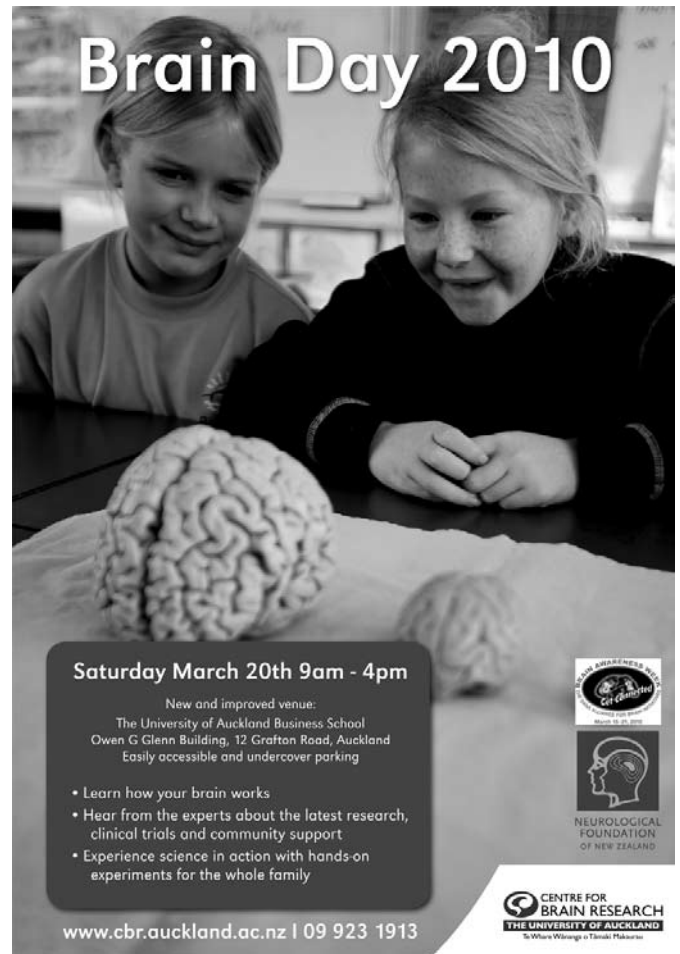
WHEN: Saturday March 20th
9am-4pm Free event

WHERE:

The University of Auckland Business School
Owen G Glenn Building
12 Grafton Road, Auckland

Easily accessible and serviced by public bus services
50, 348, 487 and LINK

Undercover parking for \$5 all day



Brain Day 2010

Saturday March 20th 9am - 4pm

New and improved venue:
The University of Auckland Business School
Owen G Glenn Building, 12 Grafton Road, Auckland
Easily accessible and undercover parking

- Learn how your brain works
- Hear from the experts about the latest research, clinical trials and community support
- Experience science in action with hands-on experiments for the whole family

www.cbr.auckland.ac.nz | 09 923 1913

NEUROLOGICAL FOUNDATION OF NEW ZEALAND

CENTRE FOR BRAIN RESEARCH
THE UNIVERSITY OF AUCKLAND
Te Whare Waiorangi o Tamaki Makaurau

NEWS FROM THE REGIONS

Auckland / Northland News

Hello Everyone

I hope you have all had an enjoyable festive season and some time to enjoy the best of the beautiful weather. As the Auckland and Northland region will know, I have had an extended summer break, so I am now reenergised and ready for 2010. Jane has done a fantastic job in my absence.

On 11th February we were fortunate to be present at the Brainwaves Seminar on Huntington's disease at the Centre for Brain Research in The University of Auckland - the audience was 50 emerging neuroscientists.

The presenters were:

- Virginia Hogg, Research fellow, department of psychology.

Virginia is coordinating the CREST-E creatine trial in Huntington's disease with Dr Roxburgh at ADHB. She is a member of the neuropsychology research

team with Dr Lynette Tippett in the Centre for Brain Research

- Toby Lowe, PhD student Department of Anatomy with Radiology

Toby is co supervised by Dr Henry Waldvogel in the lab of Professor Richard Faull in FMHS and associate Professor David Christie in the faculty of science.

He is researching the effects of creatine on human brain cells, one of the only teams in the world currently doing this

- Jo Dysart family liaison coordinator for HDA and Huntington's Disease Nurse Specialist for ADHB
- A wonderful and brave Huntington's disease client

Together we were able to show a unique insight into the care and treatments of Huntington's disease which families need and deserve.

Continues on page four

Continued from page three

It was a positive and energising afternoon drawing emerging researchers, research, HDA, clinicians and HD families **TOGETHER**.

The Auckland and Northland Association needs you!

Our AGM will be held in June or July we would like you start thinking about what skills you have and how you can help your association to continue growing from strength to strength.

We need your help! Would you be willing to donate a couple of hours of your time each month as a committee member?

Committee member's roles are as follows

Chairperson – Someone with a good business sense and strong leadership skills

Treasurer – Someone with financial acumen to guide the charity's finances. *All bookkeeping is done by an external accountant.*

Committee members – People with time, energy and enthusiasm to help us keep up our good work!

If you are interested in helping, please contact Jo Dysart at huntingtonsakld@xtra.co.nz

Don't forget Brain Day 20th March 2010 9am till 4pm

Bye for now

Jo and Jane

Wellington News

(Covering the following Wellington Huntington's Disease Association areas Hawkes Bay, Taranaki, Wanganui, Wellington, Wairarapa and Gisborne).

Greater Wellington

Happy New Year to you all. Unfortunately, down this end of the North Island the weather over Christmas and New Year was terrible and of course, now that we are back at work and school, summer has arrived. I hope you all had managed to have a good Christmas in spite of this.

I am catching up with clients and if I haven't seen you yet I will do so as soon as possible. I have been busy over January with new clients and also did manage to have a great night away and Chinese dinner with some carers. It is so helpful for people to share their personal experiences in an environment where the others understand the trials they are each going through and we all felt the benefit of this.

I am hoping to have an information stand at **Brain Day on Saturday March 20th**. This is held as part of Brain Awareness Week 2010 and was well attended last year. It features lectures and seminars with displays by community awareness groups and is run from 11am to 4pm at Rutherford House Pipitea Campus of Victoria University. This event is supported by the Neurological

Foundation and it would be great to see any of you there.

We have restarted swimming at the hydrotherapy pool last week. This is always a popular activity for Amaryllis House residents and community clients and runs year round.

My lemon juice was a great seller at Christmas as people gave it as a gift to friends and colleagues. I am fortunate to now have the sugar donated monthly by Pak 'n Save Petone which means that the profit increases and more clients and families can be assisted. Donations of lemons continue to arrive on a regular basis.

I am anticipating a busy year with some new initiatives. I hope to establish and continue with visits to families and carers.

If I can help you specifically and haven't visited you yet, please call me.

Regards

Jeanette Wiggins

Taranaki, Wanganui and Palmerston North

Well the Christmas break and holidays have been and gone and we are now into February. The weather in New Plymouth has finally warmed up and we are enjoying some long hot summer days, but seem to be plagued by the wind.

I started back at work on 18th January and have been busy since then meeting new people, supporting families and presenting education programmes throughout the area. I have had a two day trip to Palmerston North,

Continues on page five

Continued from page four

Wanganui and Fielding. I am hoping to get to these areas at least twice a month.

In the Taranaki area the support group is up and operating. We had a great Christmas lunch on the 17th December with 15 people attending including families, caregivers and people affected by Huntington's. The Wellington Association committee provided funding for this inaugural lunch, so thank you. It was certainly worthwhile with people arriving about 12.00pm and the last ones leaving about 4pm. It was a great opportunity for everyone to chat and get to know each other.

We have another meeting on 16th February that we are all looking forward to. Our group would like to make a trip to Amaryllis House so that families can see the facilities and talk to staff, hopefully we can organize this for the near future.

Since starting back at work this year I have focused on presenting education sessions and have already completed three sessions with more booked for the coming month.

These have included several rest homes, DHB and will soon be presenting sessions to GPs and PHOs.

In the near future I will be sending letters of interest to Palmerston North and Wanganui families to investigate the idea of setting up support groups in your area. I have already spoken to several people and received positive feedback. If I have not yet contacted you and you are interested please email at ljans.taranakihda@hotmail.com. I hope to have the first Wanganui meeting in March before Easter.

Please don't hesitate to contact me at any time if you would just like to chat, would like a home visit or require some support. My contact details are (06) 7581487 or 027 4966500 call or leave a message and I will get back to you as soon as possible. My email address ljans.taranakihda@hotmail.com

Kindest regards

Lorraine Jans

Hawkes Bay News

Kia ora koutou. Hello to you all and I wish you well for 2010.

Here in Hawkes Bay we continue to support each other with regular Support Group Meetings and Carers Coffee Mornings. We also join in with the MS Society on their Monday Day Programmes and will continue our Physio group with them at the Hospital. The families here in the Bay are wonderfully welcoming, so please give me a call if you would like to come along to any of our regular or

special events. New upcoming activities will include a Men's group and another GP forum with local families.

The following poem has been written by a truly beautiful woman who has taken her life in her hands and is leaving her home in Napier to begin a new adventure. She wrote this to say goodbye to us. We salute her strength and courage and send our love with her on her journey. We'll miss you, Linda.

"I want to say goodbye today and I want to do it my way.

I have a lot of questions, still, just hope they're answered one day.

We've walked together in a personal way, our journeys different... but mostly the same.

Fear and doubt are the enemy here, so I'm standing my ground against that.

I'm starting to live as I've not lived before and hoping what I sow I'll get back.

I love you all and I will miss your stories.

I want life and peace and joy for you all.

Goodbye for now and thanks for your friendships.

I'll not ever forget:

Courage, truth and the love that you share.

Linda 31/01/10

I am available to meet with individuals (usually like to take you out for coffee and cake!) and families, as well as with health professionals, and community groups. Please

feel free to contact me anytime for a chat/information/to make a time to meet up.

Looking forward to seeing you,

Kind regards

Tanya

Continues on page six

Continued from page five

Gisborne News

Happy New Year to all of you, I hope you all had a wonderful relaxing Christmas break.

Not a lot of news coming from Gisborne as it is our quiet time of year.

I would like to say good bye to two of my Huntington's friends Gwen and Grace who are both moving to Tauranga to be closer to their family; it has been a pleasure knowing both Gwen and Grace.

Our local Huntington's support group meets on the 2nd Saturday of every alternative month at 12 noon for a lunchtime meeting at the Tatapuori Fishing Club. Everyone is welcome. Please come along and share ideas, stories, needs etc. The next meeting will be 10th April 2010.

Anyone wishing to contact me for support or advice please feel free to contact me on 06 868 8878 or

027 686 9432. Please leave a message and a contact phone number and I will call you back as soon as possible.

On the 22nd February I met with Dorothy Tortell and my fellow HD Advisors at Dannevirke. It was a pleasure meeting up with such dedicated people; I enjoyed sharing and listening to the experiences of my fellow H.D. Advisors, it is great to know that there is so much help and support for H.D sufferers, Care persons and H.D. Advisors.

Any one feeling that they need some support or just a chat even just to let steam off please contact me on the numbers above often a problem shared is a problem halved.

Regards

Cheryl Morley

Christchurch News

Greetings from Christchurch ...

My, what a difference the warmer weather makes to how you look at things. Taking time out of your busy day to sit in the sun, or under the shade of a tree, just looking at the world go by is certainly invigorating.

The Christchurch HD Association has just held their annual BBQ, which is always a special time to sit and relax, catch up with friends and family members that we sometimes do not get to see that often. It is always hard to sometimes make time in our busy lives for the simple things, like sharing a meal together. I always come away from this event thinking what a wonderful group of people our HD families are. The strength we gather from each other, to carry on and support not only our own family, but those around us who need that extra help or ear sometimes.

It is a very exciting and emotional time for our association as the tenders for the Service for Residential Care of People with HD and Other Neurological Disorders under the Age of 65 draws to a close. We have met with providers, answered many questions and shared our wish list for this care package, and now are waiting to see who secures this very important service for our loved ones. We put our whole faith and our HD peoples quality of care, in the panel that will make this very important decision, and trust they will do us proud.

For an association that has been lobbying government agencies for 20 plus years, written submissions and reports galore, this is the reality of many years of hard work and struggle from families whose loved ones will never get the benefit or use the service, but we can rest easy, knowing that future families will have the very best care package for their loved ones available to them.

I must thank you all for the time and energy that you have put in to this, your honesty and stories love and tears. I look forward to celebrating with you all, as this service opens its doors on the 1st August 2010 in Christchurch.

I have just looked up my calendar to see which day of the week it falls on and was delighted to see it is a weekend day. I will not have to encroach on my employers' generosity and endless support that I have been given through this whole process, to have time off yet again for HD.

We will keep you posted on our journey, take care everyone

Dianne Collins

Chairperson HD Christchurch



Huntingtons Trust Wellington and Central North Island

The above Trust was set up in 1993. The aim was to get enough funds to enable it to help with the day to day running of the Wellington Association and/or specific projects.

Bequests to this Trust can be made in cash, shares, real estate, or any other property and can be by way of a gift during your lifetime or can be bequeathed in your will. Bequests are free from estate duty.

If you require further information please write to:

The Chairperson of the Trust,
P O Box 30420,
Lower Hutt 5040



Mailing List for Huntington's News

To help us keep the mailing list as up to date as possible, could you please remember to drop us a note when you change your address. Include the name or names you want on the envelope plus your old address and new address.

If there are any mistakes that need updating, or a family member who received the newsletter has died, please let us know about them also.

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Huntington's News is the national Newsletter of the Huntington's Disease Associations of New Zealand. It is published quarterly (March, June, September, December) as a means of communication between the Associations and all individuals with Huntington's Disease, their families, their caregivers and professionals interested in the condition.

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- ◆ Pub Charity Inc – for assisting with projects during the year
- ◆ New Zealand Post for Community Post Envelopes

Many thanks to all who continue to make private donations to our Association.



Contributions

Write to us about this newsletter, about information you may need, about information you may want to pass onto others. Write to us about controversial topics such as privacy, confidentiality, access, support, etc...

We would like to hear from you.

The next issue of Huntington's News will be published in June 2010. The deadline for material to be received for this issue will be 10 May 2010. Please send any contributions for Huntington's News to:

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PO Box 30420,
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or email: info.wellingtonhda@xtra.co.nz



IMPORTANT NOTICE: HUNTINGTON'S NEWS and the INTERNET

Please note that any article published in Huntington's News may be selected for reproduction on the INTERNET on the "Huntington's Disease Scene in New Zealand" website www.huntingtons.org.nz
If you are submitting an article for the national newsletter, please indicate to the editor if you prefer your article not to be reproduced on this site.

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