



Huntington's NEWS

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

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Issue 110

Personal Story: *Our HD Journey*

At the AGM of the Wellington Association in October, after 10 years on the committee, the last five as Chairperson, I will be leaving the Association. I would like to thank those who have helped me and my family in the 13 years since my wife, Bronwynn, was diagnosed with HD.

On 7th August 1997, Bronwynn was told by a Neurologist in Napier that she had Huntington's Disease. While she had not been well for some time, this final diagnosis was a shock, and one which Bronwynn did not handle well, developing severe anxiety which resulted in three spells of a week each in the Hastings Psych Unit. On 2nd December 1997, on release from her third hospital visit, I took Bronwynn to Noel Hamilton House in Greytown for her first respite care stay of two weeks which was the first of nine respite visits. During these early days, Jane Harkness was the Social Worker in Napier and the first person to go out of her way to help Bronwynn and our family. Thanks Jane.

Within two weeks of diagnosis, Bronwynn was unable to work again. A programme of craft work days, rest home respite days and care afternoons with friends filled her week. Faye, our carer nurse, began her daily visits to help Bronwynn with morning cares and breakfast while I worked early in the morning before taking over for the day. Friends Yvonne and Pat spent many hours with her and became closer friends when others drifted away. Many thanks, Faye, Yvonne and Pat.

We joined the Hawkes Bay HD Support Group and were grateful for the understanding of this group. I then became a member of the Disability Advisory Group of the Hawkes Bay District Health Board as they included in their wish list a facility for the care of those in the 16 – 64 age group. Within a year, I had convinced Presbyterian Support that such a facility was needed and "The Beacon" in Napier was established. HBDHB had been working on this for 15 years but without result. The "here is Bronwynn, she needs daily care – what can you do for her" approach worked.

After three years of respite care, largely at Noel Hamilton House, Bronwynn went in to full time care in Greytown. Jane Harkness and Dorothy Tortell, who was then Wellington Social Worker, were instrumental in arranging this and this difficult decision was made easier by Dorothy's understanding of when this move would be right for Bronwynn and the family. I first met Dorothy when she visited us at home in Napier. Dorothy's

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work for us and the HD community has been outstanding and she continues to do this today “as a wonderful hands on” Patron who continues to provide her experience and advice to the committee and the HD advisors in the Wellington region. Dorothy, your work is much appreciated thanks.

Noel Hamilton House was home for Bronwynn for about three years, firstly in the old Greytown Hospital and then in the new purpose built eight bedroom care facility for those in the 16 – 64 age group. Four of the eight residents there at that time had HD. The bench top is the same colour and product as that at our home in Napier and Bronwynn’s input into the original design. When she went into care, I joined the HD Association committee and the first meeting I went to was a trip from Napier to Wellington and return. The car clocked up the miles as I visited Bronwynn fortnightly, a 500km round trip, three hours each way. I decided to move to Upper Hutt which then meant that visits to Greytown were then only 40 minutes each way. The management and staff at NHH did a great job and this was the right decision to place Bronwynn there.

Approval for a specialist care facility for those with HD was approved by the Ministry of Health and because of my interest in age appropriate care and the best care that I could get for Bronwynn; I agreed that she be transferred to a temporary house in Upper Hutt while the new Amaryllis House in Lower Hutt was being built. This short term move for a few months stretched to over a year but in September 2004 Amaryllis House was opened and became home for Bronwynn until she passed away last year. AH has developed as a centre of excellence for care of those with HD. The management and staff have also developed as carer experts in this field. Thank you Margaret and your team.

The Wellington Association Committee comprises on average 10 members, most of whom are HD family members who have or have had difficult home experiences with family members with HD. We have built up a network of four advisors who cover the whole region from Gisborne and New Plymouth in the north to Wellington in the south. Dorothy is providing supervision and training for the advisors. The Committee of volunteers and advisors dealing with the difficult situations which HD provides all are deserving of thanks for the work you do for the Association. Nikki, Carol, Jeannette, Pam, Lynn and many others – thanks for your help and support.

I am moving back to Napier so the wheel has gone a full circle. I now have a granddaughter there. When Bronwynn was diagnosed I realized that this condition could affect the whole family and 13 family members now have HD or are at risk.

Cecil O’Neale



Strategies to Enhance Communication

Introduction

It is important to understand that communication is a two way process, and that changes in one person mean that modifications are often required on the part of those around them to make communication successful and enjoyable.

It is therefore important to devise a system to establish an effective way of communicating needs, feelings and emotions. Both parties can use these strategies:

1. Slow rate of speech

Model this yourself. Pause between sentences. Encourage the person with HD to “slow down a bit” so that words do not run together.

2. Overemphasize key words

The main goal is to understand the basic message being conveyed. You can do this by saying, “just tell me the main words of what you want to say”.

3. Repeat or rephrase the message

Ask them to repeat or rephrase their message. “I am sorry, I am not following that; can you tell me again in other words?”

4. Simplify the message/offer cues

Ask the person to show you via gesture or pointing to clarify the message. You can achieve this by asking questions. “Tell me the two main words. Give me the key word or thought.”

5. Ask for clarification

Repeat message back. “Did you say . . .?”

6. Spell part of the message

“Could you spell that?” You can use verbal spelling, written spelling or a letter board.

7. Use Yes/No questions (be specific)

This makes responding to questions easier.

8. Refocus the person on topic

Use the person’s name or say “We are talking about now”.

9. Go from general to specific

For example “Are you talking about family?” then “Are you talking about your daughter?” etc.

10. Monitor preservative (repetitious) behaviour and provide feedback

Reduce the number of times you change topics during a conversation. Allow some time to pass before introducing a new topic. Let the person know when they are stuck on a topic. “Let’s talk about now”.

11. Allow adequate time for communication

This means making time to fully understand the message and giving the person time to think of a way to respond.

12. Reduce distractions when having a conversation

13. Use communication aids if they have been found to be useful

Try letter boards, word boards and picture boards. All communication aids need to be designed individually and change, as the person’s needs change. The basic guideline in achieving effective communication is for the listener to consciously accept the responsibility for the conversation exchange. Because of the cognitive deficits, which occur, the person with HD often needs to rely on external cues and guidance from the listener to achieve communication. It is also important to realise that whilst you accept the responsibility for the exchange, you must not control the conversation. When interacting with a person with HD who has communication difficulties, it is recommended that you speak with a Speech Pathologist to help you implement, monitor and adjust communication strategies.

REMEMBER It is the skill that degenerates, not the need to communicate.

Acknowledgement:

Newsletter – Huntington’s Queensland – May 2010

Useful Tips When Visiting a Care Facility

Visiting people with Huntington's Disease is sometimes avoided because of the difficulties experienced with communication and speech. However, it is important to the person with Huntington's that you visit as it helps sustain an awareness that the person is a valued part of a family or community. Remember that the visit is not just for communicating facts and information but also for nourishing the love and relationship that you share together.

Plan your visit

- a) Gather pictures of people to flesh out family news and bring in samples of any projects you have underway. For example, show the person swatches, fabric, patterns or paint chips as you describe what you are doing.
- b) The person with HD may enjoy listening as you read something relating to their past interests or hobbies. If this becomes difficult, books with pictures relating to the person's interests may be something to do together. For example, pictures relating to past trips around Australia or overseas.

Check with the staff if you can bring along

- a) A favourite treat
- b) A pet, if the person enjoys animals
- c) Flowers, pot plant, anything to brighten up the person's environment. The more people have to comment on the greater the number of exchanges.

Try to visit at a regular time

- a) This makes your visits predictable to both the staff and the person you are visiting. Predictable routine is one of the most useful orientation devices we can offer a person with cognitive impairment. It gives the day and the week a structure and allows the person time to prepare themselves for the next event.
- b) Remember people will have some times of the day when they perform better than others. Similarly their abilities may vary from day to day. Take this into account when visiting and don't immediately give up if the visit didn't go as expected.

Relaxation

- a) If the person with HD has difficulty conversing, gentle touch or holding the person's hand may be soothing.

Anything that can help the person relax, or become calm is most likely pleasurable.

- b) A simple hand massage with a pleasant lotion or fragrant oils is a good start. Some female clients may also enjoy a manicure or pedicure.

Communication

- a) Address the person by name and speak face to face using short, concise and simple sentences. Maintain eye contact and focus on one idea at a time. Avoid environments that are noisy, crowded or have too many distractions.
- b) Avoid questions they can't answer. Instead of "What did you have for lunch?" perhaps ask "I hear you had fish for lunch today, did you enjoy that?"
- c) The person with Huntingtons needs time to frame their answer, so allow time for a response.

Be Aware of the Huntington's mask

Recognise that it becomes difficult to see how people are really feeling or what they are actually thinking due to changes in muscle tone and muscle impersistence. They may be smiling inside but present as being bored and indifferent.

Reminiscing

- a) For example, bring a picture, cut one out of a magazine, or make one to put on their bulletin board. Make a scrapbook or memory book full of photos that depict the person's interests, hobbies, family, career and preferences. Write in large letters and illustrate it with photos, newspaper clippings, bits of fabric, medals etc. Use smell, music, colour, photos and textures during your visit.
- b) Bring up old memories and stories about family members, favourite holidays, fishing trips, and pets. Talk about the family, neighbours or gossip. Even if the person is not fully aware of the issues, s/he can enjoy the act of listening and talking. Being together is important for both of you.

Music

Sing a familiar song. Nobody will mind if your singing isn't very good. Take along recordings of the family or children. Listening to familiar music can be

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purely enjoyable or it can provide some openings for reminiscence or conversation.

Walking

Go for a walk to parts of the facility they may not usually see.

Smile! People enjoy a smile even when they can't smile back.

Just being there; never underestimate the power of your calm and attentive presence.

Welfare Team

Huntington's Queensland

Acknowledgement:

Newsletter – Huntington's Queensland – March 2010



Huntington Disease Discovery Provides New Hope For Treatment

Huntington's Disease is a genetic disease with no cure, characterised by a steady decline in motor control and the dysfunction and death of brain cells. The cause of the disease has long baffled scientists. Symptoms tend to first appear when the person is in their thirties or forties. The most common symptom is jerky movements of the arms and legs. A person with Huntington's Disease may also have difficulties with speech, swallowing and concentration.

Using state of the art technology, Dr Danny Hatters and his colleagues at the University of Melbourne's Department of Biochemistry and Molecular Biology at the Bio 21 Institute observed how human mutant 'huntingtin' proteins form into large clumps, which kills brain cells and leads to progressed HD. "Steps prior to the clustering of the mutated proteins were thought to damage cells, but these steps were not clearly detectable under a microscope," Dr Hatters says. "Understanding this process and finding the right target to block the ultimate death of the brain cells has been extremely difficult to determine," he says.

The technology called analytical ultracentrifugation and the methodology the researchers developed enabled them to visualize this process in much greater detail. "What we have shown and are the first to show, is that mutated huntingtin protein forms three different sized clusters in the damaged cells," he says. "This discovery will help to develop a targeted treatment that shuts down the key processes causing the clusters to form and for the disease to progress."

While researchers previously thought that small clusters of the mutant protein kept accumulating over time until they overwhelmed and killed the brain cells, Dr Hatters' team found that these clusters were static, which means they form in a more unpredictable manner than previously thought. The discovery reveals the clusters place a steady stress on cells over time rather than steadily building up over time to some critical "toxic" level as previously thought.

"Why it takes so long for the cells to die in human disease is not known - however it could be that cells eventually cannot compensate anymore from the process where toxicity is built up to form one cluster called oligomers," he says. "The real key of our work is that we now have direct targets in the critical steps in the process of cell toxicity and death and to gauge any therapeutic effects of drugs on these targets. We can also measure how this alleviates cellular toxicity and brain cell death."

"Importantly our research techniques could have application in assisting to find drug targets for other neurodegenerative diseases where toxic clusters of proteins play a role in the progression of the disease, such as for Parkinson's Disease."

The research is published in the current issue of the *Journal of Biological Chemistry*

More information: Contact Rebecca Scott, Media Officer, University of Melbourne. Mobile: 0417164791

Source URL: <http://newsroom.melbourne.edu/news/n-328>

Acknowledgement:

Newsletter – Huntington's Queensland- August 2010

Auckland / Northland News



Dr Henry Waldvogel talking to the HD Auckland Conference

HD Auckland's Annual Conference

The HD Auckland Conference and Annual General Meeting on July 24th was a big success. Around 80 members participated in the day, featuring reports from the committee, ideas for the future and talks on the latest research.

It was the first time our new chairman, Mark Dunlop, took to the floor to greet members and outline his vision for the association. He described how the global 'Credit Crunch' has affected many charities, with funds harder to access and also needing to go further. However, Mark said that he is hopeful for the future of the group, thanks to careful financial guidance from Richard Price.

"My view is that our focus going forward needs to be client-centred" says Mark. "We should always be asking ourselves 'how best do we meet the needs of a growing clientele of more than 300 current clients north of the Bombay Hills?' We need to make sure that the services we provide through Jane and Jo and others, are our priority."

Mark talked about the possibility of separating the management of the operational side of the association from the funding committee. "These are the two key streams of running the association and with separate focus we believe that both can be improved," he said.

The AGM saw Richard officially resign as Chairman of the association and take up the role of Treasurer. He said "I have been honoured to serve with the Huntington's Association Committee, and I hope my work has put

the governance of the group on to a more stable footing. With the skills brought in by Mark, I know we will go forward to help where it really matters – the families living with HD."

The group has had a very successful year for funding applications, actually bringing in an extra \$10,000 to fund vital services. The group has also grown in its ability to support members, with 895 more face to face visits this year. The team has also made 16,759 client contacts this year as opposed to 14,502 in 2009.

Family Liaison Coordinator Jo Dysart described the range of activities undertaken throughout the year. The group has given talks across the country to help educate people on the management of HD, including three carers days and visits to allied groups in Whangarei, Dargaville, Taranaki and Invercargill. Jo Dysart and a very brave HD family member talked to the Centre for Brain Research young scientists in March, which was received with much enthusiasm. Jo and our Family Liaison Officer Jane Devine also visited Vancouver to present the latest research on HD care in New Zealand. The model of working with patients in the community created great interest with international researchers.

Jo Dysart says, "We had a fantastic opportunity to network with the other associations from around the world and were very privileged and reassured that here in NZ we are at the leading edge with our knowledge and approach to managing individuals and their families with HD.

Jo added that it has been an exciting year for the association. "Once again we have been privileged to meet and work alongside many families and professionals," she said. "Our 'Huntington's Heroes' are all the families living with the disease. We were very proud this year when Lotus finished the Auckland half-marathon in two hours and thirty minutes, which is only ten minutes off of his personal best, and raised \$2000 for the association. We are also very excited by the continuing involvement with the Centre for Brain Research."

Professor Richard Faull and his research team from the Centre for Brain Research at The University of Auckland also joined the conference to present their latest findings. The team described the work undertaken across the Centre, from biomedical science to psychological research. Research Fellow Dr Henry Waldvogel updated

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Mark Dunlop (right) thanking Professor Richard Faull (left) for his research talks

the group on the Huntington's sheep model, while PhD students Toby Lowe and Eric Kim talked about their research looking at nerve cell death in Huntington's disease.

Dr Richard Roxburgh from Auckland District Health Board also joined the conference to talk about the creatine study, called 'CREST-E', which is currently underway. The clinical team is currently recruiting participants for the three year study, which is a rigorous look at whether the nutritional supplement creatine can help brain function.

The conference was also an opportunity for Laura Fogg to ask members what ideas they had for the future of the association. Many exciting proposals were put forward, including taking part in the 'Round the Bays' fun run in March, selling HD T-shirts, and social coffee mornings.

One exciting suggestion was to set-up a charity 'Trade Me' site, which you can read more information about down the page.

The existing committee were all re-elected, with an additional new member joining the group, Angela O'Dea. Many offers of help were also put forward from people who want to help the association with specific projects.

Our thanks go to all who helped organise the day and offered their help in the future!

Our new website



HD Auckland now has a website just for the Auckland and Northland region. Here you will find all the latest news, events and information, as well as opportunities to help us. The presentation from the AGM is also online. Check it out!

<http://www.hdauckland.org.nz/>

Donate your unwanted items to HD Auckland to sell on Trade Me!



Following our AGM, we have set up a Trade Me account. You can donate your unwanted items to the HD Association, and we will sell them online. Please email huntingtonsakld@xtra.co.nz for more information.

Waikato News

I would like to introduce myself – my name is Tracy Hobbs and I am pleased to be the newest member of the MS Waikato team.

I have been employed as a Part-time Client Service Coordinator supporting people with Huntington's Disease, MS and their families. My role also includes the bi-monthly MS Newsletter and updating of the MS Website.

I have spent the majority of my working career working with people with an intellectual disability and was employed as a Service coordinator for IDEA/IHC for eight and a half years. For the past three years I have

been working with my husband as the office manager within our Coach building and Equestrian business.

I have two teenage children one living at home, and I foster a 15 year old boy with an intellectual disability. In my spare time I enjoy Motorsports, Fishing, golf, reading and spending time with my family and friends. On the 14th August I will be competing in the Tough Gal Challenge in Rotorua.

I am currently studying Te Ara Reo Maori (Maori conversation) level 2 through Te Wananga o Aotearoa and I am completing the NZ Certificate in Tertiary Studies

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through the Open Polytechnic of NZ, and will continue on to a Diploma in Applied Mental Health,

My passion has always been working with people and I am looking forward to my role with the MS Waikato Trust.

My normal hours of work will be: Monday, Tuesday, Friday mornings and Wednesday afternoon.

I can be contacted on 07 834-4745 / 027-385-5425 or via email: tracy@mswaikato.org.nz

I look forward to meeting all of you in the near future

Kind regards

Tracy Hobbs

Wellington News

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

Greater Wellington

Hello everyone, I hope you are surviving what has been a wet, cold winter for us here in the lower north island so far. It has continued to be a busy time for me with regular visiting of clients, supporting those undergoing predictive testing and dealing with crisis situations as they arise.

In addition, I have been to New Plymouth to support Fleur in her new position and have very regular trips to Greytown to visit our families who are resident at Noel Hamilton House.

Along with the residents and families connected to Amaryllis House, we have four Huntington's residents in Greytown who enjoy their living in such a tranquil environment in the Wairarapa.

Regular activities have continued and swimming is still popular despite the cold weather and I have been fortunate to meet extended family members from a lot of my client families and learn more about family histories and relationships.

Our Annual General Meeting is to be held on October 10th with Alison Douglass, a barrister talking on a variety of legal aspects that I think will be of interest to everyone, from power of attorney and welfare guardianship, to legal implications of predictive testing. I hope a large number of you will be able to attend and as with last year, we will provide a light lunch at the end of the meeting. Please contact me if you require further details. It is a great opportunity to meet and chat with others and to share experiences and gain valuable information.

I will be overseas for most of September so I apologise in advance if I am unable to assist you. If you need information or assistance over this time, please call Amaryllis House on 04 569 7290 and they will be happy to help you. I will catch up with most of you as I am able, on my return. In the meantime, stay safe and warm and as always, please contact me if I can help you.

See you soon

Jeanette Wiggins

Hawkes Bay News

Kia ora koutou – Welcome to you all from Hawkes Bay.

Our small, friendly family groups here are always happy to welcome new people to our regular gatherings/support / social events. We recently had a winter pamper afternoon open to all our families and friends.

I am available on a flexible basis to meet up with people and families and talk with you about your situation, about how things are going, as well as to look at available services to provide support to you and your family if you wish. It may be that inclusion in our physiotherapy group could be helpful, or joining in with our local MS

group for social and mental stimulation, being part of our small carers group, or the wider caring for carers group, allowing me to facilitate you meeting up with someone in a similar situation, joining in a local exercise programme, practical support from the group to allow you to have a break, or provide support with respite, or let me take you out for a coffee and a chat... the list is long, so give me a call, I would love to meet up with you. Contact any time (06) 8353020

Kind Regards

Tanya Jeffcoat

Gisborne News

Hello to you all, I hope every one is managing to keep warm, I am sure this winter has been colder than usual.

I have very little to report from Gisborne as we are very quiet at this present time.

I have attended our social group meeting and enjoyed catching up with our group, last meeting we had a lovely lady come and share some of her H.D journey with us and I am sure we all learned a lot.

I was unable to attend our Support Workers training in May, I know that I missed a wonderful meeting; I look forward to our next training.

We have a support group meeting on the 2nd Saturday morning every second month. We meet at the Tatapouri Fishing Club for lunch and everyone is welcome, the next meeting will be 9th September.

Anyone wishing to contact me can contact me by phoning 06 868 8878 or 027 686 9432.

Regards

Cheryl Morley

Taranaki, Whanganui and Palmerston North

Hello to all the families and caregivers affected by Huntington's Disease in the Manawatu, Whanganui and Taranaki area. My name is Fleur Brett and I am the new Huntington's Advisor for this region. I am a Registered Nurse with a background in Well Child and Public Health Nursing.

I have now been a Huntington's advisor for three months (the time has flown by) and am working my way around seeing everyone I have contact details for.

We are definitely in the grips of winter and it is nice to know that in a few weeks it will officially be spring. We have had some wild weather and look forward to some warmth and sunshine.

I look forward to meeting those of you I haven't talked to yet and continue to be of support and assistance.

My contact details are:-

Fleur Brett

Huntington's Disease Association (Wellington) Inc

PO Box 50

Rongotea 4865

Tel: 06 3248307

Mob: 027 4966 500

Email: fleur.huntingtons@hotmail.com

If I haven't contacted you yet please give me a call or drop me an email. I would love to hear from you.

Kind regard

Fleur Brett

Christchurch News

Greetings from Christchurch. The days are starting to get longer and it is no longer dark when I leave work at night which is great. We have had a busy three months since the last newsletter with interviewing for a new Family Liaison Coordinator. This is a position that you want to get right because as an Association you rely on this person working out in the community with the HD families.

We were very please to appoint Anne Wilson to this position in Christchurch. Anne has 'a vast hands' on knowledge with HD and is really keen to make a difference with our families. Anne has attended a Carers Support meeting and met quite a few of the family

members out there caring for their loved ones. Over the next few weeks she will get around everyone and introduce herself to you all.

Maggie Drury the Huntington's Disease Clinical Coordinator appointed by our local DHB has been out amongst our HD people in Christchurch, ensuring that all their needs are being met. She has been proactive with different agencies advocating for our HD families, and this has certainly made a difference.

News of the Residential Services for people under the age of 65 with HD still eludes us. The services were meant to open on the 1st August 2010 but the ministry has still not even announced who has secured the contract. Maybe

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we should be aiming for 1st August 2011 but we are desperate for this facility to open as we have HD loved ones inappropriately housed.

Denise Forbes, our treasurer, and I flew up to Wellington on the 31st July to meet with the other two Associations for our annual meeting. Unfortunately Auckland were unable to attend this meeting as it is a valuable time to give an update of what is happening in our areas and also to share valuable information on funding, grants and

association matters. Thank you to Wellington Association for hosting us, and sharing so much with us. It was a very worthwhile day and we have come back with many ideas and plans.

Take care everyone

Dianne Collins

Chairperson HD Christchurch

Christchurch welcomes new Family Liaison Coordinator

We have appointed Anne Wilson to fill the role of Family Liaison Coordinator with our HD families.

Anne is the second born of 11 children. Born and raised in the North Island. She has six children of her own and eight grandchildren, with three more on the way. Anne has been in the Health Industry for 15 years and currently has been working in the Mental Health sector for the last six years.

Anne enjoys a challenge and loves people. Her number 1 hobby is gardening and at present is landscaping her property. Anne enjoys crafts, is very family orientated she prides herself on being supportive and has a great listening ear. Anne comes to us with 18 months hands on experience of caring for someone with HD.

Anne can be contacted on (03) 327 7898 or (021) 023 07343



Huntington's Disease Research Opportunity

Clinical neurologists from around New Zealand are interested in collaborating over research into Huntington's Disease (HD). There are opportunities to link with international studies based in Australasia, USA and Europe as clinicians and scientists strive to advance knowledge about HD and to develop and test promising treatments.

HD affected families in the Christchurch area are therefore invited to consider participating in this future research.

The initial stage would involve collection of relevant information about those with symptoms as well as those who are pre-symptomatic. Data collected will include genetic information that confirms the diagnosis of HD as well as information that is routinely collected during a clinic visit. Much of this information will already be held in medical records and researchers will seek consent to access and use that data for research purposes. There will be strict procedures in place regarding the confidentiality of all information gained during this project.

If you are interested in finding out more about this opportunity,

Please contact: Professor Tim Anderson

Van der Veer Institute for Parkinson's and Brain Research

through his Personal Assistant Kathryn Mulcock

Phone (03) 378 6079 or email Kathryn.Mulcock@cdhb.govt.nz

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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- ◆ 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 December 2010. The deadline for material to be received for this issue will be 10 November 2010. Please send any contributions for Huntington's News to:

Glenys Shepherd (Editor)
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or email: info.wellingtonhda@xtra.co.nz



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