



# *Huntington's* NEWS

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

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Issue 109

## *25th Anniversary Edition*

# *University congratulates world class neuroscientist*

The University of Auckland is delighted that neuroscientist Professor Richard Faull has been named Supreme Winner at the 2010 World Class New Zealand Awards.

Vice Chancellor Professor Stuart McCutcheon says it is entirely fitting that Professor Faull should receive the supreme award.

“Richard is indeed world class – not only in his research and teaching, but also in the generosity with which he gives his time to roles in University governance, leadership and mentoring of others. His own scholarship, and the influence he has on others around the world, means that he has done much to bring New Zealand to the forefront on international scientific endeavour.”

“This award is just recognition of Richard’s skills not only as an outstanding researcher, but also as a scientific leader and an advocate for patients and families of those suffering with some of the most debilitating neurological diseases,” says Professor Iain Martin, Dean of the Faculty of Medical and Health Sciences.

“It is a privilege to count Richard as a colleague. His passion and enthusiasm for science and science education have done much to encourage the next generations of researchers both in and beyond neuroscience. I can think of no more worthy recipient.”

Professor Faull is an internationally recognised expert on neurodegenerative disorders. During his 35-year career he has made major contributions to scientists’ understanding of changes that occur in the brains of people with diseases such as Alzheimer’s, Parkinson’s, Huntington’s and epilepsy, opening the way for the development of new treatments.

He is perhaps best known for research showing that the adult brain contains stem cells. This groundbreaking work countered the long-held belief that adults have a finite supply of brain cells that cannot be replaced once they have died, and offers hope to people with neurodegenerative disease or brain injury.

Professor Faull founded the Neurological Foundation of New Zealand Human Brain Bank, which houses brain tissue donated by people with neurological disorders and their families. It is a crucial resource for neuroscientists and an example of the strong links Professor Faull has forged with the community.

He is also Director of the University’s Centre for Brain Research. Launched in 2009, the centre is the realisation of Professor Faull’s vision for better research through partnership between scientists from across the University, New Zealanders affected by brain disease, and the clinicians who work with them.

Professor Faull is the recipient of numerous awards including the Royal Society of New Zealand’s Rutherford Medal in 2007 and the Health Research Council of New Zealand’s Liley Medal in 2005. He was made an Officer of the New Zealand Order of Merit in 2005.

The World Class New Zealand Awards, now in their seventh year, recognise outstanding individuals who have made major contributions to New Zealand’s success on the world stage. They are presented by Kea New Zealand with assistance from Trade and Enterprise New Zealand.

The 2010 awards were presented this evening at a gala dinner at the Langham Hotel in Auckland.

## **Notes**

The Centre for Brain Research, launched in October 2009, investigates diseases of the brain and nervous system including stroke, epilepsy, Alzheimer’s disease, Parkinson’s disease, Huntington’s disease, multiple sclerosis, motor neurone disease, and muscular dystrophy. It brings together scientists from The University of Auckland with neurologists and neurosurgeons from District Health Boards in the Auckland region and community groups that support people affected by brain disease. Its goal is to develop treatments for brain disease through more integrated and collaborative research that draws on the strengths and expertise of the three partners.

For more information about the centre  
[www.cbr.auckland.ac.nz](http://www.cbr.auckland.ac.nz) contact

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# *Dealing with Survivor Guilt*

*By Julie Stauffer*

Everybody understands that when you toss a coin, the result is random. Whether it comes up heads or tails is a matter of pure chance; there's no rhyme or reason involved.

It's a little more difficult to come to terms with the pure chance that dictates who inherits an HD gene and who doesn't. For people who test negative for the gene, the relief and happiness is often mixed with guilt and confusion. Why did they escape when other friends or family members weren't so lucky?

Susan Creighton, a genetic counsellor and clinical assistant professor at the University of British Columbia, provides the example of one young woman who tested negative. When she first got her results, she was overjoyed. In the days that followed, however, she began to feel bad that she would never have the disease that was killing her mother – and then felt worried because she was feeling guilty instead of happy.

"It can really play a number on people," says Susan C. That's why one of the topics she brings up during pre-test counselling sessions is survivor guilt. She also points out that every test result can create ripple effects within families and beyond.

Helen Zwart, for example, was never at risk of Huntington's herself. But when genetic tests revealed that neither of her two children inherited the Huntington's gene her husband carries, she nevertheless had a nagging sense of guilt.

"I'm ecstatic for my children," she says. "I can't begin to express how excited we are." At the same time, however, she feels sad, knowing several parents whose children have tested positive or developed Huntington's.

"Why us and not them?" Helen explains. "Why are we so privileged?"

According to BC Resource Centre Director Susan Tolley, survivor's guilt is common in the Huntington's community, even if it's not acknowledged as much as it should be.

It's also common for that guilt to lead to silence. Helen, for example, hesitated to share her good news with the support group she and her husband belong to, not wanting to focus on their good fortune while others continue to suffer.

"A lot of times when people find out their good news, they don't really share it," Susan T. explains. "They're afraid they're not going to be considered part of the group any longer, or they don't want to be gloating."

It's important to choose the right time and the right way to discuss your news, Susan T. says, but she also believes it's important to speak up.

The Huntington's community needs to hear good news stories to balance out the gloom. "It provides hope for others," she says. Not sharing the news also creates the danger that it may come out at the wrong time, with unfortunate results.

If you're struggling with the mixed emotions a negative test result can create, or if you need help deciding how and when to share your news, don't be afraid to contact your genetic counsellor, resource centre director or Individual and Family Services worker.

"Often, people don't recognize the importance of talking to an expert," says Susan T., "but we understand the issues you're dealing with, and we can offer shortcuts."

*Acknowledgement: Horizon – Issue No 131 – Spring 2010*



# *Living a fulfilled life with Huntington's disease*

*First published in Mindfood magazine in November 2009*

*By Lotus*



I grew up in a very small village in South Africa. While at University I met my lovely wife and we dreamed of opening a legal practice together. We chose New Zealand as our new home, and we've been here now for eleven years. We just loved the country and our lifestyle here-life seemed to be progressing wonderfully.

It was in 1999 that we received a phone call from the doctor. My father, who was living in South Africa, had been diagnosed with Huntington's Disease (HD). This was my first introduction to HD. I did some reading up and found out more about the symptoms we could expect. HD is an inherited brain disorder that causes progressive deterioration of the physical, cognitive and emotional self. It leads to severe incapacitation and eventual death 10-40 years after the onset of the disease. Common symptoms are uncontrollable movements, abnormal balance when walking, slurred speech, difficulty swallowing, thinking difficulties and personality changes. There is currently no medical cure, but the symptoms of the disease are treated in order to ensure that quality of life is affected as little as possible. The disease eventually caused my father to pass away at the age of 55.

Watching my father go through all this confronted me with a new reality. Each child of an affected parent has a 50% chance of inheriting HD. So the big question looming over me now was whether I too would develop the disease. I was offered the option of genetic counselling and genetic testing and my wife and I discussed the matter in great depth. It's such a big decision to make but

we needed certainty – if I had HD, this would enable us to plan for the future. At the age of 32 I decided to take the test. It was our worst nightmare. The results indicated that I had inherited HD from my father.

I worked until I was 39 but I'm now no longer able to. We sold our house and changed our lifestyle. We had to scale down a bit, which was difficult but necessary to help manage the disease. I'm now 42 and run our household whilst my wife works full time. In the years since I was diagnosed we've struggled with our situation, but I've also seized the chance to enjoy life while I can. We've been blessed with a beautiful daughter aged 4, which has opened my life to new wonderful experiences. I like to cook, run, read, paint, play the guitar and potter in the garden. We love tramping and camping as well – New Zealand is just beautiful! Most weekends will find us somewhere in the Coromandel or next to the beach. Life is full on!

I want to thank my lovely family members, friends, local church, medical personnel and HD support staff for all they have, and are still doing for our family. I have come to realise that it is good to work hard in life and to set yourself some goals. In November I completed the Auckland half marathon, which was a huge challenge to train and fundraise for! I wanted to pay back all the time and attention the Huntington's Auckland Association has dedicated to my family. The charity provides advice and liaison officers to help entire families deal with the journey of HD. That's the thing about my condition – it doesn't just affect one person but an entire family, in more ways than one.



## *Auckland / Northland News*



### *A big welcome to our new Chairman Mark Dunlop!*

It's been a time of change at HD Auckland, so we thought we'd take this special opportunity to introduce your Committee. After one year of incredible service to the Association as both Chairman and Treasurer, Richard Price has stepped down from his Chair role.

Taking up the reins of Chairman is Mark Dunlop. Mark is the General Manager of Training and Development at Foodstuffs Auckland and is excited by the opportunities for the Association.

#### **Mark, tell us a bit about yourself!**

Well, I'm a family man with two daughters. I love skiing and any sport with a ball. I'm a bit of an opera buff, in fact I used to sing in the New Zealand Opera Company chorus! But these days I limit my singing to singalongs around my piano.

#### **You have an impressive history in business, so what brought you to the HD Committee?**

I trained in Organisational Change and Leadership, and currently I'm helping Foodstuffs employees get the best out of themselves. I realised pretty quickly in my career

that it's people who make machines work, so if you want to improve your business, it's people you need to focus on.

As part of my development I joined the Leadership New Zealand training programme. This not for profit organisation helps to develop future leaders for New Zealand. Through that programme I heard Professor Richard Faull speak about neuroscience and brain disease. I was inspired to help and so joined the Skillsbank at Leadership New Zealand. I wanted to put some of the skills I learnt back into the community, and that's when I joined the HD Auckland Committee. I see it as a real opportunity and I'm privileged to join.

#### **So what's next for the Association?**

I really want to make a difference to the lives of people with Huntington's disease. Brain disease is something close to my heart. My mother has mild cognitive impairment, and my brother-in-law has Parkinson's disease. So the focus for the Association will always be family care and people.

As a Committee, we need to sustain the organisation to sustain helping patients. I'll be looking at ways we can make the Committee more effective, and any synergies we can make with other organisations to make our efforts more valuable. It's an exciting time.

## *Join us for the Annual General Meeting of the Association in July*

Mark Dunlop and the HD Committee will be organising the AGM for the Association on July 24th. Our Patron Professor Richard Faull and his team will be speaking, and we'll give you the latest updates on HD care and research. It's also a great chance to find out more about the Committee and how you can help. The AGM will be held in Ferndale House again after such a successful meeting last year.

*July 24th*

*10.00am – 4.00pm*

*Ferndale House, 830 New North Road, Mount Albert, Auckland*

*Continues on page six*

## Meet your Committee

The Committee organises the support services, funding and governance for the Association so that Jo and Jane can continue to help all HD families.

### **Richard Price, Association Treasurer**



I have been on the committee for over four years starting as Association Secretary for three years then becoming the Chairman / Treasurer last year. Now with Mark coming on board I am able to focus on the Treasurer's role. My responsibilities as Treasurer include managing the budget and cashflow, financial reporting, book-keeping, bills, banking and payroll, insurance and fundraising. My inspiration and passion for the Association comes from how it helps those with HD maintain the best quality of life. Personally the association has helped my wife (who has Huntington's) and I manage her symptoms and understand how to live with HD.

### **Laura Fogg, Association Secretary**



I am the Communications and Liaison Manager for the Centre for Brain Research at The University of Auckland. As a fellow Brit, Jo and Jane won me over to the HD Association Committee, and I've just been voted in as Secretary. I have also been asked to join the Editorial Board of the Huntington's News. I'm a trained journalist with a science degree, so science communication has always been my passion. I live with my partner Greg, and we've been in New Zealand for one year now. Working with the Association is wonderful to see the difference we can make to people's lives.

### **Jo Dysart**



I have worked with Huntington's Disease patients for the last 23 years, and I'm currently the Family Liaison Coordinator for HD Auckland. I met my first HD lady when I was 17 and she had a huge effect on me. I then trained as a Registered Mental Health Nurse in the UK and worked in health and social care for the next few years. My team was instrumental in bringing in a full HD service in the UK, and I brought that knowledge with me when I came to New Zealand in 2003. I joined the Association in 2004, and in 2007 I also took on the role as the HD Nurse Specialist for Auckland Hospital. I joined the Committee formally in October 2009, and I'm

passionate about fighting for the rights of HD families. I believe that while there may be no cure, there are many treatments which can enhance your quality of life. Being part of the Committee means that I can ensure the important protocols and governance are in place to help HD families.

### **Miriam Rodrigues**



I trained as a genetic counsellor in Brisbane and subsequently worked with families with HD as an associate genetic counsellor for both the Queensland Clinical Genetics Service and also Genetic Health Services Victoria. When I started work for the Muscular Dystrophy Association of NZ I met Jo Dysart and was very impressed with her work and very pleased to be able to support HD families in Auckland and Northland through supporting Jo in her role. I'm currently on maternity leave from MDA but am enjoying being able to continue committee work for the HD Association.

### **Christine Stent**



I am retired and the mother of three children, one of whom has Huntington's Disease. I wish to support the Association in whatever way I can. My main role in life has been that of childcare, fostering children and raising a family. I worked for seven years in an office and was the Manageress of a ladies wear shop for another 7 years. I have also been leader of a Brownie Pack and in later years, I have been a Nanny and Housekeeper for one family. On joining the Committee two years ago, my role has mainly involved arranging venues and helping to organise the AGM, the Carers' Retreat and Carers' days.

### **Dr Maurice Curtis**



I am a biomedical researcher at the University of Auckland's Centre for Brain Research. I trained as a radiographer but during my training the neuroscience lectures I attended got me hooked on the brain and this led me to pursue postgraduate studies with Professor Richard Faull. Since then I have worked in a laboratory in Sweden for four years and currently am a Senior Lecturer in Anatomy at the Centre for Brain Research. My research has throughout this time been focussed

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on neural repair and neurogenesis in Huntington's disease. My role on the Committee is to offer a scientific perspective to decision making and to help inform the Committee of scientific advances that may be of interest to the Huntington's disease community. I have a passion for studying how Huntington's disease affects the brain and how the brain tries to repair itself when affected by Huntington's disease.

### ***Kristen Bottrell***

I got involved with the Committee during my time in Auckland working with Jo at ADHB. Her obvious passion for the cause inspired me to join the Committee and help out any way I could. I've since moved back to Melbourne to study Psychology but stay in touch to lend a helping hand. It's so rewarding to be involved with a team that is so committed to helping families with HD, and I hope to continue my involvement from 'across the ditch'.

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### ***Our new website***

Your Association 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. Check it out!

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



### ***Jo Dysart visits Invercargill***

The HD Auckland team was honoured and privileged to be invited down to Invercargill in late April. The hard-working MS Invercargill team provides care for HD families in Southland, and asked for advice from the HD Auckland team. Jo Dysart shared her experiences with the field workers and says, "It was great to be invited down to share best practice on managing HD. I think it was a very worthwhile and educational visit for all concerned, and we're really glad we had such a valuable opportunity."

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## ***Waikato News***

Greetings from the Waikato

We have some good news: we are currently beginning the recruitment process to employ a Field Worker whose first priority will be to provide service for our Huntington's clients and families.

As you may know MSWT (Multiple Sclerosis Waikato Trust) is an organisation which provides a comprehensive service to clients with Multiple Sclerosis, Chronic Fatigue Syndrome and Huntington's Disease. We like to have staff who can professionally help all our client groups, however if we can employ people with a particular interest they can then become an "expert" in that field. Our aim is to get such a person to work with our HD families in a pro active, professional and caring way. Watch this space!

On another topic, I have been having some interesting discussions with some organisations that organise/

provide care in the Waikato for individuals with illness or disability. It has become apparent to me that a number of our HD clients may need a change in their living environment in the next few years. The statistics are frankly shocking for placement of younger people (under 65's) in care facilities. In many cases rest homes are the only option and I believe they are often very inappropriate. With that in mind we would like to begin some dialogue with HD clients, family members and friends to discuss what it is YOU want in terms of supported living. If you have any thoughts please contact MSWT, (details on the Contact page) as we would like to develop a strategy and plan for the future, with the people who are directly affected having the most input.

Regards

*Liz Hogan*

# Wellington News

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

## Greater Wellington

The AGM of the Wellington Association will be held on 10<sup>th</sup> October. Full details will be provided in our usual flyer with the next newsletter. In the meantime please note this date in your diary.

We have employed a replacement advisor for Lorraine Jans who resigned recently. Our new advisor for the

Taranaki/Wanganui/Manawatu area is Fleur Brett, a registered nurse, who has now started her training and orientation and will be contacting families in the area in the near future.

*Cecil O'Neale*  
Chairperson

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Hello everyone, May is here already and 2010 almost half over. I hope the year is going well and that you all enjoy this special anniversary edition of the Huntington's News.

It is proving to be a busy year for me with a number of new families making contact which is great.

It was good to be part of Brain Awareness Week in March. By coincidence, I was booked to speak to a large Rotary group that week which was fortuitous and then on Saturday, I had a display stand at the Victoria University. They ran a series of lectures for the day. Although Huntington's was not a specific topic, there was still a great deal of interest from those people attending and it was very successful.

We now have the use of the hydrotherapy pool at Hutt Hospital on a weekly basis which means more people can be part of our water therapy classes. Everyone enjoys the warmth and ease of moving in a very pleasant environment.

The residents at Amaryllis House are also very lucky to have a wonderful music therapy student working with them for the year. Sacha Vee is a talented musician and the work she is doing with HD clients is inspirational. It

is wonderful to see such a successful partnership with the University and it would be great if we can establish similar relationships with other training institutions that can benefit our HD clients e.g. physiotherapy, occupational therapy.

Our relationship with Fertility Associates is growing notably with a number of clients investigating the option of pre genetic implantation.

The carer coffee mornings are always a pleasant occasion and a good opportunity for sharing of ideas and we will hopefully plan some further social events as the year progresses.

Unfortunately, again this year, there has not been enough interest to run a youth camp. Should this situation change, we will reconsider next year as it has always proved to be a valuable experience for those who have attended in the past.

I try to keep regular contact with the families in my area but as always, should you require something specifically or if you would like me to contact you more frequently, please call on 021344445.

Kind regards  
*Jeanette Wiggins*

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## Hawkes Bay News

Kia ora koutou. Hello to you all and hope you are keeping warm and well as we move into the cooler months!!

I am available over most days now to catch up with families and provide support and information and to follow up any issues you need help with. Please always feel free to contact me for a chat or to make a time to meet up.

Our support group continues to meet two monthly, and our carers continue to get together for a little "spoiling" two monthly as well. Our first "male partners carers group" met together for the first time over a few beers at the pub (I was very happy to be part of that group!!). We continue to look at ways to offer support to each other.

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We have a special presentation by Jon Simcock, neurologist, coming up in June for our families, so that should be very interesting and hopefully answer some questions they have. Prof Faull has again agreed to make time later in the year to talk with our families and their GPs, so, once again, hopefully families will get some questions answered and the health professionals will get their skills and knowledge base expanded.

Our group has just secured funds from the local Lions group (thanks so much to John) to enable us

to provide families with some special assistance - we're still thinking of ideas, maybe some time away together for a bit of a treat...

I look forward to hearing from you and to meeting up with you in the near future.

Kind Regards

*Tanya Jeffcoat*

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tjeffcoat.hawkesbayhda@yahoo.co.nz

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### ***Gisborne News***

We have had a busy but very sad few weeks in Gisborne.

Firstly I am sad to say we lost one of our very valued members. She passed away in April with her daughter at her side. She had lived with H.D for several years and had always remained bright and positive, I will miss her greatly.

Secondly two of our local members from the HD community moved to Tauranga to be closer to their families, so in all three of our members have left the

district so if any one is moving to the Gisborne area I would love to meet up with you.

I can be contacted by Phone 06 8688878 or Cell phone 027 686 9432

The Regular Support Group meets on the 2<sup>nd</sup> Saturday of every 2<sup>nd</sup> month. The next meeting is on Saturday 12<sup>th</sup> June at the Tatapouri Sport Fishing Club every one welcome.

Regards

*Cheryl Morley*

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## ***Christchurch News***

Greetings from Christchurch

Well the days are shorter and the nights getting a bit colder now. This usually means that winter is on its way and it won't be long until we will be wrapped up in all our winter woolies.

The Christchurch HD Association is working through so much at the moment. Our Family Liaison Worker has resigned after 4 years in the position. Lynne Switzer will leave a huge gap in our Association, please read the tribute to Lynne in this issue, thanks hardly seems enough when someone has done so much.

Well the final submissions have happened for the HD Service in Christchurch and we are waiting for contracts to be signed and sealed before they can announce who the successful applicant is. As an association we are anxious as we wait to hear where the new service will be and who will be providing it for our loved ones. Next issue I will be able to let you all know the outcome.

It seems that for years nothing was happening for our HD families and suddenly we have got it all going on at once. The Canterbury District Health Board has funded a position for a Clinical Co-Coordinator for people with Huntington's Disease, who reside in the Canterbury District Health Board (CDHB) area.

This position is a fixed term pilot study from April 2010 to June 2011. This is great news for HD, not only are we getting recognition in the community, we are also getting some much needed help.

We are selling chocolates again to help top up the coffers, this is a tried and true method of raising relatively easy money. Thank you to all the people who take boxes off us to sell in their work places, your never ending support is very much appreciated.

Take care, everyone

*Dianne Collins – Chairperson HD Christchurch*

# *Christchurch Farewell's their Family Liaison Worker*

It is with mixed feelings that we said goodbye to Lynne Switzer our Family Liaison Worker at the end of April. Lynne has held this position for 4 years with our association and it is one that we have seen her grow into. The role for someone in this position is not one that can be defined in a contract, but one of initiative and on the job learning, which Lynne picked up on very quickly.

Very early in her appointment Lynne started a Carer Support Group which consisted of spouses, and family members from HD families.

Lynne has nurtured and encouraged this group who meet every second month, to share stories, fears, tears and triumphs. There have also been speakers on many different topics who come in from time to time to talk and share with this group. Numbers have been consistent with a core group of people attending all the time, but allowing others to join in when they feel the need for support and/ or time out.

Lynne always brought along supper which was usually the treat of homemade goodies. She would always send someone home with the leftovers for their lunch the next day.

This group is very important to those who attend and while no one professes to know much about HD it is always surprising that someone else in the group has experienced something similar and can shed some light on the problem or some of their ways of handling it.

Lynne's other strengths were to maintain people's independence and be an advocate for their rights. Lynne helped many HD people find housing and worked with landlords and Housing New Zealand to achieve suitable outcomes.

The recreation groups that Lynne set up and kept going have been a huge commitment for her. The arranging, planning, picking up, taking and delivering home was all in a days work. These two groups have been on some great outings and without Lynne persisting with these, some of our HD people would never have the chance to get out socially at all.

The Make A Wish Fund that we set up seemed to grow rather than diminish with Lynne always finding someone to make a donation to it.

In true Lynne form she would not let us farewell her and make a big fuss, with the HD families she has supported over the last 4 years. Instead she said goodbye to many in her own quiet way.

So on behalf of our association we would like to thank Lynne for all your dedication and endless persistent work you undertook, it is appreciated and your caring professional attitude has had a huge affect on HD Christchurch. Thank you hardly seems enough Lynne, but a huge thank you for being you and what you brought to the position, comes to you with all our love and gratitude.

*Christchurch HD Association*

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## *Southland News*

The Southland MS Society provides Support for HD in Southland. We were pleased to welcome Jo Dysart, Auckland's Huntington's Family Coordinator, to Invercargill on the 29<sup>th</sup> and 30<sup>th</sup> of April.

Jo delivered her presentation on the Holistic Approach to the Management of Huntington's Disease. The Thursday evening session was held specifically for families, who all said they found the presentation excellent and they valued the opportunity to spend time speaking to Jo individually.

On Friday the 30<sup>th</sup> Jo delivered her presentation to Health Professionals and Rest Home staff. This was also very well attended and the evaluations from these sessions, indicated everyone had found the sessions very helpful and all said they had a much better understanding of Huntington's, many commented on what a great presentation Jo delivered..

We were delighted with the turn out for these sessions and we are sure both families and health professionals supporting those affected by HD in Southland, have a better understanding and have come away with knowledge and skills that will enhance their support role.

We would like to acknowledge the Auckland Association for allowing time for Jo to come down.

Jo will be able to tell everyone in Auckland that our weather is not as bad as everybody seems to believe, and we are a very friendly bunch down here.

Jo, a big Thank you from our families for sharing your knowledge and experience, you would be very welcome to come down this way again any time.

Regards

*Maree Lewis, Field Officer*

*Southland MS Society*

## ***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 September 2010. The deadline for material to be received for this issue will be 10 August 2010. Please send any contributions for Huntington's News to:

Glenys Shepherd (Editor)  
PO Box 30420,  
Lower Hutt 5040  
or email: [info.wellingtonhda@xtra.co.nz](mailto:info.wellingtonhda@xtra.co.nz)



### ***IMPORTANT NOTICE: HUNTINGTON'S NEWS and the INTERNET***

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