

Huntington's NEWS

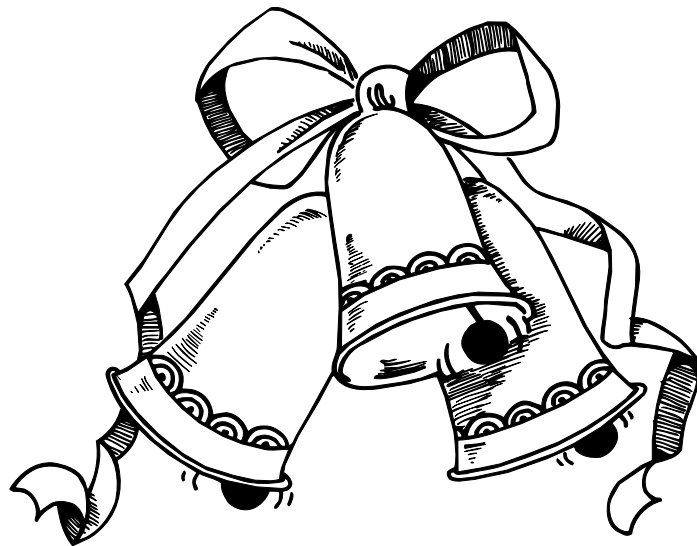
*The quarterly newsletter of the
Huntington's Disease Associations of New Zealand*

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December 2010

Issue 111

Seasons Greetings And Best Wishes For The Festive Season



From the Editorial Board

From the Editor:

It has been decided that the *Huntington's News* will now only be published three times per year instead of the four issues. We believe this will not in anyway jeopardize the number of important articles on research, care of those with Huntington's and family stories.

Huntington's News will now be published in April, August and December.



Update on the Creatine Safety Tolerability and Efficacy in Huntington's Disease (CREST-E) Clinical Trial

As many of you are aware, the CREST-E trial finally began here in Auckland in March 2010. This trial is being conducted here by Dr Richard Roxburgh, Virginia Hogg and Janneke George.

Currently we have ten (wonderful) volunteers who are taking part in this study. Many of these ten people have now been taking part for over 6 months. To all our volunteers - we would like to thank you very much for your commitment, support and involvement.

We hope eventually to have between 15 and 20 persons enrolled by the end of 2011.

Auckland is one of the 44 sites around the world where this trial is being conducted.

Worldwide the trial is still in its early days but there are now at least 130 people enrolled in this trial and the aim is to have 650 participants.

This trial is being led by the Huntington's Study Group, an international not-for-profit organisation which seeks to develop new treatments for Huntington's disease (HD). The trial is being funded by the National Institute of Health (USA)/ National Centre of Complementary and Alternative medicines.

The trial compares the effects of pharmaceutical grade creatine-mono-hydrate in persons who have symptoms of Huntington's Disease (HD). CREST-E is designed to evaluate whether or not creatine use will delay the progression of functional decline in HD over a 37 month period. This research study will also look at the long-term safety, tolerability and effectiveness of treatment with up to 40 g/day of creatine-mono-hydrate, as compared to a

placebo, in patients with HD. Additionally, this research will evaluate how a variety of biological processes are affected by the study drug or how they may reflect disease activity. Participants are randomly assigned to receive either active study drug or placebo (looks like study drug but has no active ingredients). There is a 50/50 chance that participants will receive the study medication or the placebo, neither the participant nor the staff here in Auckland who run the trial will know which study medication you are on.

To participate you must:

- Be at least 18 years old.
- Be able to provide written informed consent.
- Have some symptoms of HD and a confirmation by family history or genetic testing
- Be living independently.
- Be willing to comply with the study procedures.
- Not be pregnant, lactating or intending to have a child.

Participants need regularly to attend appointments at Auckland City Hospital (18 visits over the 37 month period) hence they need to live in the greater Auckland area.

If you should have any further questions about this study or you think you might like to participate please feel free to contact Dr Richard Roxburgh or Virginia Hogg, Study Co-ordinator, on (09) 307 4949 ext 25747 or vhogg@adhb.govt.nz

A Fishy Tale

This is a fishing story – and like all fishing stories it'll probably get better with every re-telling. This is a story about young Steve, one of our 'H' boys (that's Huntington's to the uninitiated) from exercise class.

Steve decided it was time to go on a decent fishing trip before the delightful disease he has taken hold of him. So, in October he, along with three mates (from a dubious former life as a Hamilton Old Boys rugby player) took off to Vanuatu for an eight day fishing trip – operation Marlin.

As far as fishing goes Steve is no Mat Watson (or Graeme Sinclair for that matter) having only taken up the sport seven years ago. Why so late in getting started? "I didn't know anyone who owned a boat" was Steve's somewhat obvious answer to what I thought was an insightful, searching question. Anyway, one of his friends (one of the aforementioned three) fixed that problem when he acquired one funnily enough about five years ago. Since then Steve and co have been crossing 'the bar' out of Raglan Harbour every couple of months. As he headed off to Vanuatu Steve's biggest conquest to date had been a 20 kg Snapper.

Back to the story as the lads touch down in Vanuatu for eight days of R&R at a tidy resort called...something starting with a K – hey the boy's a fisherman not a linguist!

The lads spent eight hours a day, six out of the eight days on the water in a 28 ft launch with a friendly skipper provided by the resort. That's a lot of fishin'! "Yep, it was pretty tiring" says Steve with a grin. "The skipper reckoned I did pretty well considering my disability." "Well" I coax "Did you catch a Marlin?" "Yep" Steve says with a bigger grin, "I was the only one that hooked one". "Bet that's mounted on the wall in your house," I offer enthusiastically. "Nah" he says "It's the rules that any marlin caught are just tagged and let go. It was



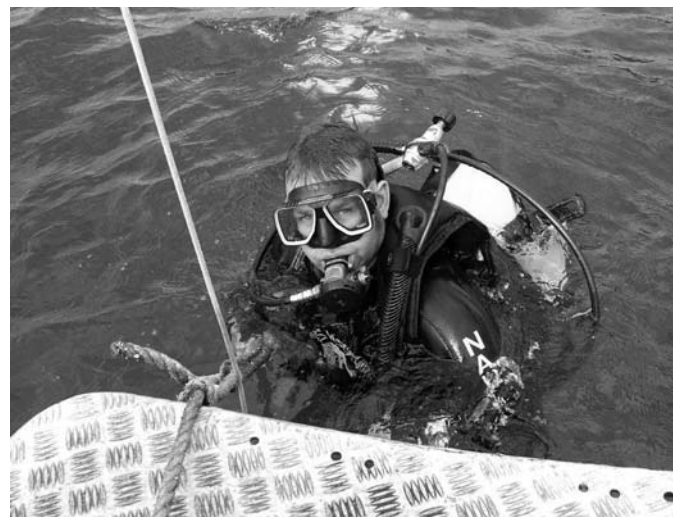
big one though – about 100 kg!" "But you got a photo right?" "Well no. We weren't allowed to bring it on board" I smell a rat – or is that a rotting fish. "So there's no evidence of this conquest?" I pressed. Silence. Now I've watched that TV program 'Lie to me' so I did the glare thing. He met my gaze, there was no dilating of the pupils, no beads of sweat on the brow, no twitching eye or finger pulling the ear lobe. So I can declare Steve an honest man – and the catcher of a 100 kg marlin – well done son!

And the rest of the fishing. "Yeah, we got heaps. We had a competition with some blokes from Tauranga and beat them easy. I got a 15 kg Giant Trevelli too (apparently there is photographic evidence of that one).

The lads spent their 'rest' days doing a bit of canoeing and diving. "Enjoy the diving?" I ask. "It was alright. Saw plenty of Moray eels and those 'Nemo' fish. But I prefer 'sport' fish and being on top of the water."

So, it's back to normality, back to the gym doing the lunges and the weights ... and telling the fishy tale of the 100 kg marlin.

Written by Ian Maxwell



Weight Loss and Sleep Problems in Huntington's Disease

Why do Huntington's patients suffer from sleeplessness, and why do they lose so much weight?

This was the question which Ahmad Aziz sought to answer in the research which he undertook toward his PhD. Dr Aziz obtained his PhD from Leiden University in the Netherlands on Wednesday 31 March 2010. He was the first Leiden PhD researcher to obtain his doctorate funded by a Mosaic subsidy. Mosaic is a grant program for students from ethnic minorities so that they can complete a PhD research program.

An aggregating protein causes many of the symptoms of Huntington's Disease, an incurable and frequently fatal brain disorder. Mosaic winner Ahmad Aziz discovered that the abnormal protein also aggregates in the hypothalamus, the part of the brain that regulates the autonomic nervous system and the endocrine system. Ahmad Aziz investigated the severity and causes of a number of less well-known symptoms of HD: weight loss, sleep disturbances and a poorly functioning autonomic nervous system. He established that many patients suffer from weight loss and sleeping problems.

Abnormalities in the hypothalamus appear to account for some of these symptoms. The hypothalamus was an obvious suspect for Aziz, as it regulates the autonomic nervous system and the endocrine system. Aziz established that certain nerve cells are lost in a part of the hypothalamus. In this part as well as in other parts of the hypothalamus abnormal protein aggregates were found. These hypothalamic nerve cells play an important role in the maintenance of body weight and a normal sleeping pattern.

SLEEP AND DEPRESSION

Many of the patients investigated by Aziz get to sleep too late and wake up later in the morning than healthy people. Moreover, it appeared that the further the sleep rhythm is displaced, the more depressive the patients are. These patients also suffer from more cognitive abnormalities. The disruption of the sleeping rhythm could partly be due to a shift in the rhythm of the 'sleeping hormone' melatonin. That rhythm is regulated by the biological clock in the hypothalamus. Many

Alzheimer's patients also have an abnormal sleep/wake rhythm. This can partially be corrected by light therapy and the administration of melatonin. Huntington patients might also benefit from such an approach.

WEIGHT LOSS

Although the mutated HD gene mainly causes damage in the brain, it is expressed in virtually all tissues, even though it does not cause damage everywhere. However, Aziz demonstrated that weight loss in the initial stages of HD is not the consequence of other symptoms, such as hyperactivity, but is directly related to the mutation. This indicates that the cause must partly lie in the peripheral tissues, such as muscle and fat tissue. The defective gene probably causes damage there as well. Influence of the normal gene HD is caused by a mutation in the huntingtin gene. In the mutated gene the DNA sequence C-A-G is repeated too often. Aziz's research reveals that weight loss and the number of CAG repeats are directly correlated: the greater the number of repeats, the greater the loss of weight.

The number of CAG repeats in the normal huntingtin gene can also influence the symptoms of the disease. This is because each person carries two copies of the huntingtin gene. In a normal gene there are 35 or less CAG repeats. Huntington patients have one normal gene and one defective gene with 36 or more repeats. Aziz discovered that the number of CAG repeats in both the normal gene and the defective gene is important for the rate at which the disease progresses. However, the effect of the normal gene is small and is mainly important for understanding how the disease develops and for a correct interpretation of future drug studies. It follows that such studies must take into account the differences in the number of CAG repeats in both genes.

Acknowledgement: Ahmad Aziz Leiden University Netherlands

Acknowledgement: Gateway News AHDA (NSW) Inc – Volume 13 No 3 – Spring 2010



HD Research Update: **“New Insight into Wasting Disease”**

by Jennie Curtin

Australian researchers have for the first time been able to see inside the mutant proteins that are responsible for the incurable illness Huntington’s disease.

The Scientists from the University of Melbourne hope their work may one day lead to effective treatments for Huntington’s and other degenerative diseases.

Dr Danny Hatters, from the University’s Department of Biochemistry and Molecular Biology, said the team used state of the art equipment that enabled them to see in greater- detail than ever the clumps of proteins that: ultimately destroyed brain cells.

“It’s really very exciting,” Dr Hatters said. “Trying to understand how these clusters form has baffled scientists for a long time. This is the first time anyone has been able to see these clumps. It also allowed them to identify areas that could be targeted in drug treatments, he said.

Huntington’s is an inherited disease where the brain cells degenerate and eventually die. It affects coordination and leads to a decline in mental facilities and emotional reactions. Symptoms which usually appear between the ages of 35-45 include uncontrolled and jerky movements, walking difficulties, problems with speech and swallowing, difficulty concentrating, short-term memory loss, depression and mood swings.

Treatment focuses on alleviating the symptoms with a range of antipsychotics, anti-depressants and tranquillizers. A closer understanding of how the protein clusters form and change should lead to better knowledge of how drugs work, and a better drug treatment regime, Dr Hatters said.

“Importantly our research techniques could have applications 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 Parkinson’s disease,” he said.

The above article appeared in The Sydney Morning Herald Friday 30th July 2010

The research findings referred to in this article are from the following publication: -

Olshina MA, Angley LM, Ramdzan YM, Tang J, Bailey MF, Hill AF and Hatters DM (2010)
“Tracking mutant huntingtin aggregation kinetics in cells reveals three major populations including an invariant oligomer pool”

Journal of Biological Chemistry 285, 21807-21816.

Acknowledgement: Gateway News AHDA (NSW) Inc – Volume 13 No 3 – Spring 2010



Auckland / Northland News

Fundraising fever hits HD Auckland

It's been a busy few months for the team here in Auckland, as we have been fundraising furiously for the Association. Sunday 7th November saw our volunteers donning their best barbeque outfits for a full day of sausage sizzling. The sausages were kindly donated by the Mad Butcher in Onehunga, and certainly went down a treat with the locals. It was a glorious spring day, so our thanks go to Christine and Ted Stent who gave up their whole Sunday to sizzle over the grill! All proceeds from the event will go towards buying a new work car for Jane Devine, our family liaison officer.



Volunteers from HD Auckland running the sausage sizzle

The weekend of 20th and 21st November also drew out the volunteer crowds to raise money for the Association. A team of helpers waved the HD flag outside the Westfield Mall in St Lukes, helping to raise awareness of the disorder. Volunteers handed out leaflets about the disease, as well as collecting money towards Jane's new transport. Thank you to all who helped with our collection.

HD Charity Dinner and Auction

The HD team were overjoyed when Leanne Knox came to visit them this month. Leanne had suffered a huge disappointment with her engagement plans, but had decided to turn it into a massive positive for people living with Huntington's Disease.

"I was walking up Mount Eden," says 25 year old Leanne, "when I started thinking about a recent church sermon about being extraordinary. Suddenly the idea to hold a banquet dinner to raise money for Huntington's Disease popped into my head. I kind of pushed it off and thought "I can't pull that off yet, I'll wait until I've got more networks", but the idea kept coming back to me. Then I thought "if only I had a free venue to hold it at...". It was this instant thought, Butterfly Creek, 27 November- the date that was meant to be our wedding date and reception venue."

Leanne kindly offered to donate her wedding venue to the Association to hold a fundraising dinner- with just six weeks to go! Of course our committee scrambled to help, along with Leanne's friends and relatives from Auckland and the Waikato. Leanne, who is originally from the Waikato, has Huntington's Disease in her family, and wanted to help people living with the condition.

The Huntington's patron, New Zealand scientist Professor Richard Faull agreed to speak at the dinner and offers for charity auction items came flooding in.

"I'm so excited that this has become a reality," says Leanne. "We're still working out how much we raised on the night, but it will all go to help the work of the Huntington's Disease charities in Auckland and the Waikato. They help my family and others like them all around the country. I know just how needed that support can be, and I'm so glad my disappointment will help to provide a better life for others."

The HD Charity Auction and Dinner was held on 27th November 2010 at Butterfly Creek, Auckland Airport.

Farewell to Miriam Rodrigues

It's a sad farewell to one of our committee members this month, as Miriam Rodrigues leaves to spend more time with her new daughter. Miriam has played a huge role in the committee as the former Secretary and fundraiser. Our thanks go to Miriam for all her hard work, and the committee will make sure we still get to see the family at our family days.

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TV Stars needed

Would you and your family be interested in telling your story on TV? Huntington's Auckland has been approached by Open Door Productions and Attitude TV, which want to make a feature on Huntington's Disease. They are looking for someone with Huntington's Disease in their family who can talk about the impacts of the disease.

You would need to consent to being filmed, and have the permission of your family as well.

Please contact the committee if you are interested on huntingtonsakld@xtra.co.nz

Waikato Region

Kia ora whanau – It's nice to finally see the sun and some warmer weather. Roll on summer. Everyone appears to be happier and the walking shoes are now out of the cupboard and beating the footpaths, the silly season will be here before you know it with only four weeks to go until Christmas.

The past three months have been an exciting and busy time for me as I continue to learn my role as HD/MS Co-ordinator, meeting my clients and their families, attending support Groups and working on our MS Manuscript Newsletter.

It has been nice to see that the Huntington's Disease has not stopped one of my clients making the most of what he can do by having an eight day fishing holiday with his

mates in Vanuatu – (see article *Fishy Tale*).

As I work through my caseload and continue to learn from you all, I am thinking of a new HD Support Group for 2011.

Any thoughts/ideas that you may have/want are more than welcome. You can contact me on DDI: 07 834 4745, mobile: 027 3855425, or email: tracy@mswaikato.org.nz

Wishing you all a Merry Christmas, Happy New Year and safe holiday period.

Hei Konei rà – Farewell until next time
Tracy Hobbs

Wellington News

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

Greater Wellington

Here we are almost at the end of 2010. How quickly the year has flown by. It seems to have been a very busy year for me and for the Wellington Association.

Although we have had no major new initiatives this year, I do have a number of new clients and have continued to have regular contact with all the other family members in our area.

I have had a close relationship with Noel Hamilton House in Greytown where we have some residents and others go for respite care. It is a lovely home and will be of even greater value now that Amaryllis House no longer has a respite facility.

Margaret Simmons the manager at Amaryllis is retiring at the end of November after a long contribution to caring for Huntington's residents. We at the Association have worked closely with Margaret and we will miss her knowledge and assistance.

I will work with the new manager to continue our relationship and maintain close contact with family members of the residents.

I have made contact with a number of health professionals and other agencies over the year and hope that by providing information, understanding of HD improves

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throughout society. I am also looking to undertake a new course being offered in Human Clinical Genetics in 2011 which will be of great value and indicates the increased interest in the implications of genetics in healthcare in general.

I hope that we can all look forward to a great summer and Christmas. I will be on holiday over January for

some of the time but will be in contact with my clients and anticipate a great 2011.

Please as always, feel free to contact me by phone or e mail at any time.

Regards

Jeanette

Taranaki, Wanganui and Palmerston North

The sun is shining (some days) and people are starting to think about Christmas and the summer holidays.

Just as I got to the point where I felt I was getting a handle on all things Huntington's Disease, having met many of the families in my area, and getting to know who's who, my family got turned upside-down, and I went into survival mode for a couple of months.

One of the major things that has happened is that I have moved, so am now located half way between Hawera and Wanganui. The move will enable me to visit both New Plymouth and Palmerston North on a regular basis.

I am now able to give inservice education to community groups, and any other people who would like to know a little more about HD.

If I haven't contacted recently and you would like to catch up, please send me an email, text or give me a call and I will happily call you back.

Best wishes you all for a Happy Christmas and New Year.

Regards

Fleur Brett

Hawkes Bay News

Kia ora koutou.

Hi everyone and welcome to our families in Hawkes Bay as we head into another beautiful summer.

My main role continues to be visiting families regularly to provide ongoing support for people with HD and their carers and family members. I am also visiting people in rest homes and going out with them for coffee and wheelchair walks in the sunshine to provide some relief and distraction, as well as support for their families and ongoing information to the staff.

We continue to have regular "get-togethers" as a group with opportunities to have some relaxed fun, and share time with others who know what living with HD means! We have recently had our Xmas Gathering which was very enjoyable – what a wonderful group of families we have here! - and look forward to a pizza-making evening at one of our family's homes in early February.

A few of our members continue to access the hospital physiotherapy group, and the local MS Society continues to welcome us at their groups and activities. There are a number of community services that we can put families in touch with that could be helpful.

If anyone out there would like a chat, or to find out what we do and what we can offer to you and your family, please give me a call anytime, or a text, or drop me an email – I would love to hear from you and talk about how we can support you.

Kia Kaha,

Tanya Jeffcoat

HD Assoc Hawkes Bay - ph (06) 8353020

Gisborne News

Hi Everyone, Wow summer is almost here I can't believe how fast this year has passed!

Not a lot happening in Gisborne at the moment for Huntington's.

This last year has been very challenging for me with the loss of one of my HD friends and another two have moved to another district. Also this year my husband has had to go to Auckland several times to have treatment for his spine.

This year I met a wonderful lady who was prepared to share her HD journey with me and our support group. I had always wanted to ask those questions that are difficult to ask - she was wonderful and allowed me to ask them and then answered them all for me. I am so honoured to be allowed into someone else's life to learn and be able to observe.

During the year we have been kept up to date with the latest research that is being done for HD. It is wonderful to see that so many people care about finding a "Cure" for HD. I wish them all the best and hope that their research will turn up some form of relief for HD sufferers. I couldn't think of a better way to become redundant than to be told that HD had been cured and I was no longer needed to help out!

I would like to take this opportunity to wish you all the best for Christmas and the New Year; I look forward to working with you in the coming year.

Best Regards

Cheryl Morley

Christchurch News

As I sit writing this it has been a really hot day in Christchurch which is a welcome change from after shocks. A lot has happened since our last newsletter with everyone in Christchurch being woken up on the 4th September with a 7.1 earthquake. The devastation that it caused has been huge, and the on going effects of the after shocks are playing on everyone's nerves, we have had over 2500 after shocks now, and they still make you stop in your tracks and pause waiting for them to carry on. Some of our HD families have had to be re-housed because of damage to homes and the earthquake has brought to our attention the plight of some of our HD people and their living conditions. Thankfully we have been able to move quickly and get help for them all.

Our new Family Liaison worker Anne Wilson and the HD Service Co-ordinator Maggie Jury have visited Amaryllis House in the last month, and spent some time with the Wellington Liaison worker. This was a very

valuable experience for them both and we want to thank Wellington Association for their generous hospitality and for making this happen for them.

Christmas is just around the corner with families trying to focus on the time ahead. We, as an Association, will be gearing up to the opening of the new HD service in the New Year. This is a really exciting time for us all and for some, a life-long dream come true. The opening of this service has been slowed by the demand in Christchurch for tradespeople.

I want to wish you and your families a wonderful relaxing time over the Christmas period and may you all have a good quality family time together.

Regards

Dianne Collins

Chairperson HD Christchurch



New HD Service for Christchurch

Well the builders have started and things are full steam ahead in Christchurch for this service to open in the New Year.

To those of you who have not heard, NZ Care secured the tender to provide this service from the Ministry of Health. NZ Care have an extensive association with HD care and provide this service up in Lower Hutt at Amaryllis House.

The new service is situated on the corner of Woodham Road and Brittan Street and will be based in an early 1900's villa that has a newer annex attached. This is currently being gutted to convert it from a 16 bed rest home to a 10 room service, comprising of 8 permanent rooms and 2 respite rooms. This facility provides 2 spacious lounges, with separate spa bath room, huge kitchen and dining room and covered in verandah. There will be an addition next year of 2 respite units on the property as well. We are fortunate that this property has really lovely established gardens with many private areas for families to enjoy while visiting.

NZ Care have established an Advisory Group to help with the setting up of this service and for ongoing regular input and monitoring. Denise Forbes and I are representing HD families on this and will endeavor to be your voice.

Our association has purchased flat screen televisions for each bedroom that will be wall mounted, as well as a 42 inch television for one of the lounge areas, with another television to be purchased for the family room. We were

very fortunate to receive money towards these purchases from a long time close associate of our association. We would like to take this time to thank her for her ongoing financial support to us.

There will be a chance for those interested to look through this facility before it officially opens so we will contact as many as possible to advise you of this date. The service hopes to be up and running early in the New Year.

This has been a long process and we are grateful to the Ministry of Health for listening to us, parents of HD people who never gave up fighting for this kind of service, HD Christchurch past and present committee members and families who fought and fundraised for such a service. The Wellington HD Association and many others, including Dorothy Tortell who have had valuable input into this service being established in Christchurch. It is a dream of so many in our association, that there be appropriate level of care and support for our HD loved ones, when we can no longer care for them.

Thank you everyone for being part of an incredible journey that we will all reap the benefits of in the years to come. Also to NZ Care who have been driven by our plight to provide this wonderful service for the families of Christchurch.

I promise photos of the facility in our next magazine.

*Dianne Collins
Exhausted 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

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.

Mrs Elaine Bradley (Membership Secretary)
159 Tutaenui Road
RD 2, Marton 4788
gebrad@xtra.co.nz



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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Laura Fogg (Auckland)
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Judith Baker (Christchurch)

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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 April 2011. The deadline for material to be received for this issue will be 10 March 2011. 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



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
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Contacts

AUCKLAND / NORTHLAND

Mark Dunlop, Chairperson
PO Box 16238
Sandringham, Auckland
Tel (09) 815 9703
huntingtonsakld@xtra.co.nz

Jo Dysart
HD Association (Auckland) Inc
Neurological Support Centre
7A Taylors Road
Morningside, Auckland
PO Box 16 238, Sandringham
Tel (09) 815 9703
Fax (09) 815 9704
Mob (027) 432 8255 or
0800 HDAUCK – (0800 432 825)
huntingtonsakld@xtra.co.nz

Jane Devine
HD Assn (Auckland) Inc (as above)
Mob (0274) 328 256
jane.hda@xtra.co.nz

WAIKATO

Tracy Hobbs
Client Service Coordinator
PO Box 146, Hamilton
Tel (07) 834 4745
Mob (027) 385 5425
tracy@mswaikato.org.nz
www.mswaikato.org.nz

ROTORUA

Lorree Adam
20A Whitworth Road
Rotorua
Tel (07) 348 4267

Alison Whitfield, RN
1115 Haupapa Street, Rotorua
PO Box 811, Rotorua
Tel (07) 346 1830
Fax (07) 346 1840
ms.rotorua@xtra.co.nz

GISBORNE

Cheryl Morley (Huntington's Advisor)
PO Box 1020
Gisborne
Tel (06) 868 8878
Mob: (027) 686 9432
gisbornehuntingtons@gmail.com

HAWKES BAY

Tanya Jeffcoat (Huntington's Advisor)
PO Box 4211
Marewa, Napier 4143
Tel (06) 835 3020
tjeffcoat.hawkesbayhda@yahoo.co.nz

BAY OF PLENTY / TAURANGA / TE PUKE / WHAKATANE / OPOTIKI

Cheryl Standring
MS Society
PO Box 15 309
Tauranga
55a Edgecombe Road
Tauranga
Tel (07) 571 6896
fieldworkerbopms@xtra.co.nz or
bopms@xtra.co.nz

TARANAKI / WHANGANUI / PALMERSTON NORTH

Fleur Brett (Huntington's Advisor)
PO Box 50
Rongotea 4865
Tel (06) 324 8307
Mob (027) 496 6500
fleur.huntingtons@hotmail.com

BLLENHEIM

Belinda Boyce
Marlborough Sclerosis and
Parkinson's Society Inc
28 Alfred Street, Blenheim
Tel (03) 578 4058
Fax (03) 577 5271
Mob (027) 255 1299

NELSON

Pam Grey
MS Society
Ph. (03) 544 6386



WELLINGTON

Cecil O'Neale, Chairperson
PO Box 30420
Lower Hutt 5040
Tel (04) 528-8094
Mob (027) 213 4113

Jeanette Wiggins
(Huntington's Advisor)
HD Association (Wellington) Inc
PO Box 30420
Lower Hutt 5040
Tel (04) 569 3252
Mob (021) 344 445
jwiggins.wellingtonhda@hotmail.com

WEST COAST/HOKITIKA

Heather Creagh
PO Box 76, Greymouth
Tel (03) 732 3827
Fax (03) 732 3813

CHRISTCHURCH

Judith Baker
PO Box 78
Cust, North Canterbury
Tel (03) 312 5612

Diane Collins, Chairperson
8 Fusilier Street
Hoon Hay
Christchurch 8025
Tel (03) 960 5913
ddc2@clear.net.nz

Anne Wilson (Field Worker)
Tel (03) 327 7898
Mob (021) 023 07343

DUNEDIN

Zena Pigden
ISIS Centre
Private Bag 1940, Dunedin
Tel (03) 476 6044 ext 5485
ZenaP2@healthotago.co.nz

INVERCARGILL

Maree Lewis
MS Society
PO Box 1561, Invercargill
Tel (03) 218 3975
maree_ms.south@xtra.co.nz