Huntington's NEWS

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

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HUNTINGTON'S DISEASE YOUTH ORGANIZATION

Launch of the Huntington's Disease Youth Organization's Website Celebrated Around the World

First organization to focus on providing much needed support to young people affected by the devastating hereditary disease.

February 6, 2012 – The Huntington's Disease Youth Organizations (HDYO) is pleased to announce the launch of www.HDYO.org, the organization developed specifically to support young people affected by Huntington's Disease (HD), a devastating degenerative brain disorder that affects an individual's ability to walk, talk and reason. Children have a 50 percent chance of inheriting the fatal gene if their parent has the disease.

The website began as a dream of one and a need by many. Matt Ellison, a 23-year-old from England, was the visionary to bring the HDYO website to life. As a young person witnessing his Dad's progression of HD, he knows firsthand of the difficulty that surrounds a young person impacted by HD.

"The impact of HD on your life can be huge, and yet the support available to young people is miniscule," said Ellison, Founder of HDYO. "I felt this lack of support and resources was unacceptable and that something needed to be done. Young people deserve to be recognized and provided appropriate support." said Ellison.

With help from other young people affected by HD around the world, Ellison and the team have made great strides towards improving the much needed support with the launch of the HDYO website. The site contains educational information created specifically for young people, by young people. The material includes articles, illustrations, videos, audio and personal stories. The goal of HDYO is to empower youth with knowledge about HD and provide a supportive community to help each other cope with realities of the disease.

"The website is truly a remarkable effort of Matt and many other young people who are dedicated to a cause," said BJ Viau, HDYO's U.S. Board Member. "Now the challenge is spreading the word and helping others realize we are here to support them."

In order to support young people worldwide, HDYO's material is currently being translated into a dozen different languages by a team of more than 20 translators – many of whom are young people from around the globe who want to help other young people in their region gain more access to information about HD.

About Huntington's Disease: HD is a devastating, hereditary, degenerative brain disorder for which there is, at present, no cure and limited treatment options. Eventually, the person with HD becomes totally dependent upon others for his or her care. Huntington's disease profoundly affects the lives of entire families -- emotionally, socially and economically.

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Message from the Editor

After being the Editor of *Huntington's News* for just over eight years, I have decided to step down from this position. I feel very privileged to have had this opportunity to bring the latest research findings, your stories and news from the Huntington's community worldwide to this Newsletter.

I am pleased with the way that the Newsletter has maintained its readership in New Zealand and overseas and continues to have a role in this age of electronic communication. I feel it has played a part in the surge of information on Huntington's – Huntington's Disease is, nowadays, in the news and TV programmes/documentaries and on the radio, making people more aware of HD and ready to talk about it.

I wish to thank Judith Baker for proof reading each issue, Dorothy Tortell for her in-depth knowledge of Huntington's Disease, and our newest board member Laura Fogg for her contributions. All have been invaluable in the production of *Huntington's News*. Also I wish to thank you, the readers, for your support and for sending in your personal stories all of which have been much appreciated.

I wish the new Editor all the best for the future publications. You will be able to make contact with the Editor in the first instance on the same email address:info.wellingtonhda@xtra.co.nz

Kindest regards

Glenys Shepherd

Thank you to our Editor

It is with regret that the Wellington Association has accepted Glenys Shepherd's resignation as editor of our national Huntington's News.

Glenys has been the editor for more than 8 years and has worked hard to present an interesting and informative newsletter. The newsletter has been an important communication for HD families and we are grateful to Glenys for giving so much time to this.

We will miss her knowledge and skill in this area but wish her and her husband a happy retirement.

Colin Wiggins

Chairperson, Wellington Association

HDBuzz

Huntington's Disease research news.
In plain language.
Written by scientists.
For the global HD community.

Double success for huntingtin RNAi gene silencing

Two bits of good news for RNAi gene silencing in HD: it's safe over six months, and a way to treat bigger brain areas

By Dr Ed Wild on January 24, 2012 Edited by Dr Jeff Carroll

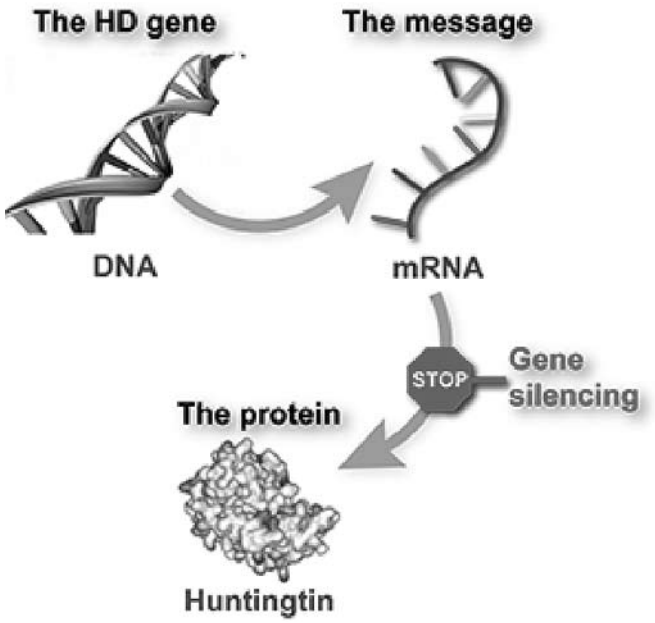
Most HD researchers are pretty excited by the idea of 'silencing' the Huntington's disease gene, to reduce production of the harmful huntingtin protein. Two challenges - safety and delivery - are now closer to being solved thanks to collaborative work by academic and industry researchers.

We're big fans of *gene silencing*. Like many Huntington's disease researchers, we think it's the approach most likely to produce an effective treatment for HD.

Gene silencing involves using a specially designed drug to intercept a message molecule, called *RNA*, that's produced from the HD gene and tells cells to make the harmful *huntingtin protein.*

The effect of the drug is that cells make less of the protein.

Put even simpler, *gene silencing* is like a stop sign for mutant huntingtin.



Gene silencing reduces huntingtin production by preventing its RNA message being read by cells.

Rapid progress

So far, *gene silencing* for HD, in various forms, has cleared every hurdle it's encountered. It's now been tested in several mouse and rat models of HD, and not only slowed down progression but actually produced improvement in both symptoms and brain damage. It seems that the brain can actually recover — to some extent — if only levels of the harmful protein can be lowered a bit.

The remaining hurdles

Several research teams are heading for human trials of *gene silencing* in HD. But there are a few remaining challenges to address before that can happen.

The first is **safety**. Unexpected side effects are always possible, and could be dramatic, since we're talking about drugs that are injected or infused directly into the nervous system, and interact directly with our cells' genetic machinery.

Another is **delivery**. *Gene silencing* drugs can't be given as pills or injections into the blood, because they wouldn't be let into the brain. So they have to be introduced directly into the nervous system. Depending on the structure of the drug, this means an operation to introduce needles or tubes into either the spine or the skull. Sounds drastic, but if the treatment is effective, it'll be worth it.

The delivery problem doesn't stop there though, because once the drug is in the head, it has to get **inside** our brain cells to work its genetic wizardry.

The *gene silencing* menu

Gene silencing researchers have to make several choices before they begin a treatment trial. Here's a checklist to help you understand future news stories.

First, we have to decide on the **structure** of the drug. The two basic choices are ***RNAi*** drugs, which are chemically

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similar to the body's *RNA* message molecules; and ***ASO*** drugs, which are slightly different but may be better absorbed by cells.

The second choice is what **target** to choose: both copies of the HD gene, or just the mutant one. Targeting both — called **non-specific silencing** — is easier, but switching off the 'normal' gene might be dangerous. Targeting just the mutant gene — called ***allele*-specific silencing** — may be safer but is much harder to do.

The third choice is **destination** — where will the drug go? *RNAi* drugs don't naturally spread far, so the drug has to be delivered right into the substance of the brain. Drugs that spread further, like *ASOs*, could be infused into the fluid around the brain or, if we're lucky, at the base of the spine.

Fourth, we need to decide on **delivery**. Will the drug be given on its own, packaged in a virus or pumped at pressure, to increase its spread through the brain?

"The RNAi drug spread further than you'd get with simple injections. A lot further, in fact."

The fifth choice is **treatment regime**. Should we give a one-off treatment or infuse the drug over weeks or months? Right now we don't know how long the effects will last, so this has to be worked out by comparing different regimes.

Whenever you read about *gene silencing* research, it's helpful to figure out up front, which option has been selected for each of these choices.

Three come along all at once

At the recent HD World Congress in Melbourne, HDBuzz reported on exciting presentations from several *gene silencing* research groups. Then in November, we brought you news of the first safety trial of huntingtin *gene silencing* using *RNAi* in a *primate* brain.

Now, two further scientific papers have been published — each the fruit of collaboration between academic researchers and biotechnology companies. Both papers involved Minneapolis-based company Medtronic and the team of Dr Zheming Zhang at the University of Kentucky.

Six-month safety

The November report of *RNAi* safety in primates was quite a short study — six weeks. The new study by Medtronic and Zhang's team, reported in the journal ***Brain***, was also done in rhesus monkeys, but lasted a full six months.

Let's look at what the researchers studied, using the checklist above:

1. Structure: this was a trial of an *RNAi* drug.
2. Target: both copies of the gene were targeted — non-specific knockdown.
3. Destination: the substance of the brain — the striatum, to be exact, which is affected early in HD patients.
4. Delivery: the drug was packaged into an empty virus, called AAV2.
5. Treatment regime: a one-off injection into five sites on each side of the brain

It's also worth noting that 'normal' monkeys were used, with no expanded copies of the HD gene. So, this trial could only measure protein changes and safety — it can't predict improvement in patients.

After treatment, the monkeys were observed for six months, looking at their general health and movement control. The surgery was well tolerated, and no new problems were seen in the treated animals.

Measuring brain volumes is more fun when you do it with M&Ms. For the record, a single milk chocolate M&M has a volume of about 600 cubic millimetres.

As hoped, levels of *huntingtin protein* fell significantly in the treated regions. At each injection site, protein levels were reduced over an area about six millimetres across — in volume, that's about three M&M's worth per brain. It may not sound like much, but in a human brain that could make a big difference, and remember these measurements were made 6 months after the one-off treatment.

Thankfully, the drug caused no harmful brain changes like *inflammation*, infection or *neuron* damage.

So, the drug did its job of reducing protein levels, and treatment didn't appear to produce any harmful effects. The authors reckon that six monkey months equates to about 18 human months. Sounds good — but as the

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authors point out, it could take even longer in humans for good or bad effects to emerge.

An innovative delivery method

The other new paper came from a three-way collaboration between the University of Kentucky team, Medtronic, and *RNAi* drug company Alnylam Pharmaceuticals. It was published in the journal ***Experimental Neurology***.

This was also a study of non-specific knockdown *RNAi*, delivered into the striatum of monkeys.

What distinguishes this work is the innovative delivery method. A technique called **convection enhanced delivery** (***CED***) was used. This involves placing tubes through the skull and into the substance of the brain. The top end of the tube is connected to a small pump that constantly squirts the drug down the tube under pressure. This pressure is the key — it causes the drug molecule to spread much further than it otherwise would.

CED is already used to get chemotherapy drugs to spread further within brain tumours. But would it work to deliver an *RNAi* drug?

First, the drug was pumped into the brain for seven days. Only one side of the brain was treated, so that the other could be used for comparison. A range of doses and infusion rates was used, to find the best combination. Then, a 28-day infusion was tried. Cleverly, the team made harmless radioactive modifications to the drug, that enabled them to measure exactly how far it had spread.

The drug did its job of reducing huntingtin levels, and the tubes and infusions didn't particularly harm the brain.

But was the additional hassle of fitting tubes and pumps worth it — did the drug spread further? In short, yes.

Measurements showed that the *RNAi* drug reached much further than you'd expect with simple injections. If both sides of the brain had been treated, huntingtin levels would have been reduced in about eleven M&*Ms*'-worth of brain.

In a nutshell…

Before these two papers came out, we already knew that huntingtin could be lowered in the monkey brain using *RNAi*. Now we can add two major check-marks to our wish-list: first, silencing works and it is safe over longer periods, and second, there are ways of getting the drug to spread further.

What could go wrong?

Cautious optimism is a wise approach here. There are certainly some things that could go wrong on the way to human trials, or during them.

These *primate* trials have shown that lowering huntingtin levels is safe in healthy monkeys. But that doesn't mean it's definitely safe in human patients. Human brains are much bigger and more complex than monkey brains. So the treatment could be less effective, or more dangerous, simply because of the species difference.

It's also possible that the healthy protein somehow protects the brain from its harmful brother in humans. If that's the case, silencing both copies could unexpectedly do more harm than good.

The brains of people with HD symptoms are probably more fragile and difficult to operate on, too. The bits of the brain that need treating are smaller than normal, because of shrinkage caused by HD. So the operations may be harder and more risky.

Finally, detecting success might be difficult in humans, because the disease progresses slowly, and we can't examine patient brains under the microscope.

But never forget — all of these problems are being worked on together by some of the best scientific minds in the world, all focused on making effective treatments a reality for patients.

2012 — the year of *gene silencing* for HD?

Could 2012 be the year of *gene silencing* for HD patients? Will we see one or more human trials in the coming months? On the strength of progress so far, we actually believe that's a reasonable thing to hope for, and several groups are working hard to make it a reality. The first trials will be small, and will be carried out slowly and with great caution, because safety is the prime concern. But if all goes well, larger trials will follow.

Acknowledgement: Newsletter — Huntingtons Queensland – February 2012

NEWS FROM THE REGIONS

Auckland / Northland News

It was a great honour and privilege that Jane Devine and I represented Auckland Huntington's Association at Jocelyn Bullock's retirement celebration. As many of our readers know Jocelyn Bullock has made a major contribution to the development of the Human Brain Bank in the department of Anatomy and Radiology, the Centre for Brain Research. Jocelyn has worked there for 38 years and has touched many families over the years. Jo and Jane would like to send our sincere gratitude for the time we have been able to work with Jocelyn and wish her well and a safe journey on her travels in retirement.

HD Auckland Association were also able to be part of the community expo at the Brain Day 2012 held in Whangarei on Saturday 10th of March and Auckland Saturday 17th of March. Again this was an opportunity for leading scientists, clinicians from the Centre of Brain Research to collaborate with community organisations offering families opportunity to attend lectures, science lab tours and gain opportunities for practical tips on living with brain disorders. Both these days were hugely successful with a large amount of people coming through from all walks of life and all ages.

We continue to hold regular sausage sizzles at Onehunga and Mangere Mad Butcher and would like to give our sincere thanks to Steve the Owner of Mad Butcher and Peter the Manager of Mad Butcher for enabling us to have regular fundraising sausage sizzles.

It is also with great delight we are able to welcome Mr Kieran Nally to our small but growing committee. Mr Kieran Nally is a wonderful gentleman with a wealth of knowledge in legal matters associated with HD families and we look forward to a very long and productive relationship with him.

As you can see it has been a very positive start for the Auckland Huntington's Disease Association and we hope this continues throughout the year. We will keep you informed.

Please do not hesitate to contact myself or Jane if you need any further assistance, support or advice.

Until next time

Warm regards,

Jo Dysart

Wellington News

Hello and happy new year to you all, here we are almost a quarter of the way through 2012, with what is left of our sad summer almost at an end.

We had a great fundraiser, organised by the committee in November where we went to a private screening of Red Dog at the Lighthouse Cinema in Petone. The Lighthouse supports us by providing discounted ticket prices for the residents of Amaryllis House who try to get to the movies monthly. It was a great night and a fun movie. We are going to do this again on May 17th for an 8pm screening so pencil the date in. We will have fliers and tickets available in a few weeks and would love to see as many family members and friends who support the HD community.

We have recommenced our swimming at the Hutt Hospital and have some new community based swimmers joining our Amaryllis and Spring Lodge group which is great. We are lucky to have access to the hydrotherapy pool and will continue to try and maximise our use of it.

Sadly, Hilly Lutter, service manager at Amaryllis House has resigned. We are sorry to lose her and will miss her positive and innovative approach. We all wish her the best for her future and look forward to the appointment of a new manager soon.

I continue to work with the families in our area in assisting them in whichever way they require and I hope that I continue to provide the support that is required. I will also continue to work with Amaryllis House and with Karen, Tanya and the HD advisors in any other areas to support HD families, many of whom are spread throughout the country.

The Wellington Association is trying to increase our profile over this year and your support, in any way is always appreciated.

If you want to contact me for any reason, please feel free to email, phone or text.

Regards

Jeanette Wiggins

Manawatu / Whanganui / Taranaki News

Kia ora everyone.

The New Year is well on its way and I'm into the swing of things once more. I enjoyed a break between Christmas and the New Year to read, cook, eat, garden, exercise and spend time with family. I hope everybody else achieved some enjoyable activities over this period.

Unfortunately several people have had family members who have been unwell and in hospital over this time. The passing of a client was also sadly marked.

A meeting in February with colleagues and our Patron Dorothy Tortell started as a wet somewhat precarious drive over the Saddle Road to Woodville where the sun came out and continued to shine for most of the time we were there. It proved a thought provoking constructive time with different view points offering new perspectives on issues, with much helpful advice and information elicited on my part.

I have travelled around and been to the far reaches of my territory trying to catch up with those of you, not still on holiday. It has been good to meet some people face to face for the first time and talking and sharing news with others as well as finding out if there's anything I can help with. It has also been great that people are contacting me for whatever reason – please feel free to do so. Assisting with finding new activities for clients has been interesting. An example was looking into volunteer work and discovering what a rich field of volunteer activities there is out there in the regions (and much easier than trying to find a GP practice to enrol with).

Some of you are doing a magnificent job exercising (under difficult circumstances sometimes), building up and maintaining your physical fitness for the health benefits it holds. Well done and keep it up, exercise is proven to have positive effects for all of us.

The vagaries of the weather have been affecting us this summer and as always have been a good old topic of conversation. I hope all you South Taranaki and Whanganui folk escaped serious damage from your wind ravaged weekend of a while ago.

I look forward to hearing from you and/or seeing you in the future.

Kind regards to all,

Karen Evans

Hawkes Bay News

Kia ora koutou. Hello everyone.

In Hawkes Bay my role is to provide support and information. I am available to meet with people and families at a time and place to suit. Coffee and cake are an important part of our lives!

We have three - monthly Get-Togethers where families can come together and share and laugh. Our next Gathering will be on Sunday 29th April. It will be held up at The Beacon, on Napier Hill, and will be a shared afternoon tea all welcome.

I provide regular opportunities for our carers to get together and provide mutual support. We have a group of male care-givers who get together for a drink and dinner from time-to-time - all subsidised by our group funds.

We have low-cost massage therapists who can provide our families with massage subsidised by the group funds. Stress management is vital for everyone.

I regularly meet with staff at local rest homes to ensure the staff are supported and equipped to best look after people with Huntington's disease who are living there. I also am able to regularly take people out for walks in their wheelchair (weather dependent!!)

During Brain Awareness Week I joined other neurological organisations and the neurological foundation in raising the profile of our organisations in the community, and engaging with many people around brain health.

Please contact me anytime if you would like to talk or need some support.

Kia kaha.

Tanya

Ph (06) 8451616 / 027 2009789

Christchurch News

Greetings from Christchurch…. Today has been an absolutely beautiful day in Christchurch which makes things look and feel very different if only for a short while.

Christchurch is still in a state of upheaval and uncertainty for all of us, 18 months on and still a lot of people are hanging in limbo not knowing the fate of their homes or jobs, as almost daily, buildings are being temporarily closed as new evidence of the aftershocks becomes apparent.

Our Association continues to grow with families being introduced as their needs arise. Last year we looked at the role and function of our Family Liaison Coordinator in conjunction with the DHB role of Coordinator of Clinical Services for Families Living with HD and decided that it was not quite meeting the needs of our HD families so we have introduced a new position of Social & Support Coordinator. This position has been taken up by Ellen Nijhof who comes to us with a Speech Language background. Ellen has taken to her new role and has already provided quite of few outing opportunities for our HD people as well as giving people in like circumstances, the chance to meet up and share ideas and problems. Ellen is working very closely with Maggie Jury and between them the gaps seem to have closed up, with no one slipping through.

Our annual BBQ which never happen last year due to earthquakes did happen for us this year. We were welcomed back to Mary & Ashley Gilmour's' home again for this event. Mary and Ashley are in the middle of the Red zone but their house is not too damaged. Unfortunately for them their home and beautiful gardens will be demolished and we assured them that we look forward to their new home hosting this event again. This is a chance for everyone to sit back, relax and spend time just chatting while sharing really yummy food.

Our AGM is to be held on Sunday 25th March, 2pm at the Hornby Day Care, 93 Carmen Road, Hornby. Everyone is welcome

The Residential Care Service in Woodham Rd has been open for 6 months now and is nearly full. The staff at this facility have been working miracles with some of the higher needs and associated problems that HD brings on a daily basis. The facility supports individuals to maintain some level of independence while providing a safe secure and family like environment for them to live in. The staff while being challenged seem to be enjoying working with our very special HD family members and are dedicated to providing a very high level of care.

Stay safe everyone

Dianne Collins
Chairperson HD Christchurch

The Wedding

10th March 2012

On the 11th January 2012, as the Coordinator of Clinical Services for families living with Huntington's disease (HD), I made one of my routine home visits to check on the health needs of Tracy Taylor, in Ashburton. Just as I was leaving, she said to me that she and her partner of 15 years, Mark, had decided to get married. "When?" I asked excitedly. Tracy explained that because neither of them are able to work due to their combined serious health conditions, they figured it would take them about two years to save up. I asked them what kind of wedding they wanted and Tracy thought they would have a barbecue in their back yard for maybe 20 close friends and family.

I was driving back to Christchurch as I mulled this over and thought to myself "hmmm … I'm not sure that Tracy has two years of quality life ahead … she may do … but I just don't know". When I reached my home (which is also now my office since the September earthquake destroyed my work rooms), I rang Mark. I asked him when he and

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Tracy would get married if money were no object and he replied without hesitation "straight away". An embryo of an idea was beginning to form in my mind. I thought of the enormity of the task ahead and didn't know where to begin.

After more mulling, I decided to email Dianne Collins, Chairperson of the Christchurch HD Association, for her thoughts as to whether the Association would be able to help with a wedding. Within a very short time, the HD Association committee had pledged a choice of either $250.00 towards the cost of the food or the offer of actually preparing and serving all the food for Tracy and Mark. Tracy, Mark and I were blown away with this kind and generous offer and this inspired us that we really could make a wedding a happening thing. Someone suggested that I contact the *Ashburton Courier* local paper to see if they would be interested in running a story about HD and Tracy and Mark's wish to get married. Tracy and Mark are shy people and I left them to sleep on the idea of a newspaper article. They didn't need to sleep on it and in a couple of hours they got back to me with a resounding "YES!

I then rang the paper and was put in touch with a wonderful reporter called John Keast. John was keen to pursue the idea and quietly confident that, once made aware, the Ashburton community would rally round to support Tracy and Mark. His first question was "and when would they like to get married?" I was kind of thinking perhaps in six months but Tracy and Mark announced it would be the 10th March! Sharp intake of breath on my part, quietly thinking "Jeez – that's pushing it – no pressure then!" John interviewed Tracy and Mark about their lives and challenges and he then wrote a powerful front page article interweaving their stories with information I had written for him to raise the awareness of HD and all that HD means to families who live with it. The paper circulated on the Tuesday and we waited with baited breath. I hardly slept that night I was so excited.

From 8am the next day my phone hardly stopped ringing. We were overwhelmed with the generosity of local people. Firstly a celebrant called Iris Officer-Holmes from Ashburton offered her services as a gift to the couple. Iris knows heaps of people in the Ashburton community. As the days went by, we had offers from folk to make the invitations, fix Tracy's hair and makeup, donate a bouquet, make the dress, provide the keyboard music during the ceremony, provide a venue, prepare and serve the food, decorate the venue, sing professionally throughout the reception, decorate a dark green jag with ribbons and provide the chauffeuring, take the photos professionally, develop the photos and put them into an album, provide the cake, provide the drinks and finally provide a honeymoon bed and breakfast. Many people also donated money, which was fantastic, as there are some things that just have to be paid for e.g., the marriage license, the food and the shirts and ties. I was a tad short of cash to be honest when out of the blue, Tracy and Mark

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came home to find an anonymous donation of $500.00 in their mailbox! We then had everything we needed for an awesome day.

And it was! A couple of days have now passed since I had the absolute honour of watching Tracy walk on her Dad's arm through the rose gardens in the Ashburton domain to meet and marry Mark. She was just glowing in her handmade cream and chocolate coloured wedding dress decorated with hand-sewn roses and a beautiful bouquet. Her bridesmaid looked stunning in maroon and the flowergirl was a picture in pink and cream. Her handsome bridegroom wore a black suit and a crisp white short-sleeved shirt. The vows they chose to say to each other were beautiful and deeply meaningful for their unique situation. We later dined on roast beef, roast chicken, gravy, the best roast potatoes I have ever eaten, carrots, peas, pumpkin and salad. This was followed by pavlova and fruit salad and later by a delicious chocolate wedding cake. The beer and wine flowed as freely as the conversation. Throughout it all we were entertained by the very lovely dulcet tones of Vicky Smith, professional singer.

The day was a window of warmth and sunshine in-between days of cold, grey windy weather. It couldn't have gone better. It was one of the best events I have ever been involved with in my whole life because it brought to mind the strength of friendship and community and the endurance of real love. I know that whether Tracy and Mark have a long time together or a short time together it will be filled with laughter, patience and devotion. I can only say thankyou from the bottom of my heart to the wonderful folks in Christchurch and Ashburton who gave so generously of time, money and tangible gifts to make this dream come true for this couple.

Written by Maggie Jury, Coordinator of Clinical Services for families living with HD in Canterbury.

Maggie A. Jury
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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.

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Huntington's News is the national Newsletter of the Huntington's Disease Associations of New Zealand. It is published three times each year (April, August, 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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- And thank you for support for our salaries and overheads from: Ministry of Health, Community Organisation Grants Scheme (COGS), Lottery Welfare, Lion Foundation, Eastern and Central Community Trust, Southern Trust and PaperPlus Marton

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 August 2012. The deadline for material to be received for this issue will be 10 July 2012. Please send any contributions for Huntington's News to:

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