

Huntington's NEWS

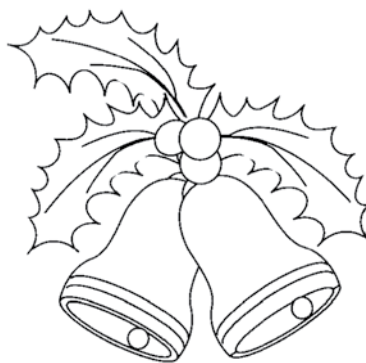
*The quarterly newsletter of the
Huntington's Disease Associations of New Zealand*

ISSN 1174 9229

December 2011

Issue 114

Seasons Greetings And Best Wishes For The Festive Season



From the Editorial Board

Ten golden rules for reading a scientific news story

Avoid the hype: HDBuzz presents ten 'golden rules' for reading a news story or press release about Huntington's disease By Dr Ed Wild on September 05, 2011, Edited by Dr Jeff Carroll

Real progress is being made on the road to Huntington's disease treatments, but sometimes it feels like scientists promise more than they can deliver. So, HDBuzz has come up with ten 'golden rules' to help you decide whether a news story or press release offers genuine promise for HD, or whether its claims should be taken with a pinch of salt.

Snowflakes and glaciers

HDBuzz loves science. In our more philosophical moments, we like to imagine all the world's scientific research as a flurry of snowflakes, gently settling on a mountain top and gradually, over months, years, and decades, compacting into a huge, unstoppable glacier that can carve entire mountains.

No single snowflake could do that, but combined, over time, the power of science to change the world — and improve the lives of people with HD — is immense.



Like a glacier, science moves slowly but can move mountains. Don't be fooled by anyone suggesting that a single snowflake can do the same.

How science reaches the public

Science becomes 'official' when an article about a piece of research is published in a peer-reviewed scientific journal. But a lot of science reaches the public through press releases.

Increasing competition over scarce funding means that getting results published in a scientific journal may not be enough for scientists to keep their work going.

The agencies that fund science take their lead from the public, so one way for researchers to secure funding is to get the public excited about their research. So when a piece of work has so far only focused on a small area, one way to excite people is to get them to imagine the whole glacier, rather than just the snowflake.

So, universities and research companies have press offices, whose job is to encourage scientists to produce press releases, in which they often speculate about what applications their work may have, down the line.

Of course, part of what science is for is to come up with real-world uses for new discoveries. But it's a two edged sword, because many things that **might** happen, never do.

Another layer of speculation can get added, when press releases are turned by bloggers and journalists into news stories. Writing about big breakthroughs in common diseases gets more clicks and sells more papers than writing about small progress and obscure conditions.

What's the harm?

The result can be that press releases and news articles sometimes end up promising things that the scientific research could never deliver — or which are much further away than an article suggests.

This isn't the fault of the individual scientists, or of the press office, or the bloggers or journalists, or of the people reading the stories. Nobody sets out to mislead — but sometimes that can be the outcome, and it's bad news because it can lead to disappointment and loss of hope.

Ten Golden Rules

The good news is that disappointment can be avoided if readers know what to look out for.

So, HDBuzz has come up with Ten Golden Rules for reading a press release or scientific news article. They're here to help you to draw hope from scientific news where it's warranted — and avoid being let down where it's not.

1. Be sceptical of anyone promising a "cure" for HD now, or in the near future.
2. If something sounds too good to be true, it probably is.
3. Has the research been published in a peer-reviewed scientific journal? If not, the press release may not be much more than speculation.
4. Ask yourself whether the press release is announcing the results of a project — or just the start of the project, a new partnership or funding approval. There's a big difference.
5. The only way to show that something works in HD patients is to test it in HD patients.
6. A positive result in an animal model of HD is a very good start — but can't be called a cure — and plenty of things that work in mice fail when tested on humans.
7. Something that hasn't been tested in an HD animal model has a very long way to go to become a treatment.
8. Your mind is like a house — it's good to keep it open, but if you leave it wide open, you never know who'll walk in.

Continues on page three

Continued from page two

9. Not sure about something you've read? Ask HDBuzz to write about it!
10. Finally, remember that every day, science moves us towards effective treatments for HD. Even negative results and treatment failures help us to focus on more fruitful ideas.

An example — 'block and replace' gene therapy.

Recently, a story headed "Molecular Delivery Truck Serves Gene Therapy Cocktail" appeared on news site Science Daily. Similar articles appeared on many other sites, all reporting on work led by Prof R Jude Samulski of the University of North Carolina, and published in the journal PNAS.

The news article revealed that Samulski's team had done something pretty impressive. The research centred on a disease called alpha-1-antitrypsin deficiency, 'alpha-1' for short.

People with alpha-1 develop liver problems, because they have two faulty copies of a gene that tells cells how to make the alpha 1 protein. Part of the problem is that the healthy protein is missing, and part of the problem is that the mutant protein made by cells is harmful.

Samulski's group used a form of 'double-barrelled' gene therapy to fix this problem in mice with the same genetic problem. First, they made a DNA-like molecule that would block production of the abnormal protein — a form of gene silencing. Then, they added a replacement gene that would be used by cells as a recipe for making the healthy protein. They packaged these two payloads into a virus called AAV, which attaches to cells and injects its contents into them. Mice treated with the virus restored healthy levels of the alpha-1a protein and didn't develop liver problems.

Great work — shame about the press release Let's be clear — this is great science and an innovative approach to a devastating illness. So what's the problem?

Well, this research came onto our radar because the news reports about it all mentioned the potential of the approach for treating other 'protein folding' diseases like "cystic fibrosis, Huntington disease, amyotrophic lateral sclerosis ... and Alzheimer's disease".

The news stories said that, because that's what was said in a press release by the researchers themselves, and again in the PNAS article.

The trouble is, the research didn't directly involve any of those other diseases — and huge obstacles stand in the way of it working in Huntington's disease or the other conditions mentioned. But you wouldn't necessarily know that from reading the news stories.

In the case of HD, there are two main problems. The first is that the huntingtin protein, the protein produced by the

HD gene that causes HD is huge — seven times larger than the alpha-1a protein. The AAV virus is just too small to deliver a replacement huntingtin gene. Other viruses might be able to, but they're not as good at delivering the cargo into cells. The other problem is that once the alpha-1 has been made, it's released into the bloodstream, which means that a little goes a long way.

Huntingtin protein on the other hand, does all its work (and damage) inside cells — so any gene therapy needs to get into lots more cells in order to be beneficial.

The result of these problems is that the approach — ingenious though it is — simply can't be applied to HD now, and even if it were radically altered, it's unlikely it'll benefit HD patients for at least a decade — if at all.

You might think you have to know all about gene therapy to be able to spot these problems in applying it to HD.

In fact, there are enough clues there to enable non-scientists to treat this particular breakthrough with caution, even though it might have popped up in a Google news alert for "Huntington's disease".

Using the golden rules Applying our golden rules to this particular press release causes several alarm bells to ring.

Rule 2. The press release suggests that this one approach could be useful for five different, major diseases — sounds amazing ... could it be too good to be true? Proceed with caution.

Rule 5. Tested in HD patients? No, this research only went as far as mice.

Rules 6 and 7. What about an HD animal model? Nope, the mice were models for alpha-1 deficiency, not Huntington's disease.

So you don't have to be an expert in the science of gene therapy for our rules to provoke some healthy scepticism about this particular press release.

That's where rules 8 and 9 come in — keep an open mind but remain cautious about breakthroughs — and if you read something you're not sure about, feel free to ask HDBuzz to investigate — either by emailing editor@hdbuzz.net or using the suggestion form at HDBuzz.net.

Rule ten

Rule ten is our favourite — because it brings us back to waxing lyrical about the snowflakes and the glacier. Rule ten is there to remind us that — whatever a particular bit of news can or can't tell us about the search for effective treatments for Huntington's disease — **we're a bit closer today than we were yesterday, and tomorrow we'll be closer still.**

Acknowledgement:

Gateway – HDNSW – Volume 14 No 3 Spring 2011

Is Huntington's Disease Twice As Common As We Thought?

In an article in the medical journal *The Lancet*, Sir Michael Rawlins claims that traditional estimates of how common Huntington's disease is, might be dramatic underestimates. Why might this be, and what does it mean for the HD community and the search for effective treatments.

There are probably twice as many people with symptoms of HD – or even more- than previously thought.

Scientists and statisticians use the word 'prevalence' to describe how many people there are with a particular disease at a given time.

For a long time, the prevalence of 'symptomatic' HD has been quoted as 4 – 10 per 100,000. That means that in England and Wales, for example, where the combined population is 53 million, there should be between 2,120 and 5,300 people with HD.

But Rawlins reveals figures from the Huntington's Disease Association of England and Wales (HDA) showing that they provide care for precisely 6,702 people with symptoms of HD. Even if that were all the patients in England and Wales, it still translates to a prevalence of 12.4 per 100,000 – higher than the upper limit of the previously accepted range.

In reality, it's likely that even this new higher figure is an underestimate. There are areas that aren't covered by the HDA's services, and lots of people with HD who have never been referred to the HDA.

What's more, there is every reason to believe that these underestimates have occurred throughout the world, not just in the United Kingdom.

Why are the old figures wrong?

The traditional prevalence figures are wrong, Rawlins suggests, for a number of reasons. First, most of the studies that led to the figures were done a long time ago, most before the genetic test for HD became available in 1993. In those days there was often uncertainty or a delay in reaching a definite diagnosis. Nowadays the genetic test often enables doctors to make a diagnosis of HD earlier, and in people with unusual forms of the disease that would previously have been missed.

Second, and perhaps more importantly, is the stigma that has long surrounded Huntington's disease. Many HD family members will be familiar with stories of relatives whose illness was not to be discussed, or who were sent to psychiatric institutions and never spoken of again. Many patients receiving a diagnosis of HD have kept it a

secret from relatives, doctors and insurers, or prevented HD from being mentioned as an official cause of death.

There are many reasons, of course, why such secrecy surrounded HD, but over the years it has contributed to a stigma that has prevented one of the most important basic tasks facing HD researchers – counting the number of people affected by HD – from being possible. If accurate figures are to be reached, urgent new research is needed with new methods capable of overcoming some of these problems. This won't be easy but Rawlins is working with expert statisticians and HD clinicians to set up such a study.

Rawlins' article triggered a number of responses in the scientific literature. A group of Australian researchers led by Clement Loy, pointed out another possible reason for the underestimate: the 'baby boomer' population surge, means that right now there are more people than ever before in their 50's and 60's, a time of life HD often becomes apparent. Patrick Morrison from Belfast, who helped to produce some of the original prevalence figures, pointed out that, thanks to improvement in symptom control and clinical care, HD patients are living longer than they used to, which has probably contributed to the increase in prevalence. His analysis of more recent data suggests a prevalence in the UK of 14 – 16 per 100,000 – about twice the current figures.

Why does prevalence matter?

This article and the more accurate numbers that will hopefully stem from it, matters because prevalence figures are among the things used by governments, health care organisations and research funding bodies, in deciding how much to spend on different conditions. If the prevalence of HD is much higher than previously thought, it is likely that these organisations have been devoting less money to HD than ought to have been received.

But as Rawlins points out, HD does not just affect those with symptoms. It is estimated that for every person with symptoms of HD, there are 5 more at risk – not to mention all those with no genetic risk – friends, partners, wives, husbands and those who've had a negative genetic test. If the prevalence of HD is higher than thought, there are a lot more of those people too.

A call to action

The timing of the article coincided with the launch of an All-Party Parliamentary Group on HD – a group of

Continues on page five

Continued from page four

UK politicians, advised by HD experts, who are pledged to eradicate stigma and promote HD research and care. The launch was accompanied by a mass-rally at the Houses of Parliament of HD family members under the banner "Hidden No More" : <http://hiddenomore.co.uk> – reflecting a new desire in the HD community to work together to remove the stigma of HD – beginning with being accurately counted.

Note: This article was taken from the new website: <http://en.hdbuzz.net> which features HD

research news in plain language written by scientists for the global HD community. Keep yourself up-to-date on the latest happenings on the world stage of HD research by logging on to this great site. We will be bringing you articles from this site in future newsletters for those who have no access to the internet.

Acknowledgement: HDA (NSW) Inc – Volume 14 – No 2 – Spring 2011

Sleep right, sleep tight

Our sleep patterns change as we get older. Developing good sleep habits is a more effective way of solving sleep problems than resorting to medicines. Sleeping tablets usually make sleep problems worse, not better, in the long term. They can also cause side effects, even those bought without a prescription. If you don't sleep well, some of these strategies might help.

Reset your body clock

We all have an internal 'body clock' that controls our daily cycle of becoming sleepy in the evening, sleeping through the night, and waking up in the morning. Being 'in sync' with your body clock makes it easier to sleep.

You can help to set your body clock by consistently going to bed and getting up at the same time every day, regardless of how well you slept the previous night. If you can't get to sleep within 20 minutes, get up and do something relaxing in another room until you feel sleepy again.

Persist with this routine until you develop a regular sleep pattern. It will also help your body to associate going to bed with sleep rather than sleeplessness and frustration, which, in turn, will help you to sleep better.

Sunlight also helps to set your body clock, so try to get outside in the sun for a while every day. Some people can sleep well despite having a short nap in the afternoon. However, if you're having trouble sleeping at night, avoid having a nap during the day. If you do nap, keep it to only 20 minutes before 3 pm.

Have a bedtime routine

Doing the same things each night in the last half hour or so before going to bed helps to remind your body that



it's time to go to sleep. Your bedtime routine might include things like having a light bedtime snack or glass of warm milk, having a warm bath, reading, or listening to music, the radio or a talking book. Avoid computers.

Be comfortable

Keep the bedroom dark while you sleep. Even dim lights, such as those from a television or computer screen, can disturb the body clock and result in poor sleep. Try to keep your bedroom and bed at a comfortable

temperature. Being too warm or cold is a common reason for waking up frequently in the night.

Relax your mind

You can't sleep well if your mind is not relaxed, so try not to take your day-time stress, anger or work to bed with you. Also, avoid work and activities involving concentration, such as working on the computer, late in the evening. If you can't relax because of chronic worrying, stress or anger, consider learning some relaxation techniques to help you 'switch off', or seek help from a GP or counsellor.

Avoid stimulants

Avoid caffeine drinks, such as tea, coffee, energy drinks and cola, close to bedtime and maybe even from early afternoon. Milk contains tryptophan, which has been shown to enhance sleep, so consider a warm milk drink instead. Alcohol before bedtime may help you to dose off. However, it also disturbs the normal sleep rhythm, so you won't tend to sleep as well.

Continues on page six

Get regular exercise

Being physically active during the day makes it easier to fall asleep and improves how well you sleep. However, the timing is important. Exercise too late in the day stimulates the body and raises body temperature, making it harder to sleep. Exercise in the morning or afternoon gives your body time to wind down and cool down.

Getting back to sleep

If you wake up during the night, relax and try not to get stressed. Try some relaxation techniques or a repetitive, non-stimulating activity like counting sheep. Remind yourself that although it's not as good as sleeping, resting in bed can still refresh your body. If you've been awake for more than 20 minutes, try getting out of bed and doing a quiet activity in dim light until you feel sleepy again.

Tackle underlying problems

Poor sleep can be a side effect of some medications and some chronic conditions, including depression, anxiety and sleep apnoea. In these situations, treating the underlying problem often alleviates the sleep problem.

If you have sleep problems, talk to your doctor or pharmacist, and tell them about any other symptoms you may be experiencing. If their suggestions don't help, consider asking for a referral to a sleep specialist or sleep clinic, so your sleep problem can be investigated.

Reproduced with permission, National Prescribing Service, Medicines Talk Winter 2010.

AND HERE'S A POEM TO READ BEFORE BED

Ode to Huntington's Disease Research

By Ronald T Roberts

On top of all the stress and strain,
The fears, the loss, the psychic drain,
Of coping with the risk ahead
Or giving care with all its dread
Now comes the jargon of the lab
As science shares its chatty gab.

Now one more way our stomachs churn,
And one more language we must learn.
Proline endopeptidase
And other terms assault our space,
Bilateral quinolinate -
Now there's a phrase to contemplate!

Take ganglionic eminence
And other terms that make not sense
There's not a one of them routine.
Explain striatal dopamine!
Or tryptophan metabolites
Or malonate and other frights

There's C-A-G and R-N-A
With dorsal caudate interplay,
And neurons that degenerate,
And aspartate and glutamate!
Excitotoxic neuron death -
There's hardly time to catch your breath.

Of all the things that cause us stress,
Much more than words can half express,
The other losses that depress
Are worse by far than this, I guess.
But still this abstract language mess
Is one more insult, I confess!

*Mr Roberts is a care-giving husband.
"To my unseen..., friends..., who give us help
or struggle with us to decipher the exciting
research material." 1996*

Reprinted from Huntington's WA Newsletter

Acknowledgment: Newsletter – Huntington's Queensland – December 2010

Charlie Reed has donated to the Christchurch HD Association a set of the "Huntington's News" newsletters from 1987 to 2010; he has had them bound into sections of five years each.

They can be borrowed and read.

Please phone Charlie on (03) 386 1233

Auckland / Northland News

Research has played a large role in the last few months of work for HD Auckland. Our two highly experienced field officers Jo Dysart and Jane Devine have been out updating health workers, families and scientists about the latest studies on Huntington's care. HD Auckland helps those affected by Huntington's Disease to live their lives to the fullest by providing support and counselling that allows them to stay at home longer and enjoy a better quality of life. There may be no known cure for Huntington's Disease at the moment but there is plenty we can do to help manage the effects of the disease.

In September, Jo and Jane joined the team from the Centre for Brain Research at The University of Auckland to fly to Melbourne. There they attended the Huntington's Disease World Congress - the world's most comprehensive conference on HD. Excitingly, Jo was asked to present three posters on the HD Association's role in organising care for over 160 families in Auckland with HD. This conference will prove vital for sharing knowledge on the best ways to look after HD families, and offers hope for future treatments.

Our committee has been busy fundraising, with Christine Stent organizing numerous sausage sizzles and mall collections. Christine and her husband Ted spent the weekend outside the Mad Butchers in Mangere East and raised \$261. Christine also joined researchers from the Centre for Brain Research, organized by PhD student Malvinder Singh-Bains, to rattle buckets at Westfield St Luke's Mall in Auckland.



Every dollar donated helps to support our team, who provide care and advice for families with HD. Our thanks go to the fundraisers and people who have donated their hard earned cash.

The HD Auckland Treasurer Trevor Lowe has also been shedding blood, sweat and tears to raise funds. Incredibly, Trevor completed the Adidas Auckland Marathon, all to raise awareness for HD. He completed the 42km course over the Auckland Harbour Bridge and waterfront in 5.38 hours in October. His efforts have raised \$2614 for HD families and we are so grateful for his energy!

Help us to raise more funds and give those living with Huntington's Disease the hope and inspiration they need when they need it most. Trevor's fundraising website is: <http://www.fundraiseonline.co.nz/TrevorLowe>



Waikato News

Hello everyone, it is nice to see that the weather is slowly but surely getting warmer, people are generally happier and are able to get outside more.

It has been a steady few months for me with continuing study which I complete at the end of November, with the view of more study commencing early next year.

In late August I completed my first education session on HD, presenting to a group of residential carers, the feedback was positive which was a huge relief for me.

In early September we had the privilege of participating in a trip to the NZ Neurological Foundation Brain Bank in Auckland, where Professor Richard Faull and Dr Maurice Curtis enlightened us with presentations around their expertise, before having a guided tour through their working laboratory by the PhD Students. Having the opportunity to be shown through the brain bank and to be able to see a snippet of the work that is being accomplished towards understanding Huntington's

Disease was truly amazing as the Brain Bank is not open to the public.

I was also fortunate enough to attend the HD World Congress Conference held in Melbourne Australia along with my colleague Liz Hogan. The four day conference was full of valuable information supported by clinicians, scientists, support groups, HD organizations, patients and family members. Information relating to this conference can be found on the HD Buzz website.

I can't believe how quickly this year has gone by so from myself in the Waikato region.

I wish everyone happiness, for the upcoming silly season and please keep your families safe over the Christmas period.

See you in the New Year.

Kind regards

Tracy Hobbs

Wellington News

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

Greater Wellington

Hello everyone, it is hard to believe we are approaching Christmas and the end of another busy year in the Wellington region.

It was a wonderful experience for me to attend the World Congress for Huntington's Disease in Melbourne in September. Hilly Lutter, the service manager from Amaryllis House accompanied me. Apart from all the information and interesting speakers, it was great to make contact with the other HD advisors, both from NZ and overseas. I am grateful to the Neurological Foundation for assisting me with the opportunity to attend. It also provided me with material to continue my study in Human Clinical Genetics which I will continue with next year. I have continued to work closely with NZ Care and the management of Amaryllis House, Noel Hamilton and Spring Lodge. Our families in the greater Wellington area are fortunate in being able to go to respite care or long term care in facilities that offer expertise in the care of HD.



Following the whole country's excitement over the recent winning of the world rugby cup, the residents of Amaryllis House were very lucky in having the Webb Ellis Trophy brought into their home for an 'up close' look. You can imagine what a thrill it was for the rugby fans, (staff and residents) with this once in a lifetime opportunity.

Our Association had our AGM in October where I reported back on the conference.

The committee is organising a fund raising movie night in early December and we look forward to the new year with enthusiasm.

I have continued to work with families and individuals and provide support wherever I can. We maintain our weekly use of the Hutt Hospital pool for hydrotherapy and welcome any HD client who would like the benefit of the warmth and weightlessness gained from the pool.

I would like to thank all my clients and families for their kindness (and sometimes patience) over 2011. It is such a pleasure to have contact with so many wonderful families and to be able to (hopefully) make their experience with HD a little more manageable.

Have a great Christmas and best wishes for 2012. Here's hoping it will be a warm sunny summer.

Until next year

Kind regards

Jeanette Wiggins



Taranaki, Wanganui and Palmerston North

Kia ora everybody, it's been nice to welcome Spring/Summer and embrace some warm weather. The Manawatu/Whanganui/Taranaki regions have a luscious green glow to them as I drive through visiting families and attending meetings. I have been contacting and meeting clients and their families, all the while increasing my understanding of what people's needs are. Please contact me if you are: having problems, are seeking advice/information, want assistance/company for an appointment or you think it's time we had a get together or chat on the phone.

Some of you, along with myself, went to listen to Professor Faull in Whanganui (for Alzheimer's Society) in September where he gave a lively talk on neurological matters and ended with some insights into aspects of current HD research.

The Wellington Association. Annual General Meeting was held in October and I was pleased with the opportunity to meet people who I knew by name but had not met in person. Jeanette's talk about some of what she heard at the international HD conference in Melbourne was interesting and generated some discussion on

Hawkes Bay News

Kia ora koutou. Hello everyone. As we head towards the end of 2011, I would like to thank all the wonderful families I have worked alongside this year. There have been some precious moments shared, and many difficult times endured. You are all amazing.

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.

We also have three monthly Get-Togethers where families can come together and share and laugh. Our next Gathering will be in January 2012 – all welcome.

This October I took four of our carers away for a well-needed break at a luxury B&B in Porongahau. I provide regular opportunities for our carers to get together and provide mutual support.

comparisons of services in different countries. Jeanette noted New Zealand rates highly in this respect.

In early November I was invited to attend a hui at a whanau marae in Taranaki. Professor Faull along with Jo Dysart and Dr Melanie Cheung all spoke on their HD fields of expertise. I know their contributions were much appreciated by those who attended. At the end, goals were set, keeping the momentum of the hui going. Thank you to whanau members for their organisation and wonderful hospitality.

I attended the Community Workers Meeting in Palmerston North recently to meet other workers and find out about any resources we could access.

Feel free to offer suggestions you may have for activities, innovations or services, I will be very pleased to get them. Thank you for your company over the past few months, it has been good meeting and getting to know you.

Warm wishes for the Festive Season ahead and a safe Happy New Year.

Karen Evans.

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

Robyn from the local MS Society continues to invite our people to all of their groups and activities – thanks Robyn.

I regularly meet with staff at local rest homes where people with Huntington's Disease are living.

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

Kia kaha.

TANYA

Ph (06) 8451616

Mob (027) 2009789



Hi, I'm Colin Wiggins, the new Chairman of the Wellington Association. I work in Wellington as an Account Director with Insurance Brokers Willis New Zealand Ltd. I'm also Chairman of our family company W Wiggins Ltd. I've been associated with HD since my wife, Jeanette, was employed as the Wellington Advisor three years ago. Over this time my knowledge and involvement has grown to the extent that I now feel I would like to contribute in a more formal way, and have therefore taken on the Chairman's role. My interests outside of work are sport and gardening.

Colin Wiggins,
Wellington Association Chairman

Christchurch News

Greetings from Christchurch. Well the after shocks are slowing down and things are slowly starting to be repaired, but this is going to be a long slow process and they are all talking about a 10 year time frame. We have been very fortunate that businesses have tried to get up and going as quickly as possible and that our main hospital was not too damaged in this series of events. We have most probably lost at least half of the local Christchurch businesses with many others being relocated and people still not knowing where they are.

This has been a very trying time, and to have to deal with this as well as the many stresses that Living with HD puts on us, has at some times been too much for some. Maggie Jury, in her role as Clinical Coordinator for people living with HD, has been a godsend and has maintained regular contact with all our HD families and continues to support them through their daily trials. This position has become so important to the people of Christchurch, that we fear what will happen if the DHB decide to pull the funding on this.

The days are starting to get warmer and longer with the hope and promise of summer on its way and with Christmas just around the corner.

The last few months have been very busy for our HD families with the unexpected opening of our HD Service

here in Christchurch. This all happened so quickly in the end that we were full steam ahead supporting NZ Care to get everything up and running in such a tight time frame. I am sure you would have read the article on the house in this newsletter.

My thanks go to all the families who gave up time to help at the working bee to prepare this home for opening. Also to my work for the generous donation of plants to enhance the gardens and provide a beautiful setting for this service to function in. To Graham, Ron, Donna, Vinetta and the team at NZ Care for accepting the challenge to get this service up and running under such trying times. This has been one huge roller coaster ride for many of our association over a long, long time; at last we have a specialized, purpose built service for our loved ones.

As Christmas fast approaches I would like to take this opportunity to wish you all a safe and Merry Christmas and wish for you all, that over this time you all get to spend quality time with family and loved ones. May the blessing of Christmas be with you all. Take care and have a safe a restful break over the Christmas period.

Dianne Collins
Christchurch HD

Christchurch HD Residential Service Finally Opens

Well after many postponements the day finally arrived that this long awaited for service opened.

We gathered as many willing hands as possible to have a working bee at the Woodham Road site on Saturday 24 September. This was a great turn out and a wonderful day working alongside HD families and staff to get the outside area looking as great as the inside. By 3 o'clock the grounds were transformed, old overgrown plants pulled out and new sensory and colourful plants put back in their place. It was almost like one of those garden make over programmes you see on television. Our thanks go to the Cremation Society of Canterbury and Harewood Crematoriums who donated \$1000.00 of plants for these gardens.

The end of the day was marred by an accident outside as we were all leaving and 2 of our committees' cars were written off by a driver who fell asleep at the wheel. We were just so fortunate that no one was hurt in this accident; it did put a real downer on such a wonderful and productive day.

Monday 26 September the first HD client moved into Woodham Road, this was followed by another client a

couple of days later and then the third a week later. The house now has 6 clients with a couple of our families utilising the respite care options that this facility offers. We have had really positive feedback from the family members and are delighted that this dream has become a reality. Our thanks go to Graham, Ron, Donna, Vinetta and staff of NZCare for all the time and effort they have put into getting this service up and running.

The house setting is very tranquil and I am sure clients, family members and staff will enjoy the surroundings especially as the warmer weather approaches. The rooms are spacious and beautifully decorated, with many little touches to make them feel like home. Thank you to everyone for the many years of fundraising, writing letters and never giving up, it is all this that has made this possible. Our association was able to support and purchase things for the house and gardens because of everyone's hard work. Thank you all.

Dianne Collins
Chairperson

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.

Editorial Board: Glenys Shepherd (Wellington)
Laura Fogg (Auckland)
Dorothy Tortell (Wellington)
Judith Baker (Christchurch)

Design & layout: Stephanie Drew Design
Printing: TruPrint Ltd

Thank you To Our Funders

- ◆ JR McKenzie Trust
- ◆ The Thomas George Macarthy Trust for their support in the production of this Newsletter
- ◆ Telecom New Zealand Ltd for sponsoring the new residential unit phone line
- ◆ Ministry of Health, Community Organisation Grants Scheme (COGS), Lottery Welfare and PaperPlus Marton – for supporting us with salaries and overheads
- ◆ 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 April 2012. The deadline for material to be received for this issue will be 10 March 2012. 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
If you are submitting an article for the national newsletter, please indicate to the editor if you prefer your article not to be reproduced on this site.

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

Karen Evans
C/- PO Box 30420
Lower Hutt
Tel (06) 213 0307
Mob (027) 496 6500
kevans.wellingtonhda@hotmail.com

BLENHEIM

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

Lesley Brown, Chairperson
PO Box 30420
Lower Hutt 5040
Tel (04) 235 5091
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) 768 7320
Fax (03) 732 3813
Email heathercreagh2@xtra.co.nz

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

Viv Gillan
MS Society
PO Box 1561, Invercargill
Tel: (03) 218 3975
vivg.mssouth@xtra.co.nz