Huntington's NEWS
The quarterly newsletter of the Huntington's Disease Associations of New Zealand
ISSN 1174 9229 June 2009 Issue 105

The ultimate test

Many people at risk of passing the incurable Huntington's disease to their children do not use the technology that could stop this happening.

"Do you really want to know you are going to have a disease that will reduce you to awful circumstances?"

Jeanette Wiggins

Bridget Lyon and son James

For David Lyon, the worst aspect of Huntington's disease is not the awfulness of the condition, even though he is watching it take its inexorable toll on 67-year-old wife Judy, but knowing the couple have passed the gene on to another generation.

"Look what we've inflicted on our kids," says Lyon slowly, and with the burden of regret audible in every word.

From their family home on a hill above Mana, north of Wellington, the Lyons can look out at the Tasman Sea from their lounge, then turn around for a fabulous view over Pukerua Bay in the other direction. On a fine day, they are views to lift spirits – which is good for Judy, whose world is shrinking as the degenerative brain condition takes more of a hold, and good too for her husband, who is both a devoted carer and tireless advocate for his wife, Judy's mother died of Huntington's disease (HD), as did Judy's grandmother, but not a lot was known about it then. Not until near the end of Judy's mother's life was the diagnosis made. A relative looked it up in a *Life* magazine, where HD was described as "the worst hereditary disorder you can inherit in the world".

Symptoms of the disease usually show between age 35 and 50, but sometimes long before this. It is characterised by memory loss, gradual cognitive failure and uncontrolled jerky limb movements, which means those with HD are often confused with drunks. Sufferers can become obsessive, compulsive, irrational and sometimes violent. Eventually, death occurs – usually within 15 years of the symptoms first showing, and usually due to pneumonia or choking. Along the way, and because HD repeats in generations, many families become dysfunctional. There is a higher than normal rate of suicide, and marriage breakdowns are not uncommon. The children of HD-symptomatic parents may be isolated if they feel they can't bring friends home because the condition is too difficult for other people to cope with. Sometimes one sibling who has the gene might become bitter towards other siblings who do not have it. Sufferers become unable to work, so are often poor.

By the time Judy's mother was diagnosed with HD, David and Judy already had one daughter and two sons of their own – and if Judy turned out to also have the HD gene, then the dice had already been rolled for their three children

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HD is unusual in that carriers of the gene do not simply have a susceptibility to the disease: they will develop it. And those who do not have the HD gene can neither develop it nor pass it on.

When she was 54, Judy was tested: the result was HD gene-positive.

"By then, our children were in their 20s and all living overseas," says David. "We had to try to communicate, over the phone, that they could develop HD." Of the three, Bridget, now 36 and a film editor in Sydney, is the only one to have become a parent. She says her first pregnancy was unexpected. She and her partner went to genetic counselling, where they discussed testing her fetus, but she was told there was little point unless she would terminate the pregnancy if the baby was found to be HD gene-positive. And if it was, it would also mean Bridget had the HD gene.

It was too much to deal with right then, so she went ahead with the pregnancy without any tests and her son Finn, now four, was born. His HD-status is unknown and will remain so until he is an adult, when he can choose to be tested. "The idea of him having it is horrific," Bridget says.

Because she wanted another child, she felt she needed to determine her own gene status. "I thought I'd get lucky, not have HD and would be clear to have more children." But like her mother, she too tested positive.

So, for their next child, the couple opted for in vitro fertilisation (IVF), using pre-implantation genetic diagnosis (PGD). First, they had to find about $15,000 - half of which was later refunded by Medicare, "but we were still scraping the money together on the morning of the procedure".

In due course, four embryos were produced. Three tested positive and the one that was free of the HD gene was implanted, with Bridget then facing the usual stress of IVF patients hoping the pregnancy held. It did, and she subsequently gave birth to another son, James.

The decision to have PGD may seem obvious; David says he and Judy would have been in "boots and all" had the technology been available when they were starting a family.

But Jeanette Wiggins, the Huntington's Disease Association's Wellington branch adviser, says not many people at risk of HD avail themselves of PGD. "The HD community is not full of people saying, 'We're going to have PGD', although there are certainly many who choose never to have children."

Fertility services provider Fertility Associates says 40 PGD cycles are publicly funded each year, although that also covers conditions other than HD, and some patients have more than one cycle, meaning fewer than 40 couples a year use the process.

"A lot of people at risk of HD themselves simply don't want to think about it, so they just go ahead and have kids," says Wiggins. "We run camps for children of HD parents, and take a geneticist and talk to the children, but as far as I can ascertain, it doesn't always get through."

She is becoming more understanding of those who are at risk but who say they simply do not want to know.

"I started out in this job thinking 'well, of course you'd want to know your gene status' and 'of course you wouldn't have children', but now I understand it better.

"Do you really want to know you are going to have a disease that will reduce you to awful circumstances? Or do you carry on until you become symptomatic? Or do you just carry on and nothing ever happens because you never had the gene anyway? It is so harrowing for some people. They have watched terrible things happen to their family and do you want to know that is going to happen to you?"

Wiggins says she sometimes visits a woman in her 70s who has started working as a cleaner so she can pay the $200 a month for the thickener many HD sufferers consume once swallowing becomes more difficult, and which her son needs to eat to help him get enough nutrients. There are many such desperate stories.

But in Sydney, Bridget Lyon is determined not to see HD as the grim prognosis suggested by *Life* magazine and delivered to her family so many years ago. For a start there is the possibility of new medical breakthroughs. Also, she is free of symptoms so far and still finds it difficult to imagine herself succumbing.

"Sometimes I engage with it and have a little cry. My psychologist asked what it was that scared me most and I said I wanted to end up being a wise old woman and now I'm going to be a stupid one at best.

"I know for lots of people it is the movement associated with the disease that is the big thing, but for me it is the loss of ability to be emotionally engaged and to experience life. I have thought that would be horrifying, the thought of it happening to Finny is horrifying, and I think, 'What a nightmare.'

"But my parents are remarkable -they are determined, they keep trying- and I imagine some of their motivation is to make us have a more positive attitude towards it. I don't view it as a death sentence."

Acknowledgement:
Joanne Black – The New Zealand Listener
14 March 2009

Avoiding a passive lifestyle may delay the onset of Huntington disease

The findings of this study were presented at the Christchurch HD Conference 2008.

This was a collaborative study between, Virginia Hogg, Lynette Tippett, Richard Roxburgh, Zoe Horton, Veronica Collins, Andrew Churchyard, Martin Delatycki and Kaye Trembath, who are researchers based in Melbourne and in Auckland.

Background.

For many years the researchers had been interested in whether environmental factors, such as activity levels, could influence the age at which symptoms begin in individuals with HD. Other research evidence, summarized to follow, had contributed to this interest.

Huntington disease (HD) mouse-model studies show that rearing mice in an enriched environment delays the onset of symptoms and slows the progression of HD.

The only known factor which influences the age of onset of HD symptoms is the CAG number, however this only accounts for between 50% and 73% of the variance at which symptoms appear in individuals. This leaves a lot of room for other factors to have an influence. In addition, research suggests identical twins may have different symptoms and different ages of HD onset. This suggests that lifestyle or environmental factors may affect the age of onset.

Evidence from other studies suggests that lifestyle factors, for example, regular activity prior to the onset of symptoms, can delay or ameliorate other diseases including Alzheimer's disease.

How was this study done.

The group in Melbourne had already begun this research and we joined them in conducting questionnaire-based interviews, with 154 (NZ 25 and Australia 129) individuals who had symptoms of HD. The questions were designed to find out about individuals lifestyle (before HD), including their participation in leisure and non-leisure activities (education, occupation and domestic duties). Activities were classified as physical, intellectual or passive, and scores generated under the categories; leisure, non-leisure and total lifestyle. These scores were then matched with the age at which the individual began to have symptoms of HD and their CAG repeat length.

What we found.

After adjusting for CAG repeat size, a more passive lifestyle is associated with an earlier age of onset of HD. That is, for those who had high levels of passive activity (activities that do not require little initiative and no physical or intellectual challenge) for example watching TV or DVD's, tended to have an earlier age of onset than those who had lower levels of passive activity.

The results suggest that the difference in the onset of symptoms between the group who had the lowest levels and the highest levels of passive activity was 4.6 years (that is nearly 5 years!) A five year delay in the onset of symptoms is significant.

Finally (although this was not what we predicted) we found that activity levels for intellectual and physical activities did not affect the age of onset.

It is always much more difficult to study humans than mice, we are so much more complex and may be affected by so many more factors (e.g. diet, social support, personality), however this study begins to increase our understanding of possible environmental factors that may affect the age of onset of HD. My colleagues in Melbourne report that the Environmental Modifiers Working Group (with the European HD Network) are keen to look more fully at the impact of activity levels among other things by studying an even larger group of people throughout their life before they develop symptoms of HD.

What can we conclude from this study.

The results from this study suggest that, for those people who are at risk, or who have inherited the HD gene should try to reduce the amount of time they spend doing passive type activities (e.g. activities which take no initiative or physical or intellectual challenge). This does not mean that you should be physically and intellectually active 24/7 as rest relaxation, socialization are important too, rather make sure that you don't overdo the passive.

My thanks to:

The participants and their families in both Melbourne and New Zealand for their time and input.

Our Melbourne Collaborators, at the Bruce Lefoy Centre for Genetic Health Research.

Deb Nagel, Jo Dysart, and Lynne Farrow from the Waikato, Auckland and Wellington HD Associations and Margaret Simmons Amaryllis House for their help.

Professor Richard Faull, for his support and the Matthew Oswin Trust, and the New Zealand Health Research Council.

Virginia Hogg
HD Researcher

Real People @ The Beacon

Last week, 13th May, I was in need of some very positive inspiration as my wife, Bronwynn, had passed away the week before after a long, long illness of Huntington's Disease. I decided to call in at The Beacon which is a day respite service for people aged 20 – 65 years who have a deteriorating neurological illness, situated on Napier Hill.

I have known Lynne Parsons, who is the Manager of The Beacon, since the facility was opened in 2000. Lynne has provided the energy and inspiration to establish this wonderful service with outstanding support from Presbyterian Support East Coast, a band of willing workers both paid and volunteers, and an extremely supportive local community in Hawkes Bay.

In 1998, one year after Bronwynn was diagnosed with Huntington's Disease, I was appointed as a community representative to the Disability Support Advisory Committee formed by Bay Home Support. The interest for me was the inclusion in their proposed agenda of development of an under 65 residential care facility for Hawkes Bay. We had already required respite care and Bronwynn had been to Noel Hamilton House in Greytown in the Wairarapa which was 250km from home in Napier. The alternative was Rest Home care in Napier which in my eyes was not "age appropriate" as Bronwynn was only 44 years of age.

The DS Advisory Committee spent some time talking about care facilities and doing further surveys to establish a need for such age group units but was not making progress so I decided to take this agenda item over myself and attack the problem from the other end – find a provider who wished to establish such a facility and work back from there. I approached a Rest Home which was interested in sectioning off a wing in their existing business as a separate 16 – 65 unit, but I decided that this was not the best solution.

Then one morning by chance, Faye who was a nurse who completed personal care for Bronwynn each morning, mentioned that she had heard that the elderly residents at Hettye Charles Rest Home on Napier Hill were being moved to Atawhai, a newer and larger home in Taradale. This small home on the hill with the amazing views over Napier city would then be vacant. I had delivered bread to this home at 3am when I owned a bread run a few years before so I could see potential here.

This was great news for me as I could see that this was the ideal situation for an "age appropriate" home. Immediately I visited Frances Hemphill, who was the Manager there with Bronwynn, and asked her what the plans for the property were. As nothing had been finalised then, I outlined my idea that it be used for the care of 16 – 64 aged people like Bronwynn. Frances was very receptive to this idea so she made an appointment for us to meet Liz Andrews who was Health and Disability Manager at Presbyterian Support in Havelock North. A further receptive meeting ensued and I then wrote a proposal for the Board of Presbyterian Support. This was early 1999 and The Beacon was "born" just over a year later.

Unfortunately, Bronwynn did not see the renovated service on the hill. She would have loved to have had a massage there in the Massage Room, listened to music in the sun drenched lounge or had lunch in the newly extended dining room. Her art skills may not have been great but she would have had a go and her wonderful ability to knit any pattern may have been rekindled. However, Bronwynn's health had deteriorated and she went into full time care at Noel Hamilton House in Greytown and when the new home was built in Greytown, her input was to have kitchen and dining room benches to be installed in the same finish and colour as our house in Taradale. When Amaryllis House in Lower Hutt was opened, a specialist facility for those with Huntington's Disease, Bronwynn moved there. Her colour scheme for drapes is evident in both of these "age appropriate" wonderful care facilities.

The "Real People" at The Beacon have produced a positive inspirational book entitled "Sucking on the Lemon of Life". I recommend this book to all, not only carers and those with Huntington's Disease and their families but everyone. There are some lovely stories of achievements and overcoming difficulties recorded.

Nearly ten years later, I attended a seminar in Auckland in April this year regarding care facilities for this same age group, 16 – 64. It was great to hear senior representatives from Ministry of Health, ACC, Accessibility, care providers, funders and the representatives of users all on the same wavelength singing the same tune that it is not appropriate for those with disabilities to be placed in Rest Homes for the elderly. I now await with interest to see the establishment of further "age appropriate" homes like The Beacon, Noel Hamilton House and Amaryllis House.

I see The Beacon as Bronwynn's "legacy" to the people of Hawkes Bay.

Cecil O'Neale
Chairperson
Huntington's Disease Association (Wellington) Inc.

Copies of "Sucking on the Lemon of Life" can be obtained by emailing thebeacon@realpeople.gen.nz

This is an abridged version of an article that appeared in the AHDA (Qld) Newsletter

HURRY UP AND WAIT!

A Cognitive Care Companion

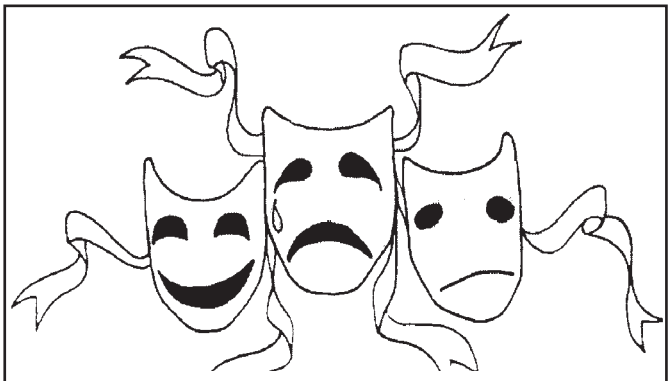
Huntington's Disease in the Middle and More Advanced Years

By Jimmy Pollard

This chapter is from Jimmy Pollard's book *Hurry Up and Wait!*. Copies of the book can be ordered at http://www.lulu.com/content/2517713

Huntington's Disguise

As HD progresses, it places a mask on the person that you love. He's the same person, but it's often difficult to see him behind the disguise. Sometimes people who are unfamiliar with him meet him and say hurtful things like 'he's a different person" or "he's not the same person that he used to be." But understanding some of the more subtle aspects of HD can help you see through the disguise, "Huntington's Disguise". It should come as no surprise that beneath it is the same person you have known, loved and cared for all these years.



Jim Pollard/Laurel Lake Centre May 2001

The two familiar masks on the left, Comedy and Tragedy, represent ancient Greek theatre. The actors wore them so they could quickly change characters and show their emotions to the large audiences in outdoor amphitheaters. The simplicity of the features quickly conveys our most basic human feelings: happiness, joy and delight or sadness, sorrow and grief. Our humanity connects to the feelings by recognizing the facial features on the masks.

Huntington's Disease places another mask on the faces of those it touches. It alters those easily recognized features. It becomes difficult to see how one is really feeling or what they are actually thinking. Sometimes it disguises them so well that we wonder if they're feeling anything. It looks like the mask on the right. This mask is "Huntington's Disguise."

Sometimes weakness and changes in the tone of the facial muscles give people the appearance of looking bored or disinterested. They may be "smiling inside" but appear to be less than excited about seeing an old friend. When the friend greets him and asks about his family, he may have to wait a few seconds for an answer. He may begin to feel that his friend is not interested in their brief reunion.

Sometimes HD makes it difficult to organize your thoughts when you need to answer questions. Just thinking about saying "Everyone's fine and my brother's back home" may take ten extra seconds. While waiting to process the answer, his friend may suspect he's not really interested in a conversation. Other aspects of changes in muscle tone may lead you to falsely believe that he isn't interested in interacting with you. But understanding these aspects helps you to see through the disguise to the person behind it, as excited as ever to see an old friend!

Physical Elements of "Huntington's Disguise"

The general appearance of the face is as if the forehead, cheeks, eyes and mouth are drooping off the skull. Hypomimia is a condition of reduced facial expression that has a number of causes.

Poor eye contact due to motor impersistence.

The difficulty maintaining a smile as one *converses* may signal that he is not very happy to see or speak with you. Very, very small muscles around the eyes and in the forehead contract very subtly when you listen attentively to someone speaking. In effect, they unconsciously communicate that the person is listening intently. Perhaps motor impersistence makes maintaining these contractions and the others involved in smiling very difficult.

Leaning to one side or other changes in posture as he listens to you may suggest that he really doesn't want to be here with you. Perhaps it's one shoulder dropped lower than the other while he's standing in front of you that suggests "an attitude."

Head tilted forward a bit, perhaps due to postural changes related to dystonia, limits his direct, sustained eye contact as you speak and listen.

Loud, plosive speech when he greets you or answers your questions may suggest that he's angry or impatient with you. When you ask, "How are you?" he has difficulty

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modulating the force of his movement and coordinating his speech and breathing. He may appear to shout back, "GOOD!!!" Or perhaps, just the opposite...

Barely audible speech in a monotone when you inquire about his day, he whispers, "I'm fine."

Slouching down while in a chair can create an appearance of boredom, irritation or disinterest with you. In fact, it may be due to changes in muscle tone, muscle weakness or some other aspect of HD.

We make eye contact when we speak with people. When it's our turn to listen, very tiny contractions in our facial muscles signal that we're paying close attention. These minuscule contractions of the muscles in our forehead and around our mouth and eyes persist until it's our turn to speak again. They are so subtle that you may not have even thought about them. We do it unconsciously. We use them to reassure each other that we are interested and fully engaged in our conversations.

"Motor impersistence" is a characteristic of HD's movement disorder. As it progresses, people may have difficulty maintaining contractions in their muscles. If it appears that your friend with HD is not interested in speaking with you, these tiny contractions that convey attention may not "persist." This prevents him using them to signal his interest in speaking with you. They may appear momentarily when he begins to listen, but they won't "persist" for long. This, too, is an element of "The Disguise."

Dystonia is often a very disabling feature. Early on it may manifest as a change in posture. There is no one characteristic dystonic posture among folks with HD. It affects posture in many ways. Over the course of HD, families become very familiar with leaning over or slouching in chairs. Most often it is related to dystonia. Although postural changes may be subtle in degree, they can make a not-so-subtle contribution to the disguise.

Cognitive Elements of "Huntington's Disguise"

No timely response *to* a greeting or compliment.

A delayed response *to* a question.

An impulsive *"No!" to* a suggestion.

Repetitive insistence when you're busy, asking for assistance, or saying the same thing over and over.

He can't wait when we he asks you for help.

An apathetic "Whatever..." to a warm invitation.

The physical elements create a mask. The cognitive elements place a veil over that mask making it even more difficult to see the person for who he is.

From "Disguise" to "Huntington's Delusions"

Sometimes the disguise fosters false beliefs about what someone is thinking or feeling. A delusion is defined as a "false belief." Such a false belief is a "Huntington's Delusion." There are many. Some are:

- "He's not interested."
- "He's bored."
- "He's lazy."
- "He doesn't like me."
- "He's impatient."
- "He doesn't understand what I'm saying."
- "He's not paying attention to me."
- "He only cares about himself."
- "He doesn't remember me."

Perhaps the most common delusion comes from these elements:

- He has difficulty with balance.
- His speech is a bit slurred.
- He doesn't answer questions quickly.
- When he does answer a question he does it loudly. Perhaps with a short fuse

It's an easy presumption that he's drunk! Several years ago the Huntington Society of Canada had a public awareness campaign whose theme was "He's not drunk. He has HD." In fact, Dr. George Huntington described those in his care as "suffering from chorea to such an extent that they can hardly walk, and would be thought by a stranger to be intoxicated" in his 1872 article.

Sometimes the grimacing that is driven by The Disguise may give the false impression that he is in pain.

Seeing Through the Disguise

The disguise presents the cognitive and physical features of HD in a way that is relatively easy to explain to people outside your family. It's a teaching tool that forewarns people that HD may mislead them. It also prevents the "delusions."

Simply labeling this collection of features as "Huntington's Disguise" creates awareness. Family members describe HD thousands and thousands of times to friends and fellow workers. We have our nutshell descriptions of HD and its symptoms. Include the notion of the disguise in those brief explanations with a few words. For example, "and it makes you look bored or disinterested." Or "sometimes it makes you look angry when you're not."

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Associations can include the disguise in newsletters and fact sheets. You can teach it to your extended family, especially those most unfamiliar with HD. It should be taught to care home staff, too, if they are to truly "understand HD". Some of the people in the life of your family may be misinformed or naïve about the disease. The disguise is a practical beginning to teaching them more.

Associations around the world have addressed the problem of Huntington's delusions with "I Have HD" cards. They are small cards that list a few of the symptoms of HD. For example, the card provided by the Scottish Huntington's Association says, "I may be unsteady and my speech may be slurred." The cards are to be used if a police officer sees someone with HD and presumes that they are intoxicated. Recalling the *Monopoly* board game, a young man with HD refers to his card as a "Get Out of jail Free" card! The disguise can be added to the cards with a few words such as "I may look disinterested or angry."

As early as our infancy we learn to read non -verbal clues about how people are feeling. The Disguise reminds us that we can no longer presume that a particular facial expression conveys the same feelings that it has in the past. An appearance that once signaled disinterest may now signal something else, if we look more closely behind the mask.

There are so few things that we can change about HD. But learning about The Disguise and teaching it to others is one that we can. Hopefully, simply a change in how we see these features will remove the disguise and let us see this person once again as the same one that we've known and loved for so long.

Acknowledgment: Newsletter (AHDA (Qld) Inc – February 2009

RESEARCH

The University of Queensland Australia

Research breakthrough targets genetic diseases

A cure for debilitating genetic diseases such as Huntington's Disease, Friedreich's ataxia and Fragile X syndrome is a step closer to reality, thanks to a recent scientific breakthrough. The finding, which was published in Science on January 15, is the result of collaboration between a team led by Dr Sureshkumar Balasubramanian at The University of Queensland's School of Biological Sciences and Professor Dr Detlef Weigel at the Max Planck Institute or Development Biology in Germany.

It identifies an expansion of a repeat pattern in the DNA of the plant Arabidopsis thaliana that has striking parallels to the DNA repeat patterns observed in humans suffering from neuronal disorders such as Huntington's Disease and Fredereich's ataxia,

Lead researcher from UQ Dr Balasubramanian said being able to use the plant as a model would pave the way toward better understanding of how these patterns change over multiple generations.

"It opens up a whole new array of possibilities for future research, some of which could have potential implications for humans", Dr Balasubramanian said.

The types of disease the research relates to, which are caused by "triplet repeat expansions" in DNA, become more severe through the generations but were difficult to study in humans due to the long timeframes involved.

A plant model with a relatively short lifespan would allow scientists to study DNA mutations over several generations, Dr Balasubramanian said.

The study, called "A genetic defect caused by a triplet repeat expansion in Arabidopsis thaliana", also had implications beyond human disease, Dr Balasubramanian said.

While the DNA patterns were previously only seen in humans, current findings have shown the patterns occur in distant species such as plants, providing new scope for researchers in all disciplines of biology.

Story printed on: January 21, 2009, 5. 37pm. Story from UQ News Online:

http://uq. edu.au/news/?article+17223

Acknowledgement: Newsletter – February 2009 – AHDA (Qld) Inc

Auckland / Northland News

Carers Retreat

Will take place in August we have a wonderful venue, Jane and I hope to make it an enjoyable memorable experience for those that are able to attend. We will be in touch shortly as soon as details are finalized.

Annual General Meeting

Our A.G.M. will be held on 20th June at Ferndale house, 830 New North Road, Mt Albert. Once again we are privileged as Professor Faull and his team will present latest development in H.D research.

Please note the change of venue. This meeting will be catered for – no need to bring a plate this time!

Details will be mailed out shortly. For further information or to be added to our mailing list, please contact us on (0800 432 825) or email hungtingtonsakld@xtra.co.nz

Fundraise Online

If you or a group at your work or school would like to fundraise for Auckland and Northland Huntington's Disease Association while you train and complete an event visit www.fundraiseonline.co.nz

You can create your own FREE fundraising web page complete with secure credit card donation processing facilities and help raise money for the HD association.

The set up process is easy and all the money you collect is paid directly to the HD trust account saving you time and energy. You can upload your own photos, keep a blog, email your friends your web page address, and then watch your supporters donate to your charity, all from the comfort of your PC. It's simple, rewarding and fun. You can choose from a selection of popular events or create your own event. Friends and sponsors can leave messages, your goal total is displayed and funds raised so far calculated. So to try it out visit www.fundraiseonline.co.nz !!!

Kind regards

Jo Dysart

Waikato News

We had the opportunity to have a weekend retreat in Raglan. This was courtesy of Care Community Trust who run these retreats for Hospice. Unfortunately numbers were limited but the 4 clients and their families that attended had a much needed break, and recharged their batteries. It was a fantastic weekend, a chance to meet each other and enjoy the beach. The children all swam, (yes in May!) and the food that was cooked by volunteers was yummy. Hopefully this will be an annual event.

Great news – On July 3rd Professor Faull is coming to Hamilton to talk, Keep this date free!

I have managed to telephone/visit a lot of you this year and if I have a quieter day I am supporting MS clients as well. If I haven't managed to talk to you, please contact me and let me know how you are getting on. Even though I am part time (and possibly hard to catch in the office (07) 834 4742 I will answer my cell phone (027) 835 5425, and I do check my emails.

Netball and Rugby for my children started last weekend and so did the rain! Gotta love the Waikato!

Kind regards

Deb Nagel

Wellington News

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

Greater Wellington

Hi Everyone

Unfortunately the Youth Camp that was to be held at El Rancho later in the year has had to be cancelled due to lack of interest/inadequate numbers. This is disappointing as we had thought of possibly changing the venue to a ski camp at Mt Ruapehu, which would have been great fun. If there is enough interest, we may look at booking this venue next year.

I would value comments and input from families and workers as to what you believe would be the most an appropriate venue for the young people in our HD community.

The year is flying by and I have been busy over these first few months meeting with many people in the Wellington area and also making contact with allied health professionals and social agencies who can assist in our provision of services to clients and their families.

The swimming group continues to be a source of pleasure and value to both the residents of Amaryllis House and my community based clients with the range of exercises done in the pool, having some good results in movement for clients. I am also working in conjunction with a rehab physiotherapist to establish a programme of simple exercises that can be done in the home with minimal equipment. I hope to standardise this so that clients in any area can take advantage of it.

Carers' coffee mornings continue with those attending finding the support and comradeship invaluable.

I am on the residents' committee of Amaryllis House which means I will be a link for those families unable to attend these day time meetings.

I continue to enjoy all the challenges the job brings and look forward to the rest of the year

Kind regards

Jeanette Wiggins

New Plymouth, Wanganui and Palmerston North

We are currently looking at a support group in both the Wanganui and Taranaki regions.

It would be really helpful if any one who is interested contact me so we can discuss what kind of group they are hoping for.

My social work services will continue to be tailored to suit the needs of each individual. I am available for home visits, telephone and email support or any other enquiries. I regularly visit rest homes to visit clients but also to educate and support staff which I believe is an essential part of my job.

I intend to continue to increase my involvement with other community agencies and promote the Association, and the support it offers to families facing the daily challenges of living with HD.

Please feel free to contact me at any time should you require a home visit or any other form of support.

Kind regards

Annette Turner-Steele

Hawkes Bay / Gisborne News

Kia ora koutou

Ko Tanya Jeffcoat taku ingoa.

Hi, am currently learning Te Reo Maori and taking every opportunity to practice!

Welcome to all, and especially to our new families who have made contact here in the Bay.

My main role is providing home visits and phone contacts and emails to all families in Hawkes Bay,

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including Central Hawkes Bay, and currently in Gisborne, to support and assist with families holistic needs!

I work closely with the Rest Homes who are looking after our families' members, as well as providing information talks to community groups.

We have regular Support Group Meetings and our last one in Hawkes Bay was on a gorgeous Sunday looking out at the sea with 16 people, including three new people to the group and one partner. Our families in Gisborne also have been meeting every three months when I have been visiting, for a shared lunch and chat.

In Hawkes Bay we also have regular Carers Meetings where carers get a chance for a well-earned treat and to meet others and share ideas, support, and have some fun.

Also in Hawkes Bay we have begun our weekly Water Exercise Class in partnership with the MS Society. This time of the year is a challenge to think about getting into the pool, but it is very much worth it. The class is open to all people with HD and we welcome support people, so if you are interested, give me a call.

Our next meeting will be a pot-luck dinner on 23rd June with Professor Faull and a colleague from Auckland will be coming down, and also a geneticist is coming up from Wellington before we present our HD Session for GP's in Napier.

Please feel free to phone me anytime for support, information, or a chat on (06) 835-3020.

Sadly two people from our group in Gisborne passed away in April and our deepest thoughts are with these families. It is certainly my privilege to have known David, and to know Joyce's family. Kia kaha.

SPECIAL REQUEST

Hi, am wondering if there are any parents of young people who are living with Juvenile HD out there who would be interested in talking with a mum whose 17 year old daughter has Juvenile HD. This is so terribly, unimaginably hard – for everyone – and to be able to talk with someone else who is going through or who has gone through a similar situation, would make such a big difference. So, if anyone is willing and/or would like a bit more info, please contact me for a chat.

Thanks so much

Tanya Jeffcoat
HD Association Hawkes Bay – ph (06) 835-3020

Gisborne

We are pleased to announce the appointment of Cheryl Morley as the Huntington's Advisor for the Gisborne Region. Cheryl is taking over from Tanya Jeffcoat who temporarily covered the area. Tanya will continue with her duties in Hawkes Bay. Cheryl contact number is (027) 667 7674.

Cecil O'Neale
Chairperson

Christchurch News

A.G.M.

Sunday 5th July 2009 at 2.30 p.m.

at

Hornby Day Care Centre
93 Carmen Road, Halswell
Christchurch

Do come and support your Association
Please remember to bring a plate

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)
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Huntington's News is the national Newsletter of the Huntington's Disease Associations of New Zealand. It is published quarterly (March, June, September, December) as a means of communication between the Associations and all individuals with Huntington's Disease, their families, their caregivers and professionals interested in the condition.

Editorial Board: Glenys Shepherd (Wgtn)
Dorothy Tortell (Wgtn)
Judith Baker (Chch)

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 September 2009. The deadline for material to be received for this issue will be 10 August 2009. 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.

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