



## *Embryos bring life to disease research*

*Deborah Smith – Science Editor July 29, 2009*

SYDNEY scientists will begin an Australian-first project this week to study a genetic disease at its earliest stage of development. They will compare embryonic stem cells extracted from IVF embryos affected by a neurodegenerative disorder, Huntington's disease, with embryonic stem cells from healthy embryos.

Leon McQuade of Macquarie University said this would provide insights into the genetic condition at a critical stage – from five to seven days after fertilisation. "We've never been able to do this before," he said.

In what will be one of the first practical applications of controversial embryonic stem cell research, the team will determine any differences between more than 2000 proteins on the surfaces of the diseased and healthy cells. Proteins are "a bit like human beings" and tend to behave – or misbehave – according to the social company they keep, said Mark Baker, director of the Australian Proteome Analysis Facility at the university. Identifying the earliest changes in the "social networks" of proteins in diseased cells could throw light on how the condition develops and possible treatments, Professor Baker said.

The project is a collaboration with the fertility company Sydney IVF, which has the only licence in Australia to extract stem cells from embryos carrying genetic diseases.

Using affected IVF embryos donated by patients, the company has developed disease-specific stem cells for a range of conditions apart from Huntington's, including cystic fibrosis, muscular dystrophy and Turner syndrome.

The director of research and development at Sydney IVF Stem Cells, Tomas Stojanov, said the company will also use the stem cells affected by Huntington's disease to develop assays to test the effectiveness of new drugs.

Professor Baker said his team had made an advance last year that allowed them to study proteins on the surface of cells, not just those inside, which are important because they affect how the cell interacts with its environment.

Future research will include converting the diseased embryonic stem cells into nerve cells to "track the disease across a time course", Dr McQuade said.

Determining the identity and quantity of thousands of proteins would provide a broader picture of the disease process than just studying a single protein affected by the genetic mutation, he said.

*Acknowledgement: Sydney IVF Stem Cells –*

*[www.sydneyivfstemcells.com/](http://www.sydneyivfstemcells.com/)*

*<http://www.smh.com.au/national/embryos-bring-life-to-disease-research-20090728-e06o.html>*

# *Malnutrition and eating difficulties*

Eating difficulties, which affect the ability to bite, chew or swallow food, can lead to dehydration and malnutrition. Helen Crawley looks at symptoms, complications and treatment. Helen Crawley, RD, RPHNutr, is a lecturer, School of Life Sciences, University of Kingston, Kingston, Surrey England:

Achieving adequate calorie, nutrient and fluid intake in people with swallowing problems can be a challenge but preventing malnutrition and dehydration are essential in reducing morbidity and mortality among those with eating difficulties.

## *What are eating difficulties?*

These are disorders which affect the ability to bite, chew or swallow food.

### *Dysphagia*

This disorder in swallowing may be due to a delayed or absent swallow reflex and difficulties with lip seal, tongue and jaw movements, which lead to impairment of both the oral and pharyngeal phases of swallowing. It is commonly seen after stroke, where 30% of patients have dysphagia and in dementia, particularly in the later stages. Swallowing difficulties are also associated with:

- Carcinomas of the mouth and oesophagus;
- Surgery on the jaw;
- Neurological diseases such as Parkinson's disease and Huntington's disease, cerebral palsy and multiple sclerosis.

### *Chewing difficulty and mouth pain*

These are commonly caused by dental disease, poor dentition, mouth ulcers or infections such as thrush in the mouth. Sore, painful mouths and tongues are also related to nutrient deficiencies, particularly of vitamin B12, iron or vitamin C.

### *Complications of dysphagia and eating difficulties*

- Aspiration of food and fluid into the airways can lead to chest infections and pneumonia;
- Increased length of stay in hospital, morbidity and mortality are associated with dysphagia;
- Malnutrition and dehydration are common wherever food and fluid intake are affected.

## *Why do eating difficulties lead to malnutrition and dehydration?*

- **Dehydration.** This commonly occurs as fluid intake becomes more difficult with dysphagia.
- **Coughing and choking** are common problems if drinks are not thickened.
- **Change in types of foods eaten.** This may reduce the intake of total food consumed and the intake of some important nutrients. Poor dentition and mouth pain often lead to reduced intakes of fruits, vegetables, meat and more fibrous cereal foods. This can lead to lower intakes of vitamin C, vitamin A, folates, iron and zinc, nutrients that are particularly important for maintaining the immune system.
- **Change in texture of food.** Patients with eating or swallowing difficulties may need altered textured diets and fluids, and this is likely to lead to lower energy density in meals which have been diluted. Patients on texture modified diets may only meet 45% of their energy requirements and require more frequent energy dense meals and snacks to obtain sufficient energy.
- **Loss of independence in eating.** This is associated with reduced energy intake and occurs for a number of reasons:
  - Eating may be much slower;
  - Use of cutlery may be limited;
  - The patient may be embarrassed about eating;
  - Anxiety or a fear of choking can make both patients and carers nervous and unhappy about mealtimes.
- **Reduced appeal of food** in terms of taste, temperature, variety and appearance can affect appetite.

## *Encouraging people with eating difficulties to eat an adequate diet*

- **Refer to a speech and language therapist** who can assess and monitor patients with eating difficulties. They can also advise on how to prevent aspiration and the most appropriate texture of foods and drinks. Information on texture-modified diets can be found in the shaded box below.
- **Dental care is essential**, including the treatment of mouth ulcers and thrush, investigation of mouth and tooth pain and proper fitting of dentures where appropriate.
- **Personal preferences** should always be respected. It is essential to find out as much as you can about the person's likes and dislikes.

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- **Allowing people enough time to eat** has been shown to be an important factor in increasing energy intake. Eating where there are swallowing difficulties can be tiring and flexibility in the timing of meals and snacks has been shown to be essential for these patients.
- **Portion sizes** of meals should be appropriate: small, frequent meals are often more acceptable and less daunting to patients.
- **Temperature of foods** can affect the management of swallowing disorders. If patients have decreased oral sensation then chilled or cold foods, or hot foods, may stimulate the swallow reflex more easily than warmed or tepid food.
- **Sitting in a good position** preferably upright with feet flat on the ground, the body well supported and the head tipped slightly forward will help eating.
- **Ensuring foods are energy and nutrient dense** is important where total food intake is likely to be reduced. Encourage foods which provide important nutrients to the diet such as meat, fish, fruits, vegetables, dairy products and cereals. If more energy dense meals are needed then adding extra cheese, butter or cream will increase the number of calories.
- **Use supplements with care.** Commercial supplement drinks, puddings and soups can be useful as a short-term addition to the diet when there are particular concerns about a person's calorie intake. Fortifying real food with additional nutrients is often more acceptable to patients and encourages a return to more normal eating patterns and improved nutrition in the long term.
- **Help people to maintain their independence in eating** wherever possible. Encourage the use of finger foods where the use of cutlery is difficult or consult with occupational therapists on modified utensils. If patients need assistance with eating try to think of it as 'helping someone to eat' rather than 'feeding'. The care and commitment of staff to this relationship is essential.
- **Prompt and encourage people** to eat throughout the meal. This may be particularly important where people have dementia and may need to be gently reminded to chew and swallow food.

### ***Altering the texture of food and drink***

The texture modification of foods and fluids have been described with National descriptors for five categories of fluid and six categories of solid textures (BDA/RCSLT, 2002). The aim of changing texture is to provide a steady flow of food or fluid between the tongue and the palate to aid control. Speech and language therapists and dietitians can advise on the appropriate consistency.

**Fluids.** These often need to be thickened, but it is important that staff know how to prepare thickened fluids correctly as different brands of thickeners will alter texture differently. New research shows that bubbles in carbonated drinks may also be helpful in stimulating the swallow reflex and the use of frozen fluids such as ice lollies can offer an alternative, manageable fluid source for some patients.

**Foods** and meals of a soft or pureed consistency should be made as attractive as possible. Foods should be pureed separately, preferably without water, to ensure each food is still recognisable and nutrient content is not diluted. Soaking solutions can be used to improve the visual appearance of modified foods and moulds and piping can make pureed foods into recognisable shapes which increase acceptability.

### ***References and resources***

British Dietetic Association, Royal College of Speech and Language Therapists (2002) National Descriptors for Texture Modification in Adults – <http://www.slodrinks.com/images/National%20Descriptors.pdf>

Crawley, H. (2002) Food, Drink And Dementia: How to Help People With Dementia Eat and Drink Well. Stirling: University Stirling Dementia Services Development Centre.

Dysphagia Resource Center – <http://www.dysphagia.com/>

To view this article online, please visit:

[http://www.nursingtimes.net/ntclinical/2009/01/nutrition\\_and\\_eating\\_difficulties.html](http://www.nursingtimes.net/ntclinical/2009/01/nutrition_and_eating_difficulties.html)

*Acknowledgement: HDA UK Newsletter June 2009*

The Wellington Association has the book "Handbook on Health and Nutrition for those with Huntington's Disease". This publication costs \$10.00 and can be purchased from -  
The Secretary, Huntington's Disease Association (Wellington) Inc, PO Box 30420,  
Lower Hutt 5040, Wellington, New Zealand

# *Surgical Approaches Working Group*

*By Anne Rosser and Stephen Dunnett, Cardiff University, Cardiff (United Kingdom)*

## ***Alternative Surgical Strategies for Huntington's Disease***

For more than two decades there has been interest in surgical treatments for Huntington's disease (HD).

Initially, these treatments focused on cell transplantation. More recently, consideration has been given

to gene therapies and deep brain stimulation (DBS). Although these approaches involve very different types of implant (cells, viral vectors or electrodes), they have common neurosurgical delivery strategies. The Surgical Approaches Working Group (SWG) was established to evaluate the status of different strategies and to identify areas where EHDN might play a particular role in coordinating clinical trials involving surgical treatments.

## ***Cell transplantation***

Based on what has proved effective in studies using experimental animals, trials of cell transplantation in

HD have all involved implantation of fetal striatal cells into the striatum, to replace those lost in the disease. Several clinical studies have now demonstrated good graft survival and preliminary evidence of efficacy. A major French trial is underway, co-coordinated by Dr Bachoud-Lévi. This trial has sufficient numbers to indicate efficacy and the outcome is keenly awaited. Although at present all trials use fetal cells, the ultimate aim is to use stem cell alternatives. Cell transplantation studies are already well co-ordinated through the European Network for Cell Transplantation and Repair (NECTAR), with whom EHDN co-operates closely.

## ***Deep Brain Stimulation (DBS)***

DBS employs electrical stimulation of brain areas via implanted electrodes. There is evidence of efficacy for a variety of conditions, including Parkinson's disease (at a stage that is refractory to, or complicated by drug treatment), although the mechanism of action is not fully understood. There is some evidence from animal models,

and limited evidence from isolated HD clinical cases, that DBS may be effective in controlling severe chorea in HD. There are also trials underway to study DBS as a therapy in early HD. The SWG reviewed the existing data and concluded that there is a need to investigate DBS as a symptomatic treatment for poorly-controlled and troublesome chorea. The first pilot studies are planned to determine optimal brain targets appropriate to control chorea. The long-term aim is to support a future multicentre European study of DBS in HD.

## ***Gene therapy***

Two major areas of interest are HD gene silencing and the delivery of trophic (growth) factors. Gene silencing by RNA interference aims to reduce the production of huntingtin in the hope that reducing the level of (toxic) mutant protein will slow disease progression. Trophic factors such as BDNF and CNTF may exert a neuroprotective effect on damaged striatal neurones. A number of small clinical trials are already underway to explore the potential of using such factors to slow the progression of HD. Delivery of gene therapy may be achieved either using viruses to transfer the genes into the correct brain targets, or by engineering cells (such as skin cell fibroblasts) to secrete the factors at high levels, and then transplanting the engineered cells into the brain.

Development of DBS has become the SWG's major activity, although members of the group are also active in, and continuing to monitor, progress in cell transplantation and gene therapy.

*Acknowledgement: European Huntington's Disease Network Newsletter – Issue 06 – June 2009*



# OCCUPATIONAL THERAPY

*From 'The Family Guide Series – Physical and Occupational Therapy for Huntington's Disease' written by Suzanne Imbriglio, PT. Reprinted with permission from the the Huntington's Disease Society of America, 505 Eighth Avenue, Suite 902, New York, NY 10018, www.hdsa.org*

## **Occupational Therapy in Early-Stage HD**

As cognitive changes begin to occur, an occupational therapist can help the person with HD and family members develop compensatory strategies. By employing these strategies early in the disease process, the person with HD learns that he/she can have some control over the disease and is therefore less apt to feel helpless.

### **Memory Strategies**

- Offer hints, such as word associations, to aid in the retrieval of information
- Use lists, calendars and notes
- Establish a consistent daily routine
- Label items around the house
- Avoid open-ended questions. Instead, offer a list of choices and ask questions requiring a "yes/no" answer. Difficulty in sequencing tasks is another common problem experienced in the early stages. Family members report that tasks that used to be completed in a few hours now take all day or are never completed at all. The strategies listed below can help to remedy this problem.

### **Planning Strategies**

- Write down all tasks in a logical order
- Review the steps to ensure that they are clearly understood
- Break complex tasks down into parts
- Encourage completion of each step prior to moving on to the next step in the task

### **Concentration Strategies**

- Use short sentences when giving directions
- Ask the person to repeat important points back to you
- Reduce outside stimuli whenever possible
- Underline key points in directions or recipes

### **Safety in the House**

A home consultation by an occupational therapist can identify unsafe practices and provide suggestions to improve safety. Analysis of meal preparation skills, personal hygiene, and other activities of daily living (ADL's) can lead to strategies which foster independence. Here are some examples:

#### **In the Kitchen**

- Use unbreakable dinnerware
- Avoid storage of commonly used items in high cabinets

- Use a kitchen timer as a reminder to turn off appliances
- Lower the hot water temperature to prevent scalding
- Use covered mugs for hot liquids
- Use oven mitts rather than potholders

#### **In the Bathroom**

- Use a non-skid mat in the tub or shower
- Use 'soap on a rope'
- Use a shower bench or chair
- Use safety bars

#### **In the Living Room and Bedroom**

- Stabilize furniture so that it cannot move
- Use chairs with high backs and armrests
- Clear rooms of any unnecessary furniture
- Remove scatter rugs or thick pile carpeting
- Keep tables and lamps away from walkways
- Pad doorways and furniture when contact is frequent

## **Occupational Therapy in Middle-Stage HD**

The combination of motor control problems and cognitive deficits creates a number of difficulties in activities of daily living. Again, strategies and equipment can be of great use in prolonging independence.

### **Eating**

#### **Problem**

Impaired postural control creates positioning problems at the table. Slouched sitting and inability to maintain proximal stability cause a great deal of food spillage as well as fatigue.

#### **Strategies**

- Have the person sit in a sturdy chair as close to the table as possible
- He/she should wrap legs around legs of chair to stabilise the pelvis and put elbows ON the table to stabilise the upper trunk

#### **Problem**

Motor impersistence and muscle weakness cause difficulty holding onto utensils, or difficulty bringing hand to mouth.

#### **Strategies**

- Use utensils with built-up handles
- Utensil should be put down after each bite to rest muscles and prevent fatigue

#### **Problem**

Inco-ordination of movement makes simple tasks such as cutting food seem very difficult.

#### **Strategies**

- Use non-skid placemat to prevent dishes from moving
- Use covered cups or mugs (travel mugs are ideal) to prevent spills

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## **Hygiene**

### **Problem**

Difficulty with motor planning and sequencing tasks can make even the most routine activities seem insurmountable. Though some people with HD lose interest in personal hygiene as a result of depression, this apparent lack of interest often is a result of diminished planning and sequencing ability.

### **Strategies**

- Divide morning and evening routines into simple steps
- Write out steps for completing all hygiene tasks and post in a visible place

### **Problem**

Maintaining balance while performing everyday tasks, such as shaving or brushing teeth, can become difficult and even hazardous.

### **Strategy**

- Use a shower bench or chair to prevent fatigue and assist with balance

### **Problem**

Combining a fine motor task, such as holding the soap, with a gross motor task, such as washing the torso, also presents difficulties.

### **Strategies**

- Use a shower mitt (the soap can be put right inside the mitt so it won't fall out) or 'soap on a rope'
- Use an electric razor or chemical hair remover
- Build up handle on toothbrush or hairbrush by wrapping and taping a washcloth around it

### **Problem**

Fatigue often plays a role in preventing the completion of tasks.

### **Strategy**

- Build rest periods into the routine

## **Dressing**

### **Problem**

Decision-making ability may cause people with HD to avoid changing their clothes because they have difficulty deciding what to wear.

### **Strategies**

- As with other complex tasks, reduce the routine to simple steps
- Label and pair favourite items so that decision-making is kept to a minimum

### **Problem**

As the small muscles of the hands weaken, ability to grasp objects is diminished.

### **Strategies**

- Avoid clothing with multiple fasteners
- Put a ring on zippers to aid in opening and closing
- Encourage dressing while sitting in a sturdy chair to reduce falls and fatigue

### **Problem**

Lack of initiation – the inability to start a task – may necessitate a 'jump-start.'

### **Strategy**

- Suggest an activity or task and offer help. Often this will provide the necessary impetus for the person to complete the task independently

## **Occupational Therapy in Late-Stage HD**

In the later stages of the disease, preventing injury to the body becomes of the utmost concern. Although some people with HD appear to be moving all the time, they are often not able to change position voluntarily, and therefore are susceptible to skin breakdown from constant shearing movement.

The occupational therapist can assist the caregivers by suggesting a routine of position changes. The OT can also assist in designing a protective environment for the person with a lot of choreic movement. Padding of hard furniture, wheelchair parts and sharp corners help to prevent injury from falls or choreic movements. In cases of very severe chorea, it may be necessary to pad a part of the body if constant contact is being made.

Because the person with advanced HD is no longer able to control movement, certain muscle groups are no longer used. This disuse, combined with changes in muscle tone, can lead to permanent disability called contracture.

## **Contractures**

A contracture is the permanent shortening of a muscle. Contracture management in HD can be difficult because of fluctuations in muscle tone and the presence of chorea. Frequent position changes and range of motion exercises are important weapons in the battle against contractures.

In some cases splinting can be helpful. New air-assist-type splints, which use air bladders to provide support and have enough "give" in them to avoid skin breakdown, have proven very helpful in the management of elbow and knee contractures. Foam core and hand splints have also proven useful for maintaining functional positioning of the hand. These are very lightweight and have a washable cover for easy care. Many people are able to wear splints during the night. This gives them eight to ten

hours of appropriate positioning and slows down the contracture process.

## **Conclusion**

Today, more than ever, there is hope for people with Huntington's Disease. Rapid progress is being made toward potential treatments for HD. Likewise, quality of care for people with HD has improved greatly in recent years. By seeking early intervention from health professionals such as physical, occupational and speech-language therapists, the person with HD can have control over the disease and over his/her life. By learning strategies to help them cope with the many changes that are brought on by Huntington's Disease, people with HD can live meaningful, productive lives well into the final stages.

*Acknowledgement:*

*Newsletter – AHDA (Qld) Inc – May 2009*

## Auckland / Northland News

Hello to everyone from Auckland. Hope you have all managed to keep warm and well.

Jane and I have had a busy time of it since the last newsletter.

We yet again had a fantastic turnout to the association A.G.M. It was at a new venue, Ferndale House in Mt Albert. We needed a larger venue as the previous one just could not hold our growing numbers.

Once again we were privileged to have Professor Richard Faull and his team present their latest research and developments to us, one of which is the The Centre for Brain Research.



### ***CeleBRation Choir!***

Therapeutic choir making a big noise about the CBR.

The Centre for Brain Research (CBR) is an exciting step forward for research into neurological disorders. This unique partnership brings together world-class neuroscientists at The University of Auckland, skilled clinicians at Auckland's regional District Health Boards and dedicated community NGOs. The Centre will launch in November, and they need YOU to make a big song and dance about it!

Do you want to join the CeleBRation Choir?

Do you have a neurological condition, or support someone who does?

Would you like to try free music therapy and have fun singing with others?

If so, please join the CBR Choir to help raise awareness of neurological disorders and neuroscience research.

Renowned music therapist Alison Cooper, from the Raukauri Music Centre, will guide choristers through vocal exercises and songs on a weekly basis. Aided by skilled volunteers from the CBR, the new choir welcomes anyone living with a neurological condition, including patients, carers and supporters.

Rehearsals will be held weekly, starting in September.

Feel free to turn up!

For more information, contact Laura Fogg:

[l.fogg@auckland.ac.nz](mailto:l.fogg@auckland.ac.nz) or (09)9231913

**When:** Thursday September 17th 2009 onwards

**Time:** 6-730pm

**Where:** Tamaki function room, Tamaki Campus, Bldg 730, Rm 220, Cnr Morrin Rd & Merton Rd, Glen Innes, Auckland. Free parking and easily accessible.

### ***Ambridge Rose Manor Pakuranga Rest Home and Private Hospital provides well-earned break for carers***



#### **A day of pampering**

It was a wild and windy weekend but that didn't bother the team of beauticians inside the Waves Conference Centre in Orewa, who were hard at work helping carers to relax and forget their daily grind. The special carers retreat was paid for by Ambridge Rose Manor, a rest home in

Pakuranga. This private rest home cares for individuals with Huntington's Disease. The owners and their staff wanted to give something back to the families of these individuals so fund raised for the Association. We chose a day of pampering – courtesy of students from the Elite International School of Beauty and Spa Therapies. Husbands, fathers and brothers walked away laughing at their painted bright red nails, while wives, mothers and sisters ensured their cares were massaged away!

The Huntington's Disease Senior Family Liaison Coordinator Jo Dysart, the support family co-coordinator

Jane Devine, and Deb Nagel, Client Service Co-ordinator from Waikato believe that Huntington's can be a lonely disease. Often people have never heard of the condition, and many of the carers live in very rural areas where they don't get the chance to talk about their situation. A retreat like this is so important as it gives them time to relax and meet other people who are walking



*Continues on page eight*



the same journey as them. They spend their whole day caring for other people and never set time aside for themselves. To have the beauticians here helping the carers is just incredible – the gift of their time makes such a difference and helps the carers to remember to look after themselves as well!



Fourteen beauticians gave individual treatments to each of the carers, ranging from manicures, to massage to pedicures. Everyone took part, even the men, causing great hilarity!

Jodie Vaughn is a 21 year old student on the Premier Diploma course. “I love helping people and pampering them,” she said. “But the

best thing is when I can give a spa treatment for the first time to someone who’s never had a treatment before – they love it! For people, who are on their feet all day, pedicures are so good and it’s a great way to pamper them.”

It’s not an unusual event for the Premier Diploma beauticians, as Vanessa Smith-Glinterkamp, the Elite Campus Manager, explains, “Our girls have a skill which is so easy for them to do, but it means so much to people and they love it. It’s so important that we give back to the community. Elite is the largest provider of beauty therapy training in New Zealand, and our girls are the best in the industry. Community work is all part of that.

The girls love doing this, and the carers love it. It’s the simple things in life that change people’s lives.”

It certainly went down well with our carers.

**We had a lot of relaxation, Pampering and lots of fun we have many more photos but they are not for the public. Too scary!!!!**

Our Carers retreat started with a teaching and education session in the morning followed by a lovely catered lunch. In the afternoon we had the Elite International Beauty School come to give massages, manicures and pedicures to all the carers, even Jane, Deb and myself got in on the act. Everyone enjoyed it so much; the laughter coming from the conference hall said it all. After all that relaxation we went out for dinner at a local restaurant where everyone got to socialise, share their personal stories and developed some wonderful friendships. Everybody gained lots of positive problem solving and we all took home some beautiful memories.

**Special thanks must go to.**

All our carers including Jane Devine and Deb Nagel, who came from Auckland, Northland and Waikato and gave their time, their personal journeys with H.D and their friendships

info@ambridgerose.co.nz Allan & Linda Sargeant  
Phone: (09) 576 2590 Mobile: (021) 467 118 – Allan  
Mobile: (021) 237 3671 – Linda

All this would not have been possible if it had not been for the funds raised by Ambridge Rose rest home and hospital and

**Elite International School of Spa and Beauty Therapies**

Whose huge gift of time and expertise made this a memorable and enjoyable day and of course many thanks to

The Auckland committee members who work hard behind the scenes to make events like this happen

If you would like to donate money or time to the Auckland Huntington’s disease Association, please contact Jo Dysart on huntingtonsakld@xtra.co.nz or 027 432 8255

Take Care bye for now

*Jo Dysart*

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## Waikato News

Professor Faull has been to speak in Hamilton and approx 80 people turned out on a cold winter night to hear him. It was a mixture of families with HD, (carers and those gene positive), professionals who care for them, and others interested in learning something new. They were not disappointed and many left with a feeling of hope that they did not have before. Thank you Professor Faull.

We have just had a fantastic weekend with Auckland HD Association in Orewa.

The Carers Retreat was full of tears and laughter, and was well worth the drive over the Bombay Hills and the Harbour Bridge.

Carers came back feeling more informed and supported, thank you Auckland, we will continue to work with you when we can, for the benefit of HD families in 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

Despite inclement weather, it has been a busy quarter. Winter has felt very long and wet in the Wellington region so I am looking forward to spring and some warmth and sunshine.

The keen swimmers from Amaryllis House and the HD community have continued their fortnightly visit to a nice warm pool and all get a great deal of benefit from this. One of the rehab physiotherapists at Kenepuru Hospital has completed her case study on Exercise in HD. Hopefully, we can include her findings in the next newsletter.

I have made several trips over the Rimutaka Hill taking clients to Noel Hamilton House for respite care. This lovely house has permanent HD clients and also provides respite care. It hasn't snowed on my trips but has been a close thing and it can be a very windy trip over the hill.

We recently held a small carer's retreat in Martinborough. It was restful and we stayed in a very rural setting which was beautiful. It certainly felt well away from the hustle and bustle of Wellington. I think it was a successful and enjoyable night away.

The lemon concentrate I have been making as a fundraiser

has been very successful and due to publicity in a number of local papers, I am inundated with lemons and often come home to find bags of lemons on my doorstep and emails from people requesting bottles which is great.

Our \*AGM is on **20th September** and I have invited **Dr Andrew Murray** from **Fertility Associates** to come and speak on **IVF and pre genetic implantation** which will be a great opportunity for questions to be asked about this technique and a good chance for some of our families to get together. We are having a fundraising \***Garden Tour** on **4th October** at a beautiful large property in Te Horo. This will offer a chance to see a garden with many different sections and we will have food etc available for sale. I am sure that the committee and clients will enjoy the day.

I cannot believe how quickly the year is going and hope that for the remainder of the year I can continue to support all the families I am involved with in their individual circumstances.

\* See flyer inserts

*Kind regards*

*Jeanette Wiggins*

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## New Plymouth, Wanganui and Palmerston North

Welcome to all the new families in the Taranaki area. It has been a pleasure meeting you and I look forward to giving you on-going support. The number of Taranaki families has grown over the last few months and it has not been possible for me to visit everyone due to time constraints and annual leave. Please, if I have not visited you recently and you want to see me please call and leave a message so I can arrange a visit with you. I am only in the Taranaki region once a month and it is not possible to visit everyone on each visit but I will do my best to pop in for a chat whenever possible.

Some families mentioned that they would like a support group in the Taranaki region so I will be sending out a questionnaire in the next month or so to try and get some feedback on what will work for people so please take the time to fill it in and send it back to me. I will then try and hold a meeting for those who can attend to see how things can work best for the families in each area. The

support group may give me the opportunity to see more people on a regular basis rather than people having to wait so please feel free to tell me in the questionnaire.

We are also keen to set up a support group in Wanganui so once again a questionnaire will go out to families in order to get feedback.

My social work services will continue to be tailored to suit the needs of each individual where ever possible. 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.

Please feel free to contact me at any time should you require a home visit or any other form of support. Messages can be left on my answer machine.

*Kind regards*

*Annette Turner-Steele*

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## Hawkes Bay News

Kia ora koutou

Welcome to everyone.

Here in Hawkes Bay we continue to meet together in our regular support group meetings which are open to all, and monthly our carers get together for a chance to chat

and support each other over coffee and cake. I endeavour to meet up with everyone over the month. Please feel free to contact me anytime.

In June we had a very successful GP forum with Prof Richard Faull and Sian Nesbitt (from Genetic Services)

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as guest speakers for 36 local GPs and nine practice nurses. We organised this through the PHO's Continuing Medical / Nursing Education and it gave the health professionals the opportunity to learn a bit more about HD and hear the latest with regards to research as well as the genetic testing procedures. There was very positive feedback and we are hopeful this session will facilitate better communication and understanding from health professionals towards their patients with HD. We also had the chance to have a little time as a group with Richard and want to thank him very much for his time and tireless work.

We held our Water Exercise Class for 10 weeks and are now working with the neurological physiotherapist at the hospital to provide an eight week group class in their very well equipped gym, after which we will continue motivating and supporting each other to keep up the exercise. This should be starting in September and we will be partnering with the MS Society again.

We have other activities open to people with HD and their families, so please contact me anytime for support, information, or a chat on (06) 8353020.

Kia Kaha.

*Kind Regards,*

*Tanya Jeffcoat*

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## ***Gisborne News***

A Warm and sunny Hello from Gisborne.

My name is Cheryl Morley. For the last ten years I have worked for Arthritis New Zealand as an Arthritis Educator. I now bring my skills to the Huntington's Disease Association as the HD Advisor for the Gisborne Region. I look forward to meeting you all.

I have had a busy few weeks getting to meet up with people and learning about Huntington's Disease. I was given a copy of the Magazine called Familycare this magazine is designed to help families who have health and Disability needs, the magazine is bright and packed full of interesting articles, hints, letters, personal experiences, new products, give-aways and some wonderful recipes. The magazine also has a section for carers with advice on caring for themselves. This magazine is free; to apply

for your copy write to Family Care NZ PO Box 133 Mangonui, Far North 0442, Good luck it is a wonderful magazine.

I have several copies of the Association's publications; Genes & Generations, Living with Huntington's disease, Handbook on Health and Nutrition for those with H.D and Huntington's and Me, A guide for young people.

Anyone interested in borrowing any of these books please give me a ring 06 868 8878 and I will get one to you.

Anyone that would like some advice/support regarding H.D feel free to contact me on (06) 868 8878 or (027) 686 9432 give me a call or leave me a message.

Take Care

*Regards*

*Cheryl Morley*

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## ***Christchurch News***

Greetings from Christchurch.

The days are stating to get longer and a little warmer which is always a sign that spring is on its way. The Christchurch Association hosted a meeting for representatives from the three Associations in July. This was a really great day with each of us having the chance to catch up on each other's happenings, highs and lows, problems and ideas. A great deal of knowledge was shared with similar problems being the theme of the day. It made us feel part of a larger family, all with the same goal in mind. Ensuring and/or providing the very best information, care facilities and support for our HD families, being the essence of our Associations and driving us, to ensure this happens. We would like to thank the two Associations for taking the time to attend yet another meeting and giving up a weekend day for HD. I am sure you will all agree that it was a worthwhile day and we now plan to hold these meetings on a regular basis.

Our Association has been quiet over winter but are now

looking at fundraising ideas again. It has been suggested that we hold a 'Walk for HD' in the New Year, so plans are underway to see how we can make this happen.

I am currently on the steering committee driven by the Ministry of Health looking at providing and setting up of residential and respite services for HD families in Christchurch. This is very exciting for our Association as it has been the dream of many HD families for a long time to have such a service available in our city. This committee is made up of some very strong advocates for HD and I am sure we will get the very best outcome for Christchurch.

We will keep you updated on the progress.

*Kind Regards*

*Dianne Collins*

*Chairperson HD Christchurch*

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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.

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



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

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Dorothy Tortell (Wgtn)  
Judith Baker (Chch)

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- ◆ 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 December 2009. The deadline for material to be received for this issue will be 10 November 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](mailto: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](http://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**

Sarah Wilkinson, 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

## **HAMILTON**

Deb Nagel  
Client Services Co-ordinator  
c/- MS Waikato Trust  
PO Box 146, Hamilton  
Tel (07) 834 4742  
Mob (027) 385 5425  
deb@mswaikato.org.nz  
www.mswaikato.org.nz

## **ROTORUA**

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

Alison Meinhofer  
MS Society  
c/- Community House  
1115 Haupapa Street, Rotorua  
Tel (07) 346 1830  
Fax (07) 346 1840

## **GISBORNE**

Cheryl Morley (Huntington's Advisor)  
PO Box 1020  
Gisborne  
Tel (06) 868 8878  
Mob: (027) 868 9432

## **HAWKES BAY**

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

## **TAURANGA / TE PUKE**

Ann Hudson  
106 Cheyne Road  
Pyes Pa  
Tauranga  
Tel (07) 543 9344

Cheryl Standring  
MS Society  
PO Box 10376  
Bayfair  
Tauranga  
55A Edgumbe Road  
Tauranga  
Tel (07) 571 6898 (Field Officer and  
Office)  
bopmssociety@xtra.co.nz

## **WHAKATANE / OPOTIKI**

Lynette Richardson  
Tel (07) 312 9397

## **NEW PLYMOUTH /**

## **WANGANUI /**

## **PALMERSTON NORTH**

Annette Turner-Steele  
Social Worker  
PO Box 101  
Marton  
Tel/Fax (06) 327 7389  
Mob (027) 496 6500  
Annette.wellingtonhda@gmail.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**

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

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

## **WEST COAST/HOKITIKA**

Heather Creagh  
PO Box 25, Ahaura  
Tel (03) 732 3827  
Fax (03) 732 3813

## **CHRISTCHURCH**

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

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

Lynne Switzer, Field Worker  
Tel (03) 326 5189  
lynne.switzer@paradise.net.nz

## **DUNEDIN**

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

## **INVERCARGILL**

Maree Lewis  
MS Society  
PO Box 1561, Invercargill  
Tel (03) 218 3975