



NEWSLETTER

AUSTRALIAN HUNTINGTON'S DISEASE ASSOCIATION
(QLD) INC.

May 2009

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From the President

We all live in the hope for treatments for HD to delay the onset of the disease and also to find a cure for HD. I am very pleased to advise you all that the Association is in the process of establishing the "Huntingtons Queensland Fund" with the School of Biomedical Sciences of the University of Queensland to support a pre-clinical trial of the drug PMX205 with the HD R6/2 mouse model. This has been made possible through the very generous donation made by the Thorsen family. There will be more details on this in our next newsletter.

To enable the Association to support research we have had to seek endorsement as a Health Promotion Charity from the Australian Taxation Office and I would like to thank Craig Bowie and Khory McCormick from Minter Ellison for their assistance in making this happen.

The Association is still looking for members to become part of our Management Committee and I am pleased to let you all know that Lisa McGuinness has joined us as a Committee member. Welcome Lisa.

In September 2010 we will be hosting the bi-annual Australian HD Conference here in Queensland with the theme "Making the Connection". To help us in the planning of the Conference and to ensure we meet your objectives we have included a survey form so you can give us feedback on what you would like included in the Conference. Would you take some time to complete this.

Gerry Doyle
President

Operational Plan for 2009-2010: Shortly Committee and staff will be looking at our service delivery for 2009-2010. Within our resources, every effort will be made to maintain our existing services and to further some relatively new initiatives such as increased support to young people. We do have the National Conference to consider and it is hoped that through outside funding, sponsorship and registration fees all costs will be met. We have a big year coming up.

Cycle Queensland's Bicycle Challenge: Thank you to those who have supported this fundraising initiative. To date \$3,500.00 has been received. We have some way to go to meet our target and are hopeful that through continuing support by way of donations and involvement by our membership in associated fundraising events we will meet our goal.

To this end the Association is running a **Trivia Night**. This is a first for us and we have managed to bring the Rotary Club of Acacia Ridge on board to help with planning and hosting the event. Details are sketchy at present however we aim to hold the event in June or July. I ask that you keep this information in mind and if you have an interest in participating, please contact Lisa or myself for full details. You may know of people who form teams and follow Trivia Nights around town – if you do we would like to know about them.

Rotary Club of Acacia Ridge: In addition to the support offered for the Trivia Night, the Club has once again invited the Association to participate in their current raffle. You will find details regarding tickets in the fundraising section of the Newsletter. Please assist if you are able by selling tickets.

Recently we have received from the Rotary Club a donation of \$2200.00 to support the funding of Cate Barrett, Speech Pathologist at the HD Clinic, Royal Brisbane Hospital. Their generosity benefits families across the State as patients from both Brisbane and regional areas regularly attend the clinic.

There is no doubt that the ongoing support of the Rotary Club is an acknowledgement of their faith in the Association to spend their money wisely and to ensure families benefit directly as a result of their generosity. To the members of the Rotary Club, we acknowledge and thank you for the wonderful difference you have made to the Huntington's community.

Sale of Cadbury Chocolates in Workplace: A company in Brisbane is participating in a profitable fundraiser for the Association. For this to be successful the main ingredients are access to a large number of people (more so employees than customers) and a reliable person responsible for the collection of money, and this is extremely important. This fundraiser is not one we would promote widely without close monitoring. You may have some ideas to put forward to us for consideration.

Assistance through your membership, donations, fundraising and volunteering is indeed appreciated. We are very reliant on your generosity and that of supporters in the general community; without it we simply could not maintain our services to the current level that families enjoy. Kind regards,

Barbara Gray

Operations Manager

Diary Dates:

May	12-15	Regional trip to Townsville
	14	Brisbane Carers Group
	18-22	Regional trip to Rockhampton/Mackay
	21	Mackay Family Support Group
June	1	South Coast Family Support Group
	22	Toowoomba Family Support Group
	24	Brisbane Carers Group
	29	School Holiday Activity

Hurry Up and Wait!

By James Pollard

A chapter of James' book *Hurry Up and Wait* featured in our February newsletter. Due to the popularity of this article, the Association has received a great response from our readers to source this book on their behalf. At present, the book can only be purchased 'online'. If anyone is requiring assistance to purchase this book, please contact Lisa at the HD office.

Our Staff Putting faces to names

Julie Morrow



Christine Parfitt



Theressa Byrne



Barbara Gray



Lisa Gordon



Helen Johnston



OCCUPATIONAL THERAPY IN EARLY-STAGE HD

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

Incoordination 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

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

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

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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.

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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.

Pensioner Grocery Vouchers

Australians have been moved by recent pensioner struggles. Due to donations from ordinary Australians, CPSA (Combined Pensioners & Superannuants Association of NSW Inc) provides one off grocery vouchers to pensioners across Australia.

To access the one off grocery voucher write to:

**CPSA, Level 9, 28 Foveaux St,
Surry Hills, NSW 2010.**

Please provide Name, address and telephone number, as well as photocopy of the front of your Pension Card. You also need to advise CPSA which supermarket chains are in your local area so that an appropriate card can be sent to you.

Enquiries call 1800 451 488 or go to www.cpsa.org.au



New Companion Card

The Companion Card program promotes fair ticketing for people with a disability who need the care of a companion to attend activities and venues. Cardholders present their card at participating businesses, pay for their ticket and are issued with a second ‘companion’ ticket at no charge. The card will be available to eligible people with a disability. For details about the program visit www.disability.qld.gov.au or alternatively, Smart Service Queensland can mail you a cardholder application form and handbook. Contact them by telephoning 13 13 04 during business hours or by emailing cardservices@smartservice.qld.gov.au.



RESEARCH

Weight loss in Huntington disease increases with higher CAG repeat number.

N.Ahmad Aziz et al., Neurology (2008). 71:1506-1513

Reprinted from European Huntington's Disease Network, March 2009, Issue 05

This study shows that the rate of weight loss in Huntington's disease is directly proportional to the length of the CAG repeat in the HD gene, and is likely to result from a hypermetabolic state.

Background

Huntington's Disease (HD) is a genetic neurodegenerative disorder caused by the expansion of the CAG repeat in the HD gene. It is characterized by a clinical triad of motor, behavioural and cognitive disturbances. Weight loss is also a hallmark of HD, and has been observed both in humans and HD transgenic mice. Interestingly, in HD, a lower body mass index (BMI) has been associated with a higher rate of disease progression.

The cause of weight loss has been attributed to the following:

- Difficulties with swallowing that might lead to a decreased intake of calories. Note however that weight loss is already seen in pre-manifest HD individuals, and previous studies have shown that, at early stages, caloric intake is increased both in HD patients and HD transgenic mice.
- Increased motor activity caused by chorea (involuntary movements) that might lead to higher energy expenditure. However, the severity of choreic symptoms does not correlate with weight loss.
- An increased metabolic rate. Mutant Huntingtin (Htt) has been shown to perturb a number of molecular and cellular systems that could impact on energy homeostasis. This effect could vary with the length of the polyglutamine tract in mutant Htt.

Methods

The aims of this study were:

- To investigate weight loss in early stage HD over three years
- To assess whether there is a correlation between weight loss and clinical symptoms
- To determine whether CAG repeat length is directly related to the rate of weight loss and caloric intake.

Participants (517 early stage HD patients) were recruited from the European Huntington's Disease Initiative, a phase III interventional clinical trial. Riluzole, the drug tested in this trial, does not affect body weight. Patients taking neuroleptic drugs were excluded. Clinical symptoms were assessed with the Unified Huntington's

Disease Rating Scale (UHDRS) subscales for motor, behavioural, cognition and functional capacity. Data analysis was performed using linear mixed-effects models. The relationship between CAG repeat length, body weight and caloric intake was also studied in the R6/2 mouse model of HD.

Results

In HD patients, BMI significantly decreased by 0.15 units per year on average (normal BMI lies between 18–25). The rate of weight loss was greater in patients with a longer CAG repeat (see figure), although none of the symptoms assessed by the UHDRS correlated with weight loss. A correlation between weight loss and CAG repeat length was also observed in HD mice, despite the fact that mice with longer CAG repeats had increased caloric intake.

Conclusion

Weight loss in HD is directly correlated to CAG repeat length and likely to result from a hypermetabolic state. This correlation suggests that mutant Htt interferes directly with cellular energy homeostasis. Hypothalamic pathology, changes in the innate immune response and mitochondrial disturbances have all been described in HD, and could contribute to this process.



The Australian Government has announced a package called Making Ends Meet – Federal Labor’s Plan for Older Australians, People with Disabilities and Carers.

Eligible Single Customers will receive a Telephone and Internet allowance of \$33 every 3 months and \$16.50 for each couple. Contact Centrelink for more information.

FUNDRAISING

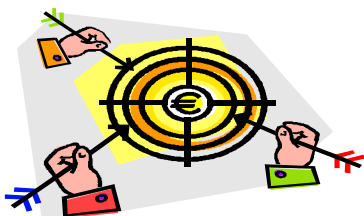
Community Assistance – We have received, and gratefully acknowledge major financial assistance from the follow donors:

H. Baker
D. Battaglone
A.R.V Canteen
W. Edwards
E. Fogarty
J.C. Flitcroft
K. Horton
GE Money
H.A. Murray
Dr. J. Lawrence
K. McCormick
G.R. Phillips
Rotary Club of Acacia Ridge
J. and C. Stride
Tilleydale Dawn Breakers Social Golf Club
M. Turner
M. White
F. and J. Williams

MAJOR FUNDRAISING EVENT

Lisa Gordon (Administration Officer with the Association) will be cycling throughout the Toowoomba region in September this year for 9 days raising money for the Association.

We are aiming high and have set a target of \$20,000.



The Rotary Club of Acacia Ridge is holding a raffle during May and June. The prize is a 6' x 4' trailer including home and gardening equipment valued at \$3,600. Tickets are \$2.00 each and for each raffle ticket sold \$1.00 will be donated to the Association. Tickets are available at the HD Centre.

The raffle will be drawn on Tuesday, 23rd June, 2009.

WORKPLACE GIVING

Thankyou

Minter Ellison for holding a charity morning tea and raising \$1,000 for the HD Association.

Thankyou

Bunnings Rocklea for supporting the Association by way of a sausage sizzle on the 28th March, approx \$1,000 was raised on the day.

VOLUNTEERS NEEDED!

**Sausage Sizzle Bunnings Rocklea
Sunday, 14th June**

Please contact Lisa at the HD Centre if you are able to assist us to raise money

*Thanking you in advance
for your support*

**Australian Huntington's
Disease Association (Qld) Inc.**

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Annerley, Q. 4103

All Correspondence to

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Australian Huntington's Disease Association (Qld) Inc. is a not-for-profit service organisation established in 1976.

Our Mission is:

To provide professional support and advocacy for all persons affected by Huntington's Disease in Queensland.

Our Services include:

- Providing individual and family support
- Facilitating the HD Day Respite Program
- Facilitating support group meetings
- Recreational activities for families with young children
- Organising respite holidays
- Providing information to families and health professionals
- Distributing a regular Newsletter
- Co-ordinating the annual National Huntington's Disease Awareness Week
- Fundraising activities

Management Committee 2008/09

President	Gerry Doyle
Vice President	Ray Bellert
Secretary	Denis Kelly
Treasurer	Cliff Farmer
Members	Pam Cummings Jan Szlapak Lisa McGuinness

Staff

Operations Manager	Barbara Gray
Senior Welfare Officer	Julie Morrow
Welfare Officer	Christine Parfitt
Welfare Officer	Theresa Byrne
Administration Officer	Lisa Gordon
Telemarketing Officer	Helen Johnston

Contributions

The Next issue of the Association's Newsletter will be published in July 2009. The deadline for material to be included in this issue will be mid June. Please send any contributions to:
Australian Huntington's Disease Association, PO Box 635, Annerley, Q. 4103.

All contributions are appreciated but may not be used due to space and suitability. Please note, articles published in the Association's Newsletter may be selected for reproduction on our Website or used in other Newsletters.