



NEWSLETTER

AUSTRALIAN HUNTINGTON'S DISEASE ASSOCIATION (QLD) INC.

July 2009

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From the President

With the completion of another financial year at the end of June, the Association will be holding its Annual General Meeting on 30th September 2009 at Florence Dannel House. I am pleased to advise that our guest speaker for the night will be Professor Nellie Georgiou-Karistianis and she will be presenting a talk on the Image-HD study that she is conducting in Melbourne. A number of families from Queensland have participated in this study so it should be of great interest to us all.

I would also seek your support in either you or your friends to nominate to become members of our Management Committee. Our Committee meets once per month so it is not an onerous imposition. There is no set number of positions for the Committee however we are currently very short on numbers. Please give this some consideration.

The Tasmanian Society held a one day seminar and dinner to celebrate their establishment 30 years ago and I attended on behalf of the Association. Both the seminar and dinner were well attended and Jimmy Pollard from the USA gave his excellent presentation on Caring for those affected by Huntington's Disease.

Queensland has a Reference Group for Young People in Residential Care and in February I was invited to become a member of this Group. Meetings are held four times per year. The question of "appropriate" accommodation for those affected by Huntington's Disease has been one of our most important challenges for many years. The funds and resources available are not sufficient to meet the required needs however it is most important that we participate in this challenging subject for the betterment of our HD families.

Many of you will use the web or Internet to keep up to date on HD research, treatments and other related matters. Michelle O'Brien has established and is the moderator of an Internet forum for Australia. Michelle is currently looking to establish a web resource targeted at young people. I would encourage anyone interested in this to contact Michelle with your thoughts, ideas and comments. The website is www.hdaustralia.org/.

Gerry Doyle, President

Cycle Queensland's Bicycle Challenge: By the time of our next Newsletter, Lisa will be either cycling around the Downs or have completed the bicycle challenge raising funds for the Association. To date donations of \$6,000.00 have come in and this amount has been boosted by \$1400.00 representing proceeds from the recent Trivia Night. The Rotary Club of Acacia Ridge provided support and numbers for the Trivia Night and I would especially like to thank Bob James from Rotary and his offsiders, Terry Gallagher and Gary Van-ooy for their wonderful contribution.

It is not too late to donate. If you have misplaced your form, simply pop your donation and name and contact details in an envelope and send to the HD Office. We will provide you with your taxation receipt.

Community Fundraising: Recently the Association has participated in sausage sizzles at Bunnings Rocklea and also in Maroochydore. Thank you to our Brisbane volunteers who gave their time and energy, resulting in a successful outcome. Several of our "old hands" rolled up their sleeves, with newcomers Anita, Gary and Mark being made very welcome. In Maroochydore, for the first couple of hours Meredith and Ken again provided great support until volunteers Bob, Marty and Neil of the South Burnett Masonic Lodge drove into town amid claims of taking the wrong turn (all Marty's fault). Spirits were not dampened by the drizzling rain – we all enjoyed a fun day.

Gambling Community Benefit Fund: I am pleased to advise the Association has received a grant from the Benefit Fund of \$8577.00 for the changeover price of a new vehicle. A new vehicle will be purchased before the end of the year. Servicing and maintenance is routinely carried out on both Association vehicles resulting in a trade-in value that is commensurate with current trends and also ensuring Welfare staff have reliable vehicles for the delivery of support services to families. **The goodwill and support of the Gambling Community Benefit Fund is very much appreciated.**

Membership: At present the Management Committee is formulating a budget for the financial year 2009-2010 and membership fees that form an important part of our budget, are under review. In addition we are reviewing our invoicing system for membership. A renewal form and an invoice will be mailed to you when these changes have been approved – this will be in the next 3 months.

National Conference Questionnaire: Enclosed with our last Newsletter was a questionnaire seeking input from our membership regarding the program for the Conference. There has been a limited response and so that we are truly representative of our membership we would like to hear from more of you. If you have misplaced your questionnaire, please ring Lisa at the HD Centre for a replacement.

Kind regards

Barbara Gray

Welfare Update

It has been six months since Theresa joined Christine and I in her part-time role as Welfare Officer. I feel we have been able to consolidate as a team and provide a more consistent service to families with these extra welfare hours. We have had time to complete the transition of regions over to Theresa and appreciate the willingness of families to adjust to these new arrangements.

Regional visits remain an important part of our welfare calendar and we share our Management Committee's goal of ensuring an equitable delivery of our service between regional and non-regional families. In most aspects of our core work, including home visits, nursing home visits, in-services, meeting with service providers and family support group gatherings, we feel we have been able to achieve similar levels of service provision. However, in regional areas, we would like to focus on enhancing respite options, carer support and individual support for people without a carer. We welcome comments or ideas from regional families on improving our service.

Carers Group

Our Brisbane Carers' group continues to meet every 6-8 weeks and we recently organised to meet at Mayes Cottage which is a house museum in Kingston built in the late 1800s by the original early settlers. It was a lovely winter morning and a very peaceful spot to bring carers together and consider the lives of those in a bygone era.

Earlier this year, participants in the carers' group made several suggestions that we have been able to follow up on. Here's an update:

- We are now listed in the Advice and Assistance section at the front of the Brisbane White Pages, under the heading of Disability and aged services. This is in addition to our current listings in the Business and Government section of the White Pages and a Yellow Pages listing under Community Organisations-Family Welfare in Brisbane and regional telephone books.
- We are finalising the 'mini guide handout' explaining HD and will be getting quotes for printing. These will be distributed to interested carers when available.
- We have discussed the idea of a HD helpline for after hours support for families with our national body. All states were interested and agreed to survey families nationally for further consultation. Carers should receive this survey within the next 2-3 weeks.
- I am currently looking into organising professionals to facilitate sessions on managing emotions and laughing therapy.

School Holiday Activity

Thanks to all the families who were able to join us for a day at Queens Park in Ipswich on 30 June. It's always a pleasure to spend time with the young people in the families we support.

Our next day out will be on 19 October (pupil free day). We'll send information about this activity closer to the date.

Younger Persons In Residential Aged Care Update (YPIRAC)

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As at May of this year, Disability Service Queensland (DSQ) have funded a total of 77 younger people with high care needs throughout Queensland under the five year YPIRAC initiative (of these, a small number of people with HD have received funding).

The final model of support to be implemented under the initiative is the 'Enhancing Support in Aged Care' model. Service providers in many regions are expected to receive funding in July 09 and will commence working with clients as soon as possible following a short service establishment phase. A minimum of a further 56 people will receive assistance through this model across Queensland.

Ongoing YPIRAC assessments will continue throughout Queensland as needed. They will also continue to monitor and contact people under 50 years who enter aged care. The Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) have confirmed a Commonwealth commitment to continue funding people in receipt of YPIRAC funding after the five year period (ending 30 June 2011).

Although the primary focus of the initiative is people under 50 years of age, people under 65 living in an aged care facility are eligible under the initiative and we would encourage families to consider registering an expression of interest with Disability Services Queensland. (Contact us if you would like a registration form sent to you or contact YPIRAC on 3235.9677)

Upcoming dates

August

- 3 South Coast Family Support Group
- 3 Brisbane Carers' Support Group
- 6-7 Regional visit to Burnett
- 12 Office closed for Brisbane Show Day
- 17-20 Regional visit to Cairns
- 20-21 Over night respite holiday

September

- 5 Toowoomba Family Support Group & send-off for Lisa on her fundraising bike ride **(TBC)**
- 7-11 HD Awareness Week
- 16-18 Regional visit to Fraser Coast
- 17-18 Regional visit to Bundaberg
- 30 AGM
- 24 Brisbane Carer's Support Group

Julie Morrow

GETTING HELP FOR INCONTINENCE

Bladder or bowel control problems are a big issue for many at-home carers. Managing incontinence adds more time to the burden of their caring role. Further, it also impacts on the emotional and physical health of the caregiver.

Colin Cassells of the Continence Foundation of Australia says carers dealing with this significant health issue are more likely to feel weary and lack energy and are more likely to feel worried and depressed.

“For both the carer and the cared-for person, it’s important to be aware of any of the following symptoms and seek help from a continence nurse advisor or your doctor” Colin said.

“If you notice any of the following symptoms such as accidental leakage from bladder (urinary incontinence), bowel leakage (faecal incontinence or ‘soiling’), needing to get to the toilet quickly (urgency), always needing to be close to a toilet (frequency), feeling of incomplete emptying of bladder or bowel or constipation or diarrhoea, you should seek assistance.”

Talk to a Continence Nurse Advisor on the **National Continence Helpline (1800 33 00 66)** – they have information about management and treatment options, referrals to local continence services, eligibility for funding assistance for the purchase of continence products, available products and where to get these, plus a wide range of printed materials.

www.continence.org.au (the Continence Foundation of Australia’s website)

www.bladderbowel.gov.au (the website of the Australian Government)

Kindly reprinted from Qld Carers Australia, May 2009 Newsletter

CARERS HEALTH & WELLBEING CONFERENCE

Are you a carer for someone who is frail with age, has dementia or a disability?

Today...it's all about you!

- Find out more about how to look after yourself
- Hear from dynamic speakers on a range of health and wellbeing topics
- Visit informative displays, have a massage and connect with other carers
 - Celebrate the important role of carers in our communities

Thursday 23rd July, 2009

Brisbane Convention and Exhibition Centre - Southbank

For more information or to register, please Freecall™ 1800 052 222*

*Calls from mobile phones are charged at applicable rates.

AUSTRALIAN RED CROSS

Telecross

A free reassuring daily phone call for people living alone.



About Telecross

With a large number of older people living on their own, Red Cross is helping older Australians remain connected with their community and live independently in their own homes.

Telecross is a community program which provides a free reassuring daily phone call to people living alone to confirm they are safe and well. The service runs 365 days a year throughout Australia and has been successfully operating for over 20 years.

Every day thousands of people who live alone are contacted by trained Red Cross Volunteers.

Although it is mostly older people who use our Telecross service, people with disabilities or younger clients who are medically dependent may also be eligible. Telecross may also be arranged for people who need temporary assistance during a period of rehabilitation or when a primary carer is absent.

Receiving a free daily phone call

If you would like to receive a daily phone call, it's just a matter of going through the following steps:

Make an enquiry

By calling the Queensland office on 1300 885 698 or Emailing qldagedcare@redcross.org.au

Arrange a home visit and assessment

Red Cross will contact you to:

- Arrange a time to telephone you at home
- Gather information to complete your application and
- Provide information about the service and how the program operates.

Red Cross will then assess your application to see if you are eligible.

Start receiving your daily calls

After your application is approved you will start receiving your morning calls from a Red Cross volunteer.

NEW EMAIL ADDRESSES FOR THE ASSOCIATION

Welfare: welfare@huntingtonsqld.com

Administration: admin@huntingtonsqld.com

These are effective immediately!!

Huntington's WA, in collaboration with Edith Cowan University, is submitting ; Page 6
application to Lottery West for funding for a research project.

The title of this project is:

“The effects of environmental enrichment on clinical measures of disease progression and quality of life for patients with Huntington disease.”

Summary of the project

The researchers are Prof Mel Ziman (ECU) Dr Carmela Connor (Neurosciences Health Dept WA) Prof Anthony Hannan (Univ of Melbourne), Dr Roger Barker (Neurologist Cambridge), Dr Joseph Lee (Psychiatrist, Neurosciences UWA) Dr Stanley Lazic (Biostatistician Cambridge), and Prof Robert Newton (Exercise Physiologist ECU)

This collaborative investigation seeks to provide and assess the effects of environmental enrichment on outcomes for people with Huntington's disease. This therapeutic intervention will be in addition to ongoing clinical services provided for people diagnosed with this condition. Specifically, we will assess cognitive function, brain volume, balance, body composition (bone mineral density/fat/muscle composition) and urinary glucose concentration to ascertain the holistic benefits of environmental enrichment on patients with Huntington's disease.

The proof-of-concept investigation proposed in this application will extend promising laboratory results determined in mouse models of Huntington's disease, to human patients and will be, as far as we know, the first of its kind globally. There is strong anecdotal evidence from Huntington's disease patients in Canada, that a combination of exercise and mental stimulation reduces the symptoms of Huntington's disease, allowing patients to remain active and functional within the community for longer periods (www.huntingtonsociety.ca/english/index.asp). The investigation proposed here will determine whether a collaborative, multidisciplinary approach utilising tailored exercise regimes and occupational therapy tasks with ongoing neurological management will ameliorate symptoms in patients. It is likely that the outcome of this assessment will assist patients with symptom management thereby improving quality of life for patients worldwide.

It is also anticipated that physical activity may play a role in normalising or delaying the progression of some of the physiological imbalances (such as muscle changes, reduced bone density and insulin resistance noted in patients with Huntington's disease) as physical exercise has been shown historically to provide positive outcomes for the above conditions in normal individuals (18-21). Measurements will therefore be taken to assess changes in neurological status, brain volume, balance, body composition and urinary glucose levels.

Whilst the intervention proposed in this study does not attempt to provide a cure for Huntington's disease, the underlying tenet of this research is TO IMPROVE THE QUALITY OF LIFE FOR PEOPLE LIVING WITH HUNTINGTON'S DISEASE, and to offer this assistance as expeditiously as possible. It is also anticipated that impeding the progression of the disease, thereby preserving as much normal

functionality as possible, will increase the likelihood of positive outcomes for individuals with respect to future therapeutic treatments.

It is anticipated that amelioration of symptoms for patients with Huntington's disease will benefit the local community financially due to decreased requirement for specialised hospitalisation and treatment. Significantly, it is envisaged that a positive outcome will play a significant role in establishing clinical guidelines for patients with Huntington's disease on a global scale. Furthermore, it is likely that the results of this intervention regime will be applicable to other community groups with neurodegenerative disorders, such as Parkinson's and Alzheimer's diseases

A demonstration of delayed disease progression in symptomatic human patients will strengthen the theory that environmental enrichment may effectively DELAY THE ONSET OF HUNTINGTON'S DISEASE in human patients, as has been revealed in mutant mouse models (11-12).

Queenslanders with Chronic Disease Face Ongoing Patient Transport Problems

Queenslanders for Patient Transport is an alliance of groups/organisations which have identified a major issue in Patient Transport in Queensland.

Many Queenslanders with chronic disease and needing transport to medical treatment do not have access to transport that is:

- Delivered in a timely manner
- Affordable
- Appropriate to the person in need
- Of a satisfactory standard

Dialysis patients can wait up to 5 hours for the ambulance service to take them home after a 5 hour dialysis session.

Chemotherapy patients most commonly require 2-6 hours one day per week in hospital. Their repressed immune systems put them at risk in group settings.

For a comprehensive account of Patient Transport issues, or to find out how to take action, go to www.tdsa.org.au and follow the link to Queenslanders for Patient Transport or contact:

Jennifer Leigh Ph: 07 3849 4193 or Email jenny.leigh@aapt.net.au

HealthInsite

HealthInsite (www.healthinsite.gov.au) is the Australian Government website that links you to hundreds of reputable health information websites providing information about medicines, medical conditions and staying healthy.

Detection of Huntington's disease decades before diagnoses: the Predict-HD study

Jane S. Paulsen et al., *J Neurol. Neurosurg. Psychiatry* (2008), 79:874–880

This study shows that small changes in clinical and neuroimaging parameters are detectable long before the predicted onset of Huntington's disease, and proposes a model establishing the relationship between different clinical outcomes and estimated age at diagnosis.

Background

Predict-HD is an international, multi-site, observational study aimed at identifying predictors of Huntington's disease (HD) onset in asymptomatic gene carriers. Given that the CAG repeat length determines only 50–70% of the variation in age of onset, there must be other modifying factors that influence the onset and progression of HD. Predict-HD investigates the nature and pattern of neurobiological and neurobehavioural changes (including cognition, emotion regulation, brain structure and function) that might occur prior to clinical diagnosis of HD. The study objectives are to identify 'state' markers of disease onset and early disease progression, and to develop sensitive tools both to track these changes and to detect putative modifiers of age of onset.

Methods

438 asymptomatic HD gene carriers were examined. Estimated time to clinical diagnosis was calculated based on the individual's CAG repeat length and current age. The features of HD that were assessed included striatal volume changes (using MRI¹), motor ability (using UHDRS² and finger topping tests), cognitive performance and odour recognition. The outcomes were used to develop a model aiming to examine the relationship between estimated time until clinical diagnosis and motor, cognitive, psychiatric and brain volumetric measures. The patients in the study had a mean estimated time to diagnosis of 13.9 years.

Results

Small changes in clinical outcomes were detectable 15–20 years prior to diagnosis. Estimated time to diagnosis was related to most of the clinical and neuroimaging markers. For all variables, the relationship was consistently non-linear, with the rate

of decline increasing exponentially as the predicted time of symptom onset approaches (see figure for examples).

Conclusion

The relationships between estimated years to diagnosis and motor scores, striatal volume, odour retention and cognitive measures were strikingly consistent. Understanding the initial steps in Hd pathogenesis could facilitate early clinical diagnosis, and improve trials of candidate drugs aimed at delaying disease onset or slowing the rate of disease progression. The authors propose a time scale model of disease onset and suggest candidate markers for use in therapeutic trials. The functional significance of these findings requires validation. This will be attempted with a Predict-HD longitudinal follow-up study.

¹ Magnetic Resonance Imaging

²United Huntington's Disease Rating Scale

FUNDRAISING

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

N.A. & P. Barnes

J. & G. Clerke

G. Dee

T. Doyle

C. & J. Farmer

R.F & J. Farmer

C. Gordon

A.A. Harding Smith

J. Hartkopf

L. Humphreys

J.W. Bell – J.W. Bell & Associates Pty Ltd

Dr J. Lawrence

B. Littlemore

B. Malone – Malones Business Advisors

C.T. Murray

J. O’Connell

M.G. O’Neill

J.D. & G.A. Philp

D.E. Pratten

E.M. Rasche

N. Robertson

R. Russell

R. Sivell

Townsville Support Group

J. Wagstaff – Wagstaff Piling Pty Ltd

J. Wallace

H. Wilson

THANK YOU

***Lions Club of Brisbane-Bunya Inc
for supporting the Association
by way of donation of \$500.00.***

Congratulations!

G. Michie of Petrie

Winner of The Rotary Club of Acacia Ridge raffle’s 6’ x 4’ trailer including home and gardening equipment valued at \$3,600.

Thankyou

Bunnings Maroochydore for supporting the Association by way of sausage sizzle on the 20th June, approx \$1,000 was raised on the day.

Thanks

Hedy and Pat Keogh and the Ipswich Multicultural Projects for raising \$272.00 for the HD Association at the recent Aladdin’s Bazaar held in Ipswich.

Left to right: Hedy Keogh, Mayor Paul Pisasale and Pat Keogh



THANK YOU

Bunnings Rocklea for supporting the Association by way of a sausage sizzle on the 14th June approx \$1,000 was raised on the day.

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

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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 September 2009. The deadline for material to be included in this issue will be mid August. 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.