



NEWSLETTER

AUSTRALIAN HUNTINGTON'S DISEASE ASSOCIATION
(QLD) INC.

February 2009

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From the President

I am pleased to report to you that for the first six months of the Financial Year the Association has achieved a good financial position with a small overall loss. Throughout 2009 the financial crisis facing us all will be a challenge and although as yet we have not seen a decline in donations and telemarketing revenues, we consider this may happen. How can you all help? Firstly we welcome any suggestions as to fundraising ideas. If you have any suggestions please let Barb know. Secondly we need more members so if you have friends or relatives that are not members please let them know what the Association does and how to become a member.

One other way you can help the Association is by becoming a member of the Management Committee. We are looking for some new faces. If you have the time and interest please let either Barb or myself know.

Membership: Please don't forget to renew your membership. If you are unsure whether your fees are current, please contact Lisa at the HD Centre to check.

Gerry Doyle, President

Thinking of different fundraising opportunities can be daunting and to then put the idea into action, making sure expenses are not too limiting and the outcome is financially rewarding can be quite challenging. We are forever on the lookout for new opportunities that we are able to promote within our staffing resources.

Cycle Queensland's Bicycle Challenge: In my musings last year on the subject of fundraising, and chatting to a friend who raised funds for "his charity" by riding a bike from Bundaberg to Brisbane with Cycle Queensland, I thought "we can do this". More to the point I thought "Lisa can do this" and I will support, supervise and encourage! Without hesitation or coercing Lisa agreed.

We have been discussing how the Association could best use the funds raised. From past articles you will know that we are active in pursuing funding opportunities, however most of these do not cover the cost of wages and travel expenses. Currently we receive funding from Queensland Health that covers the majority of direct costs for the 2 full time Welfare staff members, however there is every indication that we will not attract any funding from the Government for the additional 16 hours per week allocated to the Welfare Service in the part-time employment of Theresa Byrne. The Association therefore needs to explore possibilities that will assist in covering the additional costs.

We feel that our families and supporters would feel comfortable knowing their donations would support the Welfare Service and that in the long term it meant the Association can maintain the existing level of support to families in the challenging times ahead.

The enclosed flyer gives details of the ride and provides a tear off section for donations. On the back of the flyer is room for you to include details of other people who have donated - if requested receipts will be issued to individuals.

We have set ourselves a target of \$20,000.00. We are aiming high! I encourage you to support Lisa in her efforts to raise funds for the Association. Please consider asking your family, friends or perhaps your workplace to come on board for the ride by sponsoring Lisa by way of donations or distance travelled. We are seeking company sponsorship but in the main will be relying heavily on our membership to get behind this initiative.

You will be able to follow our progress either through the web page or in upcoming Newsletters.

Barbara Gray, Operations Manager

Thank you

Abigroup Contractors Pty Ltd

For the cost of the entrance fee to enable Lisa's participation in the Cycle Queensland Bicycle Challenge.

We appreciate and value the generosity of Abigroup Contractors Pty Ltd.

WELFARE UPDATE

Family Holiday

In December, we held our second Family Holiday at Maroochydore on the Sunshine Coast. Five families joined us for a three day break, including 6 parents and 13 children from Brisbane and regional Queensland. The aim of the holiday is to bring families with young children together to have a fun and relaxing break and we were fortunate to secure enough funding to provide this holiday cost free to families.

It was a pleasure to see these children get along and create their own fun as they got to know each other or renewed their friendship. There was lots of swimming, running in and out of bedrooms, music, singing, eating, movies, swimming and more swimming. A modified version of 'So Young Think You Dance' led to an outstanding performance by the mums to Michael Jackson's 'Don't Blame it On The Sunshine' (you know the one). However, this was eclipsed by the more modern and sophisticated choreography performed by our younger participants. (I remember being that flexible!).

Our final day was spent at Aussie World which had a range of rides and attractions including dodgems, octopus, voyager simulator and the ferris wheel to name a few.

This was also an opportunity for parents to relax, chat and have a break from the daily chore of cooking. I would like to thank Lloyd, Rayleen and staff from the Maroochydore Coast House who were once again very friendly and accommodating hosts as well as cooking great meals.

School Holiday Outing

In conjunction with Carers Queensland, we also held another activity day for young people at the Victoria Park Golfing Complex putt putt course. Despite a sudden spike in temperature and humidity, like true athletes, we faced the challenge and completed the course. Our putt putters included 8 young people (boys and girls) ranging from 7-16 years.

We plan to hold an outing day during each school holiday. Our next day out will be ten pin bowling, followed by a BBQ on the 17th of April. Please let us know if your children are interested in joining in so we can send you an invitation closer to the date with full details of the day. (Current participants are already on our mailing list and will be sent invitations).

Parents are welcome to attend if they feel their child will be more comfortable. Where possible, we try to transport participants to and from the activity, however, this will depend of the number of children attending and where they live. All staff members have a current Positive Notice blue card required for Child Related Employment, issued by the Commission for Children and Young People and Child Guardian.

Disability Services Queensland (DSQ) Registration

We recently sent letters to eligible families about registering with Disability Services Queensland. DSQ is a state government body that can assess unmet support needs and allocate funding packages for people with a disability under the age of 65 years. Completing a registration flags DSQ to the possibility of future support needs. Please let us know if you would like any assistance in completing these forms or would like further information.

Welfare Team

In January, we welcomed Theresa Byrne to our welfare team. Theresa has started visiting families in the Brisbane east areas and hopes to meet families in the Burnett and Bundaberg regions during February and March with Christine. Over time, families in these regions will receive more visits from Theresa, however, given the part-time capacity of her role, Christine and I will continue to be available, so please don't hesitate to contact us.

Julie Morrow, Senior Welfare Officer

Diary Dates:

- Feb** 27 – Burnett Family Support Group
- March** 9–12 – Regional visit to Cairns
- 17–20 – Regional visit to Bundaberg and Fraser Coast
- 23 – Brisbane Carers' Support Group
- 27 – Toowoomba Family Support Group
- April** 6 – South Coast Family Support Group
- 17 – School Holiday Activity – Ten Pin Bowling & BBQ
- 27 – Brisbane Carer's Support Group (TBC)

Theresa Byrne

Part Time Day Centre Assistant and Welfare Officer

Quite a number of you will already know me from my involvement in the Day Centre Program based at our Annerley centre. I have been part of the Day Centre team for the past 13 years, punctuated by time off to have my three girls and to complete my studies. My academic background includes a Bachelor of Arts degree and a Bachelor of Social Work and I also work part time with Alzheimer's Australia.

I am looking forward to extending my role to include community visits and meeting many more families over the next few months. Julie and Christine have already let me know what a wonderful, warm and welcoming community of people I can look forward to spending time with.

CARERS (RECOGNITION) ACT 2008 – Act No. 70 of 2008

The Queensland carers charter – Section 7

Because – the Parliament recognises that carers make a significant contribution to the people they care for and the economic and social wellbeing of the community, and that carers deserve recognition, respect and support for their role as carers; and helping carers is one of the best ways of helping someone they are caring for and the carers charter will help carers to be heard by government and their issues to be better understood in the community;

this Act establishes the following Queensland carers charter –

1. The State recognises the effort and dedication of carers in our community and that carers provide a vital service.
2. Carers deserve the respect of our community and should be supported within their community by all levels of government, institutions and organisations.
3. The views and needs of carers must be taken into account together with the views, needs and best interests of the people they care for when making policy decisions.
4. The importance of carers' work means the role of carers should be recognized by including carers, or their representative bodies, in the assessment, planning, delivery and review of services affecting carers.
5. Complaints made by carers in relation to services that impact on them must be given careful consideration.
6. Carers should be recognised –
 - a) for their unique knowledge and experience; and
 - b) as individuals with their own needs.
7. The relationship between a carer and the person they care for should be respected and honoured.
8. Children and young people who are carers should be specifically supported by all of our community.
9. The caring responsibilities of children and young people should be minimised.
10. Carers need access to a wide range of responsive and affordable services to support them and their decision making in their role as a carer.
11. Remote and rurally based carers face additional difficulties caused by isolation.

Reprinted from the *Carers (Recognition) Act 2008, Act No. 70 of 2008, The Queensland carers charter, section 7*. For further information regarding this Act, please refer to <http://www.legislation.qld.gov.au/LEGISLTN/ACTS/2008/08AC070.pdf>

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HURRY UP AND WAIT!

A Cognitive Care Companion

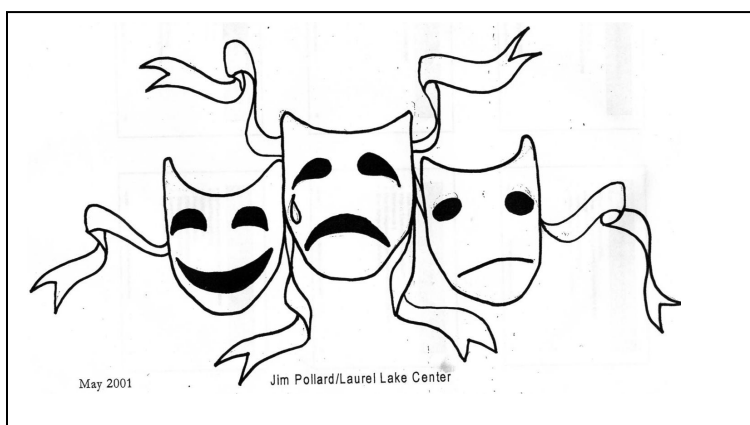
Huntington's Disease in the Middle and More Advanced Years

By Jimmy Pollard

*This chapter is from Jimmy Pollard's book *Hurry Up and Wait!* The HD Association has this book available for loan. Copies of the book can be ordered at <http://www.lulu.com/content/2517713>.*

Huntington's Disguise

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



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

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

they're feeling anything. It looks like the mask on the right. This mask is "Huntington's Disguise."

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

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

Can you tell when your family member began to have symptoms of Huntington's Disease by looking at family photographs? It may have been powerful evidence to you that the person you love dearly had, in fact, begun to develop HD. The appearance in the photograph that confirmed your suspicion is "Huntington's Disguise." It looks much like the mask on the right.

As HD progresses, "Huntington's Disguise" becomes increasingly apparent. However, as time goes by, the disguise can fool even those who know him most intimately: parents, children, husbands, wives, lovers, brothers, sisters and friends.

For those less familiar, it's even more difficult to see behind the disguise. Old friends may mistakenly think that their mate is disinterested, angry or lazy. Even worse, they may suspect that he no longer cares or understands what's going on around him. The disguise may lead them to sense that he is bored with their shared interests and mutual concerns. They may fear that the reciprocal warmth on which their relationship was based has disappeared. Sometimes his personality, manners and mood may be unrecognizable to them.

As HD progresses, old friends dwindle in number. Seeing through The Disguise to recognize your old friend is essential to sustaining friendship. If you are a potential new friend, then "first misimpressions may be lasting" and hinder the growth of the relationship. In care homes, staff needs to be taught The Disguise so that their relationship with the resident will be mutually rewarding.

Mental health professionals may refer to it as a "blunt" or "flat affect." Huntington's Disguise is a combination of the unique physical features of HD with its cognitive features.

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

Poor eye contact due to motor impersistence.

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

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

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

Loud, plosive speech when he greets you or answers your questions may suggest that he's angry or impatient with you. When you ask, "How are you?" he has difficulty modulating the force of his movement and coordinating his speech and breathing. He may appear to shout back, "GOOD!!!" Or perhaps, just the opposite...

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

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

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

"Motor impersistence" is a characteristic of HD's movement disorder. As it progresses, people may have difficulty maintaining contractions in their muscles. If it appears that

your friend with HD is not interested in speaking with you, these tiny contractions that convey attention may not “persist.” This prevents him using them to signal his interest in speaking with you. They may appear momentarily when he begins to listen, but they won’t “persist” for long. This, too, is an element of “The Disguise.”

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

Cognitive Elements of “Huntington’s Disguise”

No timely response to a greeting or compliment.

A delayed response to a question.

An impulsive “No!” to a suggestion.

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

He can’t wait when he asks you for help.

An apathetic “Whatever...” to a warm invitation.

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

From “Disguise” to “Huntington’s Delusions”

Sometimes the disguise fosters false beliefs about what someone is thinking or

feeling. A delusion is defined as a “false belief.” Such a false belief is a “Huntington’s Delusion.” There are many. Some are:

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

Perhaps the most common delusion comes from these elements:

- He has difficulty with balance.
- His speech is a bit slurred.

- He doesn't answer questions quickly.
- When he does answer a question he does it loudly. Perhaps with a short fuse.

It's an easy presumption that he's drunk! Several years ago the Huntington Soc Page 9
Canada had a public awareness campaign whose theme was "He's not drunk. He has HD." In fact, Dr. George Huntington described those in his care as "suffering from chorea to such an extent that they can hardly walk, and would be thought by a stranger to be intoxicated" in his 1872 article.

In November 1954 as an inpatient at Brooklyn State Hospital, Woody Guthrie wrote, "If it's not alcohol which has me, I wonder what it's going to be." And "I'm still glad I did fall heir to my chorea because it makes me stay dizzy and drunk all the time without guzzling down....or without paying my bartender one little blue cent."¹

His impaired balance and slow recovery, his delayed response to questions, his dysarthric speech, his short fuse and impulsive responses contribute to the misperception of intoxication. It's interesting to note, though, that you can reach that conclusion without the presence of involuntary movement. There is so much more to HD than the chorea!

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

Seeing Through the Disguise

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

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

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

Associations around the world have addressed the problem of Huntington's delusions with "I Have HD" cards. They are small cards that list a few of the symptoms of HD. For

¹ From *Born To Win* by Woody Guthrie published in 1967. ASIN # B000Q592U8.

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

Seeing through the disguise takes time and practice. For those unfamiliar with folks with HD, it's not an instant revelation. If you keep misperceiving interactions, simply say so. For example, "I'm sorry; I didn't think that you wanted to do that!" In *How to Win Friends and Influence People*,² one of Dale Carnegie's ways of "winning people to your way of thinking" is, "if you are wrong, admit it quickly and emphatically." This is a good time to do it!

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

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

² *How To Win Friends and Influence People* by Dale Carnegie. ISBN # 978-0671027032.

Iwasaki Foundation Ltd

A special place for special guests

Iwasaki Foundation Ltd offers a subsidised Holiday Scheme for people to partake in.

Total cost of Subsidised Holiday: \$275.00 per person twin share. This subsidy is for 3 meals per day and accommodation only. Transfers and tours are not included.

Arrival day will be on the Sunday from 1.30pm and departure time will be 10.00am the following Saturday. Seven (7) days, six (6) nights only.

The number of guests that the Foundation can subsidise is available for 15 only twin share rooms, therefore making a total of 30 guests per week. The Foundation will offer to twin share only and no single requests can be accepted.

For further information please contact: Iwasaki Foundation Ltd – PO Box 1005, Yeppoon, Qld, 4703 Phone: 07 4925 2487, Facsimilie: 07 4925 2488 Email: iwasaki.foundation@bigpond.com

Chronic Disease Dental Scheme

Some patients may be able to receive dental services under Medicare.

Medicare benefits will be available for most services, you will first need to meet certain eligibility criteria and be referred by your GP to a dentist. In some cases, your GP will be able to refer you directly to a dental prosthetist for denture work.

Which patients are eligible for dental services under Medicare?

To be eligible, you must have a chronic medical condition and complex care needs and your oral health must be impacting on, or likely to impact on, your general health.

A chronic medical condition is one that has been or is likely to be present for at least six months. It may include, but is not limited to, conditions such as asthma, cancer, cardiovascular illness, diabetes mellitus, arthritis, mental illness, musculoskeletal conditions and stroke.

Complex care needs means that you are receiving ongoing care from a multidisciplinary team, which includes your GP and at least two other health or care providers.

In practice, this means that you will need to be managed by your GP under certain care plans. For most people, this involves the preparation of a "GP Management Plan" and "Team Care Arrangements". For residents of aged care facilities, it involves the GP

contributing to a multidisciplinary care plan prepared for the resident by the facility.

You should talk to your GP about whether you are eligible for these plans. If you are eligible, your GP must complete the plans and bill you prior to you having your first dental service.

You may already have care plans in place. If so, you should talk to your GP about whether you are eligible for referral for dental services under these plans.

Once you have been referred by your GP to a dental practitioner, you should call Medicare Australia on 132 011 to check that the necessary GP care planning items have been claimed and paid before commencing dental treatment - even where your GP has signed a referral form. If the relevant items have not been claimed and recorded, Medicare Australia cannot pay benefits for dental services.

Information provided by the Department of Health and Ageing. Please visit www.health.gov.au/internet/main/publishing.nsf/Content/fact%20sheet_dental-patients

RESEARCH

The University of Queensland Australia

Research breakthrough targets genetic diseases



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

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

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

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

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

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

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

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

*Story printed on: January 21, 2009, 5.37pm. Story from UQ News Online:
<http://uq.edu.au/news/?article+17223>*



VOLUNTEERS NEEDED

IMAGE-HD

EXCITING NEW RESEARCH STUDY IN MELBOURNE



Monash University Associate Professor Nellie Georgiou-Karistianis is the principal investigator for the Image-HD Study. The focus of this study is the identification of reliable neurocognitive and neurobiological biomarkers in pre-clinical and early symptomatic Huntington's Disease (HD). We are looking for biomarkers that show promise as being sensitive indicators in not only detecting change early, but are reliable in tracking change with disease progression. Once such markers have been identified, we can promote them not only to large-scale multi-site studies, but also to pharmaceutical companies involved in clinical drug trials. We will be able to advise when treatment should begin and at no later than the time at which the markers become abnormal. Only via this method will we ensure that treatment efficacy in pre-diagnosis HD can be quantified as a change in the rate of progression of disease as identified by these markers. Although there are a number of current neuroimaging studies there is no other study world wide looking at brain structure, brain function and white matter changes all in the one study.

The IMAGE-HD project is currently funded for 2008 and 2009 by the Cure Huntington's Disease Initiative (CHDI) Foundation (New York, USA). We have now done fMRI scans on 50 participants, many of them from Queensland, but we still

need many more participants. We are looking for 20 more pre-symptomatic gene positive HD participants with no symptoms and an additional 20 symptomatic HD participants who have had symptoms for 5 years or less. The study closes on 31 May, 2009 so we URGENTLY need to recruit more people NOW.

This research requires three to four hours of your time at the Royal Children's Hospital in Melbourne: one hour in the scanner performing two cognitive tasks (rest breaks are provided), as well as time outside the scanner to practice the tasks and to perform various neuropsychological tasks. This project is open to anyone in Australia and we fund ALL travel expenses, including organising your flights and accommodation, parking, air port transfers, mileage and provide taxi vouchers. We will also pay you \$40 for your time.

If you would like to be a volunteer for this research, please call us NOW to register your interest so that there is enough time for us to plan your trip and make your bookings. Please call Ellen Frajman on 1800 830 127 or e-mail : registry.spppm@med.monash.edu.au.

We thank those of you who have already participated in this study and look forward to presenting you with our results later in the year! **Nellie Georgiou-Karistianis**

FUNDRAISING

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

C. Booker
I. and R. Craig
C. Dart
R.C. Eley
Dr. P. Fama
The Fletcher Family
Dr. M. Gattas
P. and S. Gordon
Patricia McLay
L.J. Norris
The Pegg Family
F. Price
B. Stabler
S. Stevenson

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, please see enclosed flyer for more information.



Planning for the Future

The Department of Families, Housing, Community Services and Indigenous Affairs has produced two booklets to assist families when planning for the future of their family member with disability:

➤ *Planning for the future: People with disability* (product number FaCSIA0427) provides families with general information about future planning for their family member/s with disability **and**

➤ *Special Disability Trusts: Getting things sorted* (product number FaCSIA0424) provides guidance to families who have decided to set-up a Special Disability Trust.

These booklets can be ordered by calling **1800 050 009** and quoting the product number. The Association has copies of these two publications available for loan from the library.

Thank you

Variety Queensland Inc.

**For generously donating a Lap
Top Computer to a young
family member.**

Thank you

Albany Dental and Sleep Centre

**For sponsoring a young family member
for free dental care through the program
called “Bright Smiles”.**

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

385 Ipswich Road

Annerley, Q. 4103

All Correspondence to

PO Box 635

Annerley, Q. 4103

Phone: (07) 3391 8833

Fax: (07) 3391 0443

Email: ahdaq@bigpond.com

Web: www.qahda.com

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

Staff

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

Contributions

The Next issue of the Association's Newsletter will be published in April 2009. The deadline for material to be included in this issue will be mid March. 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.