# NEWSLETTER

## HUNTINGTONS QUEENSLAND

**March 2010**

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## Dear Friends

I would like to extend a warm welcome to two new staff members. Lydia Hudson commenced work with us at the beginning of January to assist Theressa in the Day Respite Program on Tuesdays and will also be involved in the planning and evaluation of the program.

In early February Anne Stanfield joined the team as Administration Officer and will assist Helen and Barb with office duties and reception and the extra workload that has been created with the planning of the National Conference in September this year. Welcome to our team Anne and Lydia.

**Life Membership to Jean and Tom Paterson.** In December I travelled to Townsville to join the local Support Group for their Christmas luncheon and to acknowledge the tireless volunteering support of Tom and Jean Paterson who were the driving force behind the establishment of the first regional HD Support Group in Queensland. Congratulations Tom and Jean on your Life Membership and thank you all for making me so welcome.

**Community Self Care Funding Program, Queensland Health.** During this financial year, the Association has received a supplement to the existing funding received from Queensland Health. Funding for the period 2009-2010 has increased to $150,258, an increase of $16,142 over the previous financial year. The Association acknowledges and appreciates this increase in funding from Queensland Health that will assist in meeting the rising costs in our service delivery. Our current funding agreement with Queensland Health expires on 30th June 2010.

**National Conference – 9th & 10th September 2010.** Enclosed is a flyer promoting the Huntington's Disease National Conference to be held at the Queensland Brain Institute, University of Queensland. The facilities are ideal for our purposes and will provide participants an opportunity to view first hand, this world class research facility in Brisbane.

I encourage you to take advantage of this opportunity to attend and to have direct contact with national and international experts in the Huntington's field. The programme and registration form will be mailed to members and will also soon be posted on the HD National website www.huntingtonsaustralia.asn.au. For further information, please phone us on 07 3391 8833 or email us at admin@huntingtonsqld.com.

***Gerry Doyle, President***

**Note from Lydia**

I spent most of my younger life in Armidale, country NSW and developed my interest in healthcare through my parents who both work in social services. I had the opportunity to work in a dementia specific nursing care centre which was the starting point of my career in healthcare. After moving to Brisbane seven years ago, I continued to work in the field of dementia care both in residential and community care settings.

I have the privilege of caring for a person with Huntington's Disease and this has sparked my passion to further my education in neuro degenerative diseases. My role as Day Respite Assistant is most rewarding and I wish to thank families and staff at Huntingtons Queensland for welcoming me so warmly and look forward to meeting everyone.

**Note from Anne**

I'm delighted to be working part time on Tuesdays, Wednesdays & Thursdays as the Administration Officer. I look forward to making a contribution to this wonderful organisation and being of service to all the Huntingtons Queensland community. My thanks to Barb for her patience and kind assistance in getting me started.

## DIARY DATES

**March**

| | |
|---|---|
| 8-11 | Visit to Townsville |
| 15-18 | Visit to Fraser Coast region |
| 31 | Visit to Burnett region |

**April**

| | |
|---|---|
| 14 | Laughter Yoga Brisbane Carers' Support Group |
| 19 | South Coast Family Support Group |
| 19-20 | Visit to Bundaberg |

**May**

| | |
|---|---|
| 5 | Visit to Burnett region |
| 17-20 | Visit to Cairns |
| 27 | Brisbane Carers' Support Group |

## Laughter Yoga – all Carers welcome!

**10am Wednesday 14th April 2010**

Laughter yoga is a simple yet profound technique based on the philosophy of 'acting happiness'. It is a tremendously efficient way to unwind the negative effects of stress, it strengthens the immune system, releases 'feel good' hormones, helps control blood pressure and it is a powerful antidote for depression.

**All Carers are welcome – come along and enjoy the day!**

## TOWNSVILLE SUPPORT GROUP

Greetings from the North!

Happy New Year from a wet, wet Townsville; now it is hot and steamy, the price we pay for living in a place that is great most of the time. I hope you enjoyed Christmas and your year has started well. 2010, it is hard to believe we are here, time moves so fast.

Last year was a quiet one for us in the North but some times it feel like nothing happens and then came the end of the year, we planned our Christmas gathering and Gerry Doyle came to town. Now some of you may think he came just for the party but no, there was more to it than that. He came to honour two of our members Jean and Tom Paterson, who for so long have given of their time to listen, support, raise money for HD and help the wider community better understand Huntington's. They have spent years doing what they do so well and I am sure that initially they didn't think they would be here for so long.

They accepted Life Memberships from Gerry and had no idea they were getting them till he started talking at the morning tea. I don't know how we kept it from them but we did, good going guys! Both Jean and Tom expressed they had not done all they have over the years for this recognition but were touched it had happened. I can only talk from the time I have known them and I know if I need help I only have to call them and they will work out their lives to fit in what ever needs to be done. Thanks guys, it makes my life easy knowing you are there to call on. And a big THANK YOU from all the families in the Townsville area for all you have done.

We don't know what this year will bring but we are here and for any one in the area who wants to get in touch with us just for a chat or would like some information, feel free to give us a call.

Jean & Tom 4775 2787
Bill 4773 1816
Sue 4778 2495

Wishing you all the best for 2010 – may it be a great year.

Regards
Sue Bourne

Tom Paterson, Gerry Doyle & Jean Paterson

## Duty of Disclosure…Who must I tell that I have Huntington's Disease?

A common question that arises when someone is diagnosed with Huntington's Disease is: "Who must I tell that I have Huntington's Disease?"

### Your Employer?

Generally you don't have to tell your employer about your Huntington's Disease unless it's an occupational health and safety risk. The same is the case if you are applying for a new job.

Also, your employer can't force you to see their doctor or to sign authorities to get reports from your doctors. There are some exceptions such as for Worker's Compensation claims.

However, telling your employer might be a positive move. It may help explain any problems you have doing your job and might result in changes to your work which could mean you can continue to work productively.

It's important to consider what your employer's reaction will be and maybe get the help of your doctor, union or the Huntingtons Queensland.

If you have been discriminated against as a result of the disclosing your Huntington's Disease to your employer, you have rights under the Federal *Disability Discrimination Act* 1992.

### The Road Traffic Authority?

You may have to notify your State Road Traffic Authority of your Huntington's Disease in some circumstances. Most Road Traffic Authorities require you to tell them about your Huntington's Disease if it is likely to affect your ability to drive, as soon as practical.

It is important to note that your driving license could be affected if you disclose your Huntington's Disease. Depending on the recommendation of your doctor, your license could be suspended, cancelled or amended to include a condition requiring you to carry a medical certificate if you are driving. If you're not sure of your position you should speak with your doctor.

### Insurance Companies?

Some but not all insurance policies require you to tell the insurer if you have Huntington's Disease before you take out the policy. Life insurance, income protection insurance and disability insurance policies usually require you to fill in a health questionnaire and if you don't tell them about your Huntington's Disease they might try to cancel your policy and not pay you if they find out when you claim.

There are also many issues that arise if you have not been Gene Tested for Huntington's Disease but you are aware that one or both of your parents has Huntington's Disease. However, you don't always have to tell them if your Huntington's Disease is under control and you can often challenge decisions of insurance companies.

It might also be possible to get disability and death insurance cover without any health questions such as under "group insurance" schemes eg with your employment super, employer income protection insurance or credit union. If you start a job, join a superannuation fund or an organisation that offers insurance, check to see whether you get automatic insurance cover without any health questions.

### Your Superannuation Fund?

Most employment superannuation funds include disability and death insurance benefits without having to fill in any health questionnaires up to a certain monetary limit. If you want to get insurance cover over the limit, you will have to fill in a health questionnaire and you will probably have to tell them about your Huntington's Disease.

You can usually get lump sum cover for death and total and permanent disability and maybe also monthly income protection payments under superannuation funds if you have Huntington's Disease and you can make a claim even if you stop work because of your Huntington's Disease.

The terms and conditions vary from one superannuation fund to another so it is important to check what you are covered for and whether you have to tell the superannuation fund or their insurance company about your Huntington's Disease.

### Assistance

If you have any questions about your disclosure obligations or regarding your employment, insurance or superannuation rights, you can contact **Maurice Blackburn Lawyers on 1800 196 050** for free advice.

# INVITATION TO PARTICIPATE IN QUALITY OF LIFE IN HD STUDY

## Quality of Life in Huntington's Disease

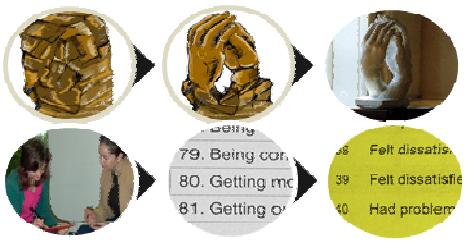
Albert Einstein once said, *"Not everything that can be counted counts, and not everything that counts can be counted."*

Now, 'quality of life' is something we all recognise as intrinsically important, and so it certainly falls into the 'worth counting' category… but, ***what*** exactly is it, and ***how*** do you 'count' it? These two questions are particularly pertinent in the context of an illness like Huntington's Disease, where the lives of people living with Huntington's and those close to them can be drastically altered by the unrelenting course of this disease. At present there is no recognised way of measuring quality of life in people affected by Huntington's in a manner that addresses all issues relevant to the experience of living with this disease. Little research has aimed to understand the first hand experience of living with Huntington's, and how quality of life may be affected.

There is no specific questionnaire that captures the experience of living with Huntington's. Such a 'patient-reported' assessment of quality of life will be essential in order to document and convey patients' or relatives' perspective of how much or little their everyday lives are affected at any one point in time. The situation is different, in Parkinson's disease for example, which is also a neurodegenerative condition, since there is a Parkinson's specific questionnaire designed to capture all the relevant aspects of living with that disease.

'Patient-reported' assessment of quality of life is now increasingly recognised as important to have, alongside other established clinical measures such as motor, cognitive and psychiatric assessments. A quality of life questionnaire that is specific to Huntington's disease could effectively help with planning and evaluating of treatments and policies as they directly reflect how a person living with Huntington's feels about their condition. The creation of a disease specific Huntington's quality of life questionnaire is a key objective of the European Huntington's disease Network's Quality of Life Working Group. We believe this work is fundamentally important, and will link in with current attempts to develop novel drug treatments for Huntington's disease. In future drug trials, a well developed and robust patient-reported outcome measure will help to evaluate if there are any meaningful changes from the patients' point of view. For example, if a new drug improved one aspect of disease but the associated side effects had an overall negative effect on a patient's daily life, then the quality of life questionnaire would be able to reflect the patient's overall perspective on these outcomes.

The scientific process of developing a robust and finely-tuned disease-specific questionnaire can be likened to that of creating a finely-honed sculpture. It involves the step by step transformation of an abstract idea or concept into a solid and tangible object.




**Raw** **Sculpting**
**Refined**

Firstly, in a series of face-to-face interviews in the U.K., we visited people living with Huntington's and their partners, and listened to their first hand experiences in order to understand in depth the many, and sometimes subtle, ways in which Huntington's affected their everyday lives. Like the master sculptor starting out with a large and roughly hewn chunk of marble, these hours of recorded conversations about people's personal experience gave the crucial

foundation from which we could develop a questionnaire. We then distilled this interview material into a list of questions that we could take back to people living with Huntington's, to see if they were relevant and adequately represented their everyday experience. We put this long-list of 81 questions to the international community, to get feedback from a large number of other people living with Huntington's disease across Europe and also Canada. The responses and feedback obtained from this long list of 81 questions directed further efforts at reducing and rephrasing the questions to arrive at a better and shorter questionnaire which would be easier to complete, without losing important information. This process of chipping away at the material under the watchful eye of the sculptor is necessary in order to transform the marble chunk to yield a more clearly defined structural form. We have now reached a critical and exciting stage where we have a prototype 40-item questionnaire which we would like to pilot test.

You are invited to take part in this pilot testing of the questionnaire in order to shape and refine it further. In order to do this successfully, we need many people living with Huntington's and their companions to volunteer to complete the questionnaire online. There are two versions of the questionnaire: 1) a HD questionnaire for people living with Huntington's (including individuals who are at risk, gene positive pre-symptomatic, and symptomatic), and 2) a Proxy questionnaire for family members, friends, partners and/or carers. We would be most grateful if you would consider participating in this pilot test going online and following links to 'EHDN Quality of Life Working Group Project: Measuring Quality of Life in Huntington's' on Huntingtons Queensland website (http://www.qahda.com); if you have any questions or concerns, please get in touch with us (contact details below and in the questionnaires).

We appeal to you to join us in this exciting endeavour, as we seek to develop a questionnaire that will convey the perspective of people living with Huntington's. Your time and effort in participating in this important and unique project will be invaluable to the success of the project, and will be part of a lasting legacy in providing the Huntington's community with a new way in which their voices can be heard. If you would like further information or have any questions about the Quality of Life project please contact us at:

Huntington's QOL project,
Department of Psychology
University of Reading
Reading RG66AL
E-mail: m.b.hocaoglu@reading.ac.uk
Telephone: 0790 888 1531

Very many people have already contributed to the realization of this project, and we cannot thank enough everyone who has welcomed us to their homes, shared their personal experiences with us, and freely given of their valuable time and energy to help us. We would also like to thank and acknowledge the Huntington's Disease Associations across the world for their continuous support.

**By Dr Aileen Ho and Ms Mev Hocaoglu**
University of Reading
On behalf of the European HD Network
Quality of Life Working Group

**HOW TO ANSWER A QUESTIONNAIRE**

If you are a person living with HD, please go to:
https://www.surveymonkey.com/s/HD_Questionnaire

If you are a family member, partner, friend &/or carer,

please go to:
https://www.surveymonkey.com/s/Proxy_Questionnaire

## SAVE WITH THE KEEPING COOL CAMPAIGN

Huntingtons Queensland is part of a statewide Keeping Cool Campaign aimed at getting discounts on electricity bills to help people on low incomes with heat intolerance to run their air conditioners in the summer. Similar government rebates on electricity bills are available in NSW, VIC and WA, but not in Queensland.

If because of your Huntington's Disease you have extra problems in the heat of summer, you might be interested in writing a letter to your local Member of Parliament to help with this very important campaign. A couple of letters can make a big difference in whether or not this campaign is successful.

Dr Michael Summers at the MS Society is working on this campaign and has offered to help people with these letters, including finding out the name of your local member. You can contact Michael on his mobile 0439 324 098 or michael.summers@msaustralia.org.au for more information and assistance.

## USEFUL TIPS WHEN VISITING A CARE FACILITY

*Visiting people with Huntington's Disease is sometimes avoided because of the difficulties experienced with communication and speech. However, it is important to the person with Huntingtons that you visit as it helps sustain an awareness that the person is a valued part of a family or community. Remember that the visit is not just for communicating facts and information but also for nourishing the love and relationship that you share together.*

### Plan your visit

a) Gather pictures of people to flesh out family news and bring in samples of any projects you have underway. For example, show the person swatches, fabric, patterns or paint chips as you describe what you are doing.
b) The person with HD may enjoy listening as you read something relating to their past interests or hobbies. If this becomes difficult, books with pictures relating to the person's interests may be something to do together. For example, pictures relating to past trips around Australia or overseas.

### Check with the staff if you can bring along

a) A favourite treat
b) A pet, if the person enjoys animals
c) Flowers, pot plant, anything to brighten up the person's environment. The more people have to comment on the greater the number of exchanges.

### Try to visit at a regular time

a) This makes your visits predictable to both the staff and the person you are visiting. Predictable routine is one of the most useful orientation devices we can offer a person with cognitive impairment. It gives the day and the week a structure and allows the person time to prepare themselves for the next event.
b) Remember people will have some times of the day when they perform better than others. Similarly their abilities may vary from day to day. Take this into account when visiting and don't immediately give up if the visit didn't go as expected.

### Relaxation

a) If the person with HD has difficulty conversing, gentle touch or holding the person's hand may be soothing. Anything that can help the person relax, or become calm is most likely pleasurable.
b) A simple hand massage with a pleasant lotion or fragrant oils is a good start. Some female clients may also enjoy a manicure or pedicure.

### Communication

a) Address the person by name and speak face to face using short, concise and simple sentences. Maintain eye contact and focus on one idea at a time. Avoid environments that are noisy, crowded or have too many distractions.
b) Avoid questions they can't answer. Instead of "What did you have for lunch?" perhaps ask "I hear you had fish for lunch today, did you enjoy that?"
c) The person with Huntingtons needs time to frame their answer, so allow time for a response.

### Be Aware of the Huntington's mask

Recognise that it becomes difficult to see how people are really feeling or what they are actually thinking due to changes in muscle tone and muscle impersistence. They may be smiling inside but present as being bored and indifferent.

### Reminiscing

a) For example, bring a picture, cut one out of a magazine, or make one to put on their bulletin board. Make a scrapbook or memory book full of photos that depict the person's interests, hobbies, family, career and preferences. Write in large letters and illustrate it with photos, newspaper clippings, bits of fabric, medals etc. Use smell, music, colour, photos and textures during your visit.
b) Bring up old memories and stories about family members, favourite holidays, fishing trips, and pets. Talk about the family, neighbours or gossip. Even if the person is not fully aware of the issues, s/he can enjoy the act of listening and talking. Being together is important for both of you.

**Music**

Sing a familiar song. Nobody will mind if your singing isn't very good. Take along recordings of the family or children. Listening to familiar music can be purely enjoyable or it can provide some openings for reminiscence or conversation.

**Walking**

Go for a walk to parts of the facility they may not usually see.

***Smile! People enjoy a smile even when they can't smile back.***
***Just being there; never underestimate the power***
***of your calm and attentive presence.***

Welfare Team
Huntingtons Queensland

# RESEARCH

## HUNTINGTON'S DISEASE: GENE THERAPY OFFERS NEW HOPE FOR TREATMENT OF NEURODEGENERATIVE DISORDER

Science Daily (Apr. 20, 2009) - Researchers from the University of Southern California have taken an important first step toward protecting against Huntington's disease using gene therapy.

Huntington's Disease is an incurable neurological disorder characterized by uncontrolled movements, emotional instability and loss of intellectual faculties. It affects about 30,000 people in the United States, and children of parents with the disease have a 50 percent chance of inheriting it themselves.

"Our findings allow for the possibility that controlled over-expression of RCAN1-1L might in the future be a viable avenue for therapeutic intervention in Huntington's disease patients," said Kelvin J. A. Davies, professor of gerontology in the USC Davis School of Gerontology and professor of biological sciences in the USC College of Letters, Arts and Sciences.

In a paper in the June 2009 issue of Journal of Biological Chemistry, now available online, Davies and his co-authors use cell culture findings to show that a form of the gene RCAN1, known as RCAN1-1L, is dramatically decreased in human brains affected by Huntington's disease. RCAN1-1L was first discovered in Davies' lab.

The investigators also show that increasing levels of RCAN1-1L rescues cells from the toxic effects of Huntington's disease, a result that could someday lead to new avenues of treatment, according to Davies. "Our discovery offers real hope and may even have wide-ranging implications for a variety of other important CAG repeat-related diseases," Davies said.

While the Huntington gene, which makes the normal Huntington protein, is an essential component to healthy nerve cells, the mutant Huntington gene makes a toxic mutant Huntington protein. Mutant Huntington contains increased levels of the amino acid glutamine, which is generated by a repetition of the DNA triplet CAG.

A normal Huntington gene has a sequence of between six and 34 CAG repeats. Any strand of DNA possessing more than 40 CAG repeats indicates the carrier will develop Huntington disease, according to the researchers. Indeed, the more repeats of CAG, the earlier the disease manifests itself and the more devastating the disease becomes. Currently available drugs do little more than help control erratic movements associated with the condition.

"It is important to keep in mind that these protective findings are in-vitro, meaning in cell cultures. Further proof of protection by RCAN1-1L will be required in-vivo, or in actual Huntington disease patients," said lead author Gennady Ermak, research associate professor at the USC Davis School of Gerontology.

Previous in-vitro research has revealed that adding the phosphate PO4, an inorganic chemical, to the mutant Huntington protein can protect against the mutant gene. This process is called phosphorylation, and can be achieved by either inhibiting an enzyme (calcineurin) or by activating an enzyme (Akt).

"Our findings point to increased phosphorylation of mutant Huntington through calcineurin inhibition as the likely mechanism by which RCAN1-1L may be protective against the mutant Huntington," Ermak said.

As Davies explained: "RCAN1-1L may actually play a role in the cause of Huntington's disease. The gene is required to down-regulate the activity of calcineurin. We have previously linked too much RCAN1-1L expression to Alzheimer's disease," Davies said. "Thus, Alzheimer's disease and Huntington's disease appear to involve opposite problems with RCAN1 expression and calcineurin activity."

In cases of Huntington's disease, too little RCAN1-1L may allow calcineurin to act unopposed and remove too many phosphates from the mutant Huntington protein. "We observed complete protection against the mutant Huntington by RCAN1-1L," Ermak said, but he reiterated the need for further research with Huntington disease patients. The results offer a new direction for further research, Davies added.

Other aging disorders also associated with the expansion of repeated CAG code include: DRPLA (Dentratorubropallidoluysian atrophy), SBMA (Spinobulbar muscular atrophy or Kennedy disease) and SCA1 (Spinocerebellar ataxia Type 1).

Research was supported by the CHDI Foundation, Inc., and the High Q Foundation, both committed to the rapid discovery and development of drugs that delay or slow Huntington's disease.

*http://www.sciencedaily.com/releases/2009/04/090420170810.htm*
*Adapted from materials provided by University of Southern California.*

## FUND RAISING

### FINANCIAL ASSISTANCE

We have received and gratefully acknowledge major financial assistance from the following donors:

*D Abbott*
*D Hewitt*
*I Dunn*
*C&R Hall*
*AN Longland*
*R&M Turner Pty Ltd*
*R Abbott*
*JA Beaumont*
*B&R Goodair*
*L Lane*
*G Pratten*
*W&C van Heel*

### IGA COMMUNITY CHEST

We continue to receive support through this program. By shopping in an IGA Store and buying IGA branded products or selected lines, a guaranteed percentage from each of these sales is set aside for a local group or charity.

If you shop at your local IGA, please consider approaching their management requesting details of their Community Chest with a view to nominating Huntingtons Queensland as your charity.

## DONATIONS

If you would like to donate to Huntingtons Queensland and have internet access – just go to our website www.qahda.com and scroll down to the 'Please Make a Donation' section on the bottom left and click on the button <CLICK HERE> and follow the instructions. All donations are receipted for taxation purposes.

## GOLD COAST – LADIES TENNIS

Our sincere thanks and appreciation to the mid-week Ladies Tennis Group for donating funds raised at their break-up luncheon.

$680 was donated to Huntingtons Queensland to support our services to families

THANK YOU!

## ACACIA RIDGE ROTARY CLUB – ART UNION

The Acacia Ridge Rotary Club is kindly supporting Huntingtons Queensland with their art union.

**1st prize is a 6' x 4' car trailer including home and gardening equipment valued at $3600**

If you would like to sell tickets on our behalf or just buy some tickets, please contact us on 07 33918833 or email us at admin@huntingtonsqld.com.

TICKETS $2 CLOSING DATE: 20th June 2010 DRAWING DATE: 22nd June 2010

## ANOTHER THANK YOU TO THE GAMBLING BENEFIT FUND

The **Queensland Government's Gambling Benefit Fund** provided $8577 to Huntingtons Queensland for the change-over price of a new vehicle for the Welfare Service. This generous funding has enabled the Association to channel savings into direct service provision to families. We appreciate their support.


## HUNTINGTONS QUEENSLAND

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**Email: admin@huntingtonsqld.com**

**Website: 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 HD Awareness activities
- Fundraising activities

### Management Committee 2009/10:

| | |
|---|---|
| President | Gerry Doyle |
| Vice President | Ray Bellert |
| Secretary | Pam Cummings |
| Treasurer | Darren Careless |