



August 2010

# NEWSLETTER

## HUNTINGTONS QUEENSLAND

### CONTENTS

From the President	1
From Lesley Frazer	1
From the Operations Manager	2
Welfare News	2
Diary Dates	3
Conference Programme	4
Units Offer New Hope	5
A Family Story	6
Family Planning Options	6
Dealing with Survivor Guilt	7
Caring for Carers	8
Medical Cooling & Heating Concessions	8
HD Discovery Provides New Hope for Treatment	9
PREDICT-HD Update	10
Fund Raising	11
Association & Contact Details	12



### MAKING THE CONNECTION – CONFERENCE 2010

Don't forget our Conference in Brisbane in September. Please see page four for the Conference Programme. For information please phone on 07 3391 8833 or visit [www.huntingtonsqeensland.com](http://www.huntingtonsqeensland.com) where the Registration Form and other information can be downloaded.

### FROM THE PRESIDENT

#### Dear Friends

I'm happy to announce Christine Parfitt's promotion to Senior Welfare Officer and the appointment of our new full time Welfare Officer, Lesley Frazer.

The National Huntington's Disease Conference is now only weeks away and I look forward to meeting many of you at the Conference and associated dinner. There is more on the Conference in this Newsletter.

Apart from the Conference in September, the 34<sup>th</sup> AGM of the Association will be held at 7:00 pm on Wednesday 22<sup>nd</sup> September and I would ask as many as possible to attend. Some members of our committee have served for the entire history of the Association, and like all of us, at some time look forward to a quiet retirement. With HD and the ongoing demands for those with the disease and their carers and families, we must have a strong committee dedicated to a sustainable organisation that is well funded and in tune with our families, Government and the wider society in which we live.

We need new members to become part of the management committee for your Association – Huntingtons Queensland.

There are many challenges but the time needed to be on the committee is not onerous – we meet once per month during the day and at other special times as needed.

Please give this your earnest consideration.

**Gerry Doyle, President**

### FROM LESLEY FRAZER

I wish to thank the Management Committee for the opportunity to be a part of the team at Huntingtons Queensland. Having lived and worked in Charleville for the past nine years, my roles were Personal Carer, Carer Respite Officer and Family Support Worker.

Last but not least, I look forward to meeting the committee members and families as well as improving my knowledge of Huntington's Disease.

**Lesley Frazer, Welfare Officer**



## FROM THE OPERATIONS MANAGER

**Christine Parfitt** Congratulations to Christine on her appointment as Senior Welfare Officer. Christine has been with us for some time now and we know that she will fulfill the role competently and with enthusiasm – well done Christine.

**Lesley Frazer** I extend a warm welcome to Lesley Frazer who will take on the position of Welfare Officer in early August. Lesley will be out and about meeting families and joining in support group activities in the very near future.

**National Conference** It is not too late to register for the Conference. We have again included a copy of the programme in the Newsletter and you will see the varied and interesting topics and speakers we have lined up. If you are interested in coming, but feel finances are restricting you, please contact me for a chat. For country people who may be worried about transport to and from their accommodation to the Conference venue, I would like to suggest that you consider accommodation around Annerley - we could arrange a collection point at the Huntington's Centre and then organise maxi taxis to transport you and others to the Conference venue. Likewise local people may like to meet at our Centre. Please let me know if you would like support in this regard.

**The Huntingtons Queensland Research Scholarship** Thank you to members who have included donations with their membership for this Scholarship. Your generosity will help us support current research into HD being undertaken at The University of Queensland. Dr Trent Woodruff will give an update of this research "Role of the Innate Immune Complement System in Huntington's Disease" at the National Conference.

**Rotary Club of Acacia Ridge Scholarship** In June 2010 the Rotary Club presented Huntingtons Queensland with a cheque to the value of \$10,000. *This is indeed a very generous gesture by Rotary and we sincerely thank them.*

At a recent Management Committee Meeting it was decided to set up a fund to provide support to families with school aged children. Terms of reference are being drawn up. The principal of \$10,000 will be kept and each year the Committee will distribute any earnings from this fund to support young family members as per the guidelines of the Scholarship. Thank you to members who kindly supported this initiative – your donations will mean more funds available for distribution to families.

Many of you have given generously to these projects and also provided much needed financial support to the Welfare Service delivery. We thank you sincerely.

**Sunnybank Community & Sports Club** The Club has recently committed to a grant of \$10,000 per year for the next three years to support the Huntingtons Queensland Youth Support Programme. The main focus of the programme is to provide support and opportunities to young family members. The Club's financial commitment over three years will provide a tremendous boost to the support offered and will also enable the Association to plan and budget ahead.

*This is a very generous and supportive commitment by the Sunnybank Community & Sports Club, and we sincerely thank them.*

**Order of Australia Medal** Mary Grant (known to many by her first husband's name Mary Steptoe) was recognised for her community work, particularly with Girl Guides and also Huntingtons Queensland. Mary served on our Management Committee for several years and also assisted with fundraising. Congratulations Mary.

**Barb Gray, Operations Manager**

## WELFARE NEWS

**Welcome Lesley!** This month we welcome Lesley Frazer to our Welfare team. Lesley will spend the next few months getting out and about to familiarise herself with the regions and people, but feel free to call and say "Hi" in the meantime. Lesley will be working full time (Monday to Friday) as our Welfare Officer.

**Change to Regional Areas** Now that Lesley has joined our team and I will be shifting into the Senior Welfare Officer position we have had to make a couple of changes to the regional areas that we visit. As you can see below, some regions have been renamed, made bigger, or split up to make them more manageable; whilst some regions will have a new staff



member visiting the area. If you have any questions about any of these changes, please feel free to give us a call. As of August, the following changes will take place:

- Christine:** Brisbane West, West Moreton / Logan, Toowoomba, Scenic Rim, Mackay, Bundaberg / Fraser Coast, Burnett (shared with Theresa).
- Lesley:** Brisbane North, Pine Rivers / Peninsula, Gold Coast, Sunshine Coast, Cairns, Townsville.
- Theresa:** Brisbane South, Brisbane East, Gladstone / Rockhampton.

**YPIRAC Initiative Update** (Younger People In Residential Aged Care) In previous newsletters we have discussed the YPIRAC Initiative. Earlier this year another model of support under this initiative, called EASIAC (Enhanced Support In Aged Care) commenced. Support under the EASIAC initiative (pronounced *easy-ac*) is available to people under 65 years of age residing in nursing homes and is tailored to the person’s needs, including social and lifestyle supports, above and beyond that which the nursing homes provide. For example, some of our clients are receiving a weekly visitor who comes along simply for a chat, do craft, go out for a coffee, go for a drive, take them out shopping, go to the movies, massage therapy, and more. For other eligible people, this initiative may be able to provide funding for specific pieces of equipment such as the “Huntington’s bed”, for example. We are already seeing some wonderful outcomes from this program for our clients and we want to make sure that all our eligible clients are registered for this support. If you would like to know more about this initiative, or if you know someone who is under 65 years and living in a nursing home who you think would benefit from this support, please give us a call at the office where we will be more than happy to assist and advocate on their behalf.

**Carers’ Information and Support Group** Last month Cate Barrett, Speech Pathologist from the Huntington’s Clinic, came along as a guest speaker to our carers’ meeting to speak about the swallowing issues that affect people with HD. Other topics covered included aspiration (breathing food into the lungs/ wind pipe), modifying diets and thickened fluids. We even had first-hand experience of thickened water. Cate left some handouts on the topics she discussed and we would be more than happy to pass them on to anyone who would like this information – just give us a call with your details and we’ll pop them in the mail. Following on from this, at our carers’ meeting on October 13<sup>th</sup> we will be having a trainer from the St John come along to talk about first aid for choking, and other first aid tips for caring with someone with HD. If you would like to come along, or if you have any ideas for future information sessions, please give us a call.

**Christine Parfitt, Senior Welfare Officer, along with Theresa Byrne and Lesley Frazer (Huntingtons Qld Welfare Team)**



DIARY DATES		
<b>August</b>	9	Gold Coast Family Support Group
	18-19	Mackay Regional Trip
	23-25	Whale Watch Respite Holiday
	23-27	Bundaberg / Fraser Coast Regional Trip
<b>September</b>	30	Brisbane Carers’ Group
	15	Eastern Suburbs Respite Group Outing
	17	Toowoomba Family Support Group
	29	Kid’s Group Activity Day (TBA)
<b>October</b>	4	Gold Coast Family Support Group
	13	Brisbane Carers’ Support Group



**CONFERENCE PROGRAMME**

<b>DAY 1 – THURSDAY 9<sup>TH</sup> SEPTEMBER 2010</b>		
<b>8.00 - 9.00</b>	<b>REGISTRATION</b>	
<b>9.00 - 9.10</b>	<b>INTRODUCTION</b>	Gerry Doyle President Huntingtons Queensland
9.10 – 9.30	Conference Opening	The Hon Anastacia Palaszczuk MP State Minister for Disability Services & Multicultural Affairs
9.30 – 10.30	Key Note Address: Worldwide HD Research Update	Professor Gary Egan Florey Research Institute
<b>10.30 – 11.00</b>	<b>MORNING TEA</b>	
11.00 – 11.45	Update on Current Initiatives in Disability, Care & Support in Aust	The Hon Bill Shorten MP Parliamentary Secretary for Disabilities & Children’s Services
11.45 – 12.30	Role of the Innate Immune Complement System in HD	Dr Trent M Woodruff School of Biomedical Sciences The UQ
<b>12.30 – 1.30</b>	<b>LUNCH</b>	30 minute tour of the Queensland Brain Institute
1.30 – 2.30	Key Note Address: Care – Session I	Jimmy Pollard MA
2.30 – 3.00	HD in Australia: A Social History	Therese Alting University of Sydney
<b>3.00 – 3.30</b>	<b>AFTERNOON TEA</b>	
3.30 – 4.15	State HD Associations’ Presentations	Staying Strong through HD
4.15 – 5.00	HD Australia / Our HD Space Making the Cyber Connection!	Michelle O’Brien Co-creator of Our HD Space
<b>5.00 – 5.10</b>	<b>CLOSE</b>	Gerry Doyle President Huntingtons Queensland
<b>7.00 for 7.30</b>	<b>DINNER</b>	Guest Speaker Prof Fellow Edmund Chiu Uni of Melbourne
<b>DAY 2 – FRIDAY 10<sup>TH</sup> SEPTEMBER 2010</b>		
<b>8.30 - 9.00</b>	<b>REGISTRATION</b>	
<b>9.00 - 9.10</b>	<b>INTRODUCTION</b>	Gerry Doyle President Huntingtons Queensland
9.10– 9.40	Exploring an LDH Nanoparticle-based Drug Delivery System for the Treatment of Neurodegenerative Disease	Associate Professor Helen Cooper Queensland Brain Institute The University of Queensland
9.40 – 10.10	Genetic Testing for HD in Qld since 1993	Dr Valentine Hyland Molecular Genetics Laboratory Herston Hospitals Campus Brisbane
<b>10.10 – 10.40</b>	<b>MORNING TEA</b>	
10.40 – 11.40	HD Clinic (Presentation & Panel Discussion)	Associate Professor John O’Sullivan HD Clinic Royal Brisbane & Women’s Hospital and panel members
11.40 – 12.10	IMAGE-HD Project	Associate Professor Nellie Georgiou-Karistianis Monash University
<b>12.10-1.10</b>	<b>LUNCH</b>	30 minute tour of QBI
1.10-2.10	Key Note Address: Care Session II	Jimmy Pollard MA
2.10-2.40	Effects of Environmental Enrichment	Dr Jennifer Thompson Postdoctoral Research Fellow, Edith Cowan University WA
2.40 – 3.15	State HD Associations’ Presentations	Staying Strong through HD
3.15 – 4.00	Seeing the Possibilities in Life	Lionel Fifield Co-ordinator Relaxation Centre
<b>4.00 – 4.10</b>	<b>CLOSE</b>	Shiralee Judge National Chairperson Huntingtons Australia



The following article has been reproduced from The Satellite Southern Edition (Wednesday 19 May 2010) with the kind permission of Kelly Daniels, Editor, The Satellite and Reporter Newspapers.

Ellen Buckley Place home to eight younger Queenslanders with a disability

# Units offer new hope



**Kelly DANIELS**

kelly.daniels@qtcn.com.au

It was a sea of purple in Inala last week, at the official opening of Ellen Buckley Place on Lavender Street.

The new housing for young Queenslanders with a disability was opened in honour of Carole Park resident Ellen, who passed away just last year after a brave fight with Huntington's Disease.

Mum Colleen Woodcock said God chose special people for disabilities, people with courage.

"God blessed me with two beautiful children and we went on a journey together, the Huntington's journey," she said. "Not once did Ellen complain."

Ms Woodcock lost both her children to the disease just last year, but the new housing will ensure they will never be forgotten.

The opening of the units also marked the 100<sup>th</sup> young Queenslanders with a disability to be diverted from aged care facilities into supported accommodation.

**"God blessed me with two beautiful children and we went on a journey together, the Huntington's journey."  
Colleen Woodcock.**

Disability Services Minister Annastacia Palaszczuk announced the major milestone while opening the \$1.8 million Ellen Buckley Place.

She said eight younger Queenslanders with a disability would soon call the facility home after being moved or diverted from aged care facilities as part

of the Younger People in Residential Aged Care (YPIRAC) Initiative.

"As a local member often we meet people who leave a lasting impression, and Ellen was one of those people," she said.

"The disease literally bit by bit takes away that person, but Ellen's motto was don't live the disease, live life.

"My life is richer for having known Ellen Buckley."

Ms Palaszczuk said Queensland was leading the way when it came to moving younger people with a disability from aged care facilities, and diverting those at risk from entering these facilities.

"We're getting them into the supported accommodation they need to live independently in the community," she said.

"This is one of my top priorities and we're leading from the front on this issue.

"Queensland is investing \$23.9 million in YPIRAC over five years, and these funds are being matched by the Commonwealth."

Ms Palaszczuk said the three two-bedroom and two one-bedroom units in Inala would give eight people with a disability a new lease on life.

"The apartments are located close to wheelchair-accessible parkland, shops and community services, helping residents to maintain their independence and lifestyle," she said.



"Remaining independent contributes enormously to people's quality of life, and by creating these new units we're also helping to free up much needed aged care beds.

Ms Palaszczuk said Ellen had touched the lives of many people.

"She passed away last year from Huntington's Disease, and was committed to living at home rather than residing in an aged care facility," she said.

"She was a role model to so many people and a great inspiration to Queenslanders with a disability."

Huntington's Disease is a genetic brain disorder which affects the body and mind's functions.

Brisbane Housing Company business development manager, Rebecca Oelkers, said the company was delighted to work with Disability Services to create the purpose built apartment complex.

"Many families encounter a lack of age appropriate accommodation and support options to care for loved ones with high care needs," she said.

"These apartments offer affordable, independent living with long term stability as an alternative to living in aged care facilities.



## A FAMILY STORY

From time to time we will feature a family story. It can be inspiring to all of us to hear how other families cope in their day to day lives. The following story is about how one family member affected by HD found benefit in taking Coenzyme Q10.

*As we are not doctors and not clinically trained, the Management Committee and staff of Huntingtons Queensland do not and cannot recommend or endorse any supplements or medications. It is imperative that you consult your doctor and / or specialist before embarking on any new supplement or medication regime.*

### A Success Story - Using Coenzyme Q10 in Slowing the Effects of Huntington's Disease

Janet Kempton was born on the 30 September 1936. She was diagnosed with Huntington's in 1993 at the age of 57. Now aged 73, Janet has been taking Coenzyme Q10 for the last sixteen years which, in her case, has been successful in reducing the effects of Huntington's, particularly the jerking movements that are associated with the Disease.

Alex, Janet's husband, heard about a trial of CoQ10 tablets in treating Huntington's in 1994, which claimed that participants took a larger than average dose per day without any side effects. This ultimately slowed the progression of Huntington's by increasing the flow of blood to the brain.

Janet started the treatment by taking a small dose each day; this resulted in jerking movements decreasing within a three-month period. The dose was then increased for nine months, with further positive impact and for the last fourteen years she has been taking the current manufacturer-recommended average daily dose.

During this period Janet stopped taking the tablets for one week and at this point the jerking increased severely. However, within five to six days of resuming the treatment her condition improved immensely and the jerking reduced.

The one stand out difference that Alex has noticed with taking CoQ10 compared to other Huntington's patients is that Janet does not have the weight loss effect that others do as she has stopped jerking and the exercise effect is reduced. As a result Janet now weighs 82kgs.

In 2007 after investigation by a Neurologist and a Neurosurgeon fluid was found on Janet's brain. They were confident that they would be able to improve her lifestyle by putting a shunt in her brain to drain the fluid. Three months after the shunt was inserted her speech and walking had improved.

Over the last four months Janet's condition has deteriorated and she is in permanent high care at a nursing home as she has decreased mobility. However, it is both Alex and Janet's belief that had she not undertaken the CoQ10 treatment she would have been put into full time care within a much shorter time frame.

*Remember, it is imperative that you consult your doctor and / or specialist before embarking on any new supplement or medication regime.*

For information on current CoQ10 studies, 2CARE and PREQUEL, go to [www.Huntingtons-Study-Group.org](http://www.Huntingtons-Study-Group.org)

## FAMILY PLANNING OPTIONS FOR PEOPLE AT RISK OR GENE POSITIVE

For some couples, family planning decisions are complicated by concerns over a hereditary condition such as Huntington's Disease (HD). If one member of a couple carries the altered gene which is responsible for HD, then each of their children has a 50% risk of inheriting this gene error. Anyone who inherits the gene error will eventually go on to develop HD.

Over the years, couples have made many choices. One was to accept the risk and have children. Another was to remain childless. Other couples adopted a child while others used donated sperm or eggs. Today there are further options available which aim to allow a couple to give birth to a child who is genetically related but does not carry the gene error.



### Testing During Pregnancy

Some couples choose to conceive naturally and then test during the pregnancy to determine if the fetus carries the gene error which causes HD. If the altered gene is detected, then the couple can choose to undergo a termination of pregnancy.

There are two commonly used techniques: chorionic villus sampling (CVS) and amniocentesis. Both of these techniques involve taking tissue from around the baby. This leaves the baby unharmed but there is a small risk (up to 1%) that the pregnancy will miscarry as a result. CVS is performed at 11-15 weeks of the pregnancy while amniocentesis is performed at 16-19 weeks of pregnancy. The sampled tissue is then tested to determine if the gene error is present or not. This test result usually takes about two weeks to become available, though may take longer.

### Prenatal Genetic Diagnosis (PGD)

PGD requires the parents to conceive using *in vitro* fertilisation (IVF). Once the embryo has started to develop in the laboratory, some cells are taken and tested. Embryos which are found to be free of the gene error can then be placed in the womb to grow and develop. As with all IVF techniques, there can be difficulties in achieving a successful pregnancy.

### If the Parent Has Not Been Tested for HD

All of the above assumes that the parent at risk for HD has been tested and knows their genetic status. If the parent has not been tested, more complex testing techniques may be available. These techniques can be used if a parent is at risk of having the HD gene error, does not want to know their genetic status, yet still wants to prevent the possible gene error from being passed on to their children. These tests are unable to determine if a pregnancy definitely has the HD gene error, only if it has the same risk as the at-risk parent. However the tests can reveal if the pregnancy has no risk of having the gene error.

All the choices discussed here have varying financial and emotional burdens associated with them. Hence genetic counselling is vital when a couple is considering genetic testing in a pregnancy to ensure all options and their possible outcomes are fully understood. To obtain further information, request a referral to Genetic Health Queensland from your family doctor.

**Lindsay Fowles, Associate Genetic Counsellor, Genetic Health Queensland**

## DEALING WITH SURVIVOR GUILT

*By Julie Stauffer*

Everybody understands that when you toss a coin, the result is random. Whether it comes up heads or tails is a matter of pure chance; there's no rhyme or reason involved.

It's a little more difficult to come to terms with the pure chance that dictates who inherits an HD gene and who doesn't. For people who test negative for the gene, the relief and happiness is often mixed with guilt and confusion. Why did they escape when other friends or family members weren't so lucky?

Susan Creighton, a genetic counsellor and clinical assistant professor at the University of British Columbia, provides the example of one young woman who tested negative. When she first got her results, she was overjoyed. In the days that followed, however, she began to feel bad that she would never have the disease that was killing her mother – and then felt worried because she was feeling guilty instead of happy.

"It can really play a number on people," says Susan C. That's why one of the topics she brings up during pre-test counselling sessions is survivor guilt. She also points out that every test result can create ripple effects within families and beyond.

Helen Zwart, for example, was never at risk of Huntington's herself. But when genetic tests revealed that neither of her two children inherited the Huntington's gene her husband carries, she nevertheless had a nagging sense of guilt.



“I’m ecstatic for my children,” she says. “I can’t begin to express how excited we are.” At the same time, however, she feels sad, knowing several parents whose children have tested positive or developed Huntington’s.

“Why us and not them?” Helen explains. “Why are we so privileged?”

According to BC Resource Centre Director Susan Tolley, survivor’s guilt is common in the Huntington’s community, even if it’s not acknowledged as much as it should be.

It’s also common for that guilt to lead to silence. Helen, for example, hesitated to share her good news with the support group she and her husband belong to, not wanting to focus on their good fortune while others continue to suffer.

“A lot of times when people find out their good news, they don’t really share it,” Susan T. Explains. “They’re afraid they’re not going to be considered part of the group any longer, or they don’t want to be gloating.”

It’s important to choose the right time and the right way to discuss your news, Susan T. says, but she also believes it’s important to speak up.

The Huntington’s community needs to hear good news stories to balance out the gloom. “It provides hope for others,” she says. Not sharing the news also creates the danger that it may come out at the wrong time, with unfortunate results.

If you’re struggling with the mixed emotions a negative result can create, or if you need help deciding how and when to share your news, don’t be afraid to contact your genetic counsellor, resource centre director or Individual and Family Services worker. (*Queenslanders can contact Genetic Health Queensland on 07 3636 1686 at Royal Brisbane & Women’s Hospital.*)

“Often, people don’t recognise the importance of talking to an expert,” says Susan T, “but we understand the issues you’re dealing with, and we can offer shortcuts.”

*Acknowledgement: Canadian Newsletter, Horizon – Issue No 131 – Spring 2010*

*Reprinted, with kind permission, from Huntington’s News June 2010, Issue 10; Quarterly Newsletter of the Huntington’s Disease Associations of New Zealand.*

## CARING FOR CARERS – beyondblue



Not-for-profit organisation **beyondblue** has developed a new free DVD and booklet to assist people who care for a family member or friend with depression or a related disorder.

*The Carers’ Stories of Hope and Recovery DVD and Guide for Carers – Supporting and Caring for a Person with Depression, Anxiety and/or a Related Disorder* booklet

provide carers with practical strategies, advice and guidance to deal with situations they might face and the impact that the caring experience may have on them.

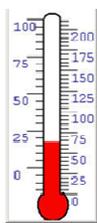
To order these resources go to [www.beyondblue.org.au](http://www.beyondblue.org.au) or call 1300 224 636.

## Medical Cooling and Heating Electricity Concession Scheme

The Queensland Government Department of Communities provides financial assistance to low-income Queenslanders with a medical condition which requires the use of electricity for cooling or heating. This assistance is provided for a period of two years, at which time eligibility will require review.

The Medical Cooling and Heating Electricity Concession Scheme assists with the electricity costs for eligible customers who have an inability to self-regulate body temperature when exposed to extremes (hot or cold) of environmental temperatures. It is associated with certain medical conditions, for example multiple sclerosis, autonomic system dysfunction, significant burns and





severe inflammatory skin conditions.

To be eligible for the concession, the applicant must have a qualifying medical condition and their residence must be fitted with an air conditioning unit. In some instances, it may be appropriate for a parent or legal guardian to apply on behalf of the person with the medical condition.

The applicant and/or legal guardian must hold a Health Care Card or a Pensioner Concession Card and be financially responsible for the payment of their component of the electricity bill.

The concession is not limited to one person per household, but all applicants must meet all of the eligibility criteria.

The application form must be signed by a relevant specialist eg neurologist, general physician, dermatologist or in the instance of multiple sclerosis, a general practitioner who has been treating the patient for more than three months.

For more information phone 1800 460 849 or email [concessions@smartservice.qld.gov.au](mailto:concessions@smartservice.qld.gov.au) or visit [www.communities.qld.gov.au/community/concessions](http://www.communities.qld.gov.au/community/concessions)

## HUNTINGTON DISEASE DISCOVERY PROVIDES NEW HOPE FOR TREATMENT



Huntington's Disease is a genetic disease with no cure, characterised by a steady decline in motor control and the dysfunction and death of brain cells. The cause of the disease has long baffled scientists. Symptoms tend to first appear when the person is in their thirties or forties. The most common symptom is jerky movements of the arms and legs. A person with Huntington's Disease may also have difficulties with speech, swallowing and concentration.

Using state of the art technology, Dr Danny Hatters and his colleagues at the University of Melbourne's Department of Biochemistry and Molecular Biology at the Bio 21 Institute observed how human mutant 'huntingtin' proteins form into large clumps, which kills brain cells and leads to progressed HD. "Steps prior to the clustering of the mutated proteins were thought to damage cells, but these steps were not clearly detectable under a microscope," Dr Hatters says. "Understanding this process and finding the right target to block the ultimate death of the brain cells has been extremely difficult to determine," he says.

The technology called analytical ultracentrifugation and the methodology the researchers developed enabled them to visualize this process in much greater detail. "What we have shown and are the first to show, is that mutated huntingtin protein forms three different sized clusters in the damaged cells," he says. "This discovery will help to develop a targeted treatment that shuts down the key processes causing the clusters to form and for the disease to progress."

While researchers previously thought that small clusters of the mutant protein kept accumulating over time until they overwhelmed and killed the brain cells, Dr Hatters' team found that these clusters were static, which means they form in a more unpredictable manner than previously thought. The discovery reveals the clusters place a steady stress on cells over time rather than steadily building up over time to some critical "toxic" level as previously thought.

"Why it takes so long for the cells to die in human disease is not known - however it could be that cells eventually cannot compensate anymore from the process where toxicity is built up to form one cluster called oligomers," he says. "The real key of our work is that we now have direct targets in the critical steps in the process of cell toxicity and death and to gauge any therapeutic effects of drugs on these targets. We can also measure how this alleviates cellular toxicity and brain cell death."

"Importantly our research techniques could have application in assisting to find drug targets for other neurodegenerative diseases where toxic clusters of proteins play a role in the progression of the disease, such as for Parkinson's Disease."

The research is published in the current issue of the Journal of Biological Chemistry

More information: Contact Rebecca Scott, Media Officer, University of Melbourne. Mobile: 0417164791

**Source URL:** <http://newsroom.melbourne.edu/news/n-328>



## PREDICT HD UPDATE

For those involved with, or following, the PREDICT-HD study, the University of Iowa has new videos on YouTube with updates to the study.

### Background: From Predictors to Prevention: The PREDICT-HD 2.0 Huntington's Disease Study

<http://www.youtube.com/watch?v=w8Xpk0jBuPA&feature=related>

November 16, 2009 1:56 Minutes:

Jane Paulsen, PhD, University of Iowa Principal Investigator, PREDICT-HD2.0 explains the PREDICT-HD study.

YouTube Videos – February 16 2010:

An Update on the PREDICT-HD Huntington's Disease Study – 3:26 minutes

<http://www.youtube.com/watch?v=k7cdMj4Fb90>

An Update on the PREDICT-HD Part 2 – 5:09 Minutes <http://www.youtube.com/watch?v=86dbTLzKNtl&feature=related>

An Update on the PREDICT-HD Part 3 – 8:03 Minutes <http://www.youtube.com/watch?v=1AWktEu3Ljc&feature=related>

Investigator for PREDICT-HD, updates study participants and other interested persons on the Huntington's Disease study and recent study findings at the HDSA 2009 Convention in Phoenix, AZ on June 5, 2009. In this clip, Dr Paulsen covers the renewal of grant funding and an overview of PREDICT-HD.



The PREDICT-HD study uses a variety of tests to examine the nature and pattern of neurobiological changes and neurobehavioral changes that occur in the period leading up to a diagnosis of Huntington's Disease. Researchers are learning more about the beginning changes in thinking skills, emotional regulation, brain structure and brain function as a person begins the transition from normal health to Huntington's Disease. These findings will be useful in designing effective clinical trials for treatment of early HD.

Volunteer recruitment of gene positive, pre-symptomatic and gene negative individuals for PREDICT-HD is ongoing. For information, visit <http://www.predict-hd.net> or the Huntington Study Group at <http://www.huntington-study-group.org>

"In 1993, I sat with colleagues and HD families and talked about how the gene discovery had given us new hope. Dreams for drugs to treat HD seemed possible, yet our discussion emphasized how treatment should begin as early as possible, before jobs are lost and children's soccer games are missed. We talked about doing research with persons at risk before they become sick and struggled with how to best advance knowledge. PREDICT-HD is the result of much teamwork involving late hours and challenges too numerous to detail. It is a study we consider critical to make a difference in the quality of life for HD families."

**Jane Paulsen, PhD, University of Iowa, PREDICT-HD Principal Investigator**



## FUND RAISING

### FINANCIAL ASSISTANCE

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

R Dredge	K Horton	M Buchanan
H Wilson	G Pratten	L Saffy
R Eley	A McKinless	P&E Noonan
S Willis	J Callum	K Neal
P Webb	B&R Goodair	M Bruce
E Denham	W Abraham	I&F Linley
B Gillespie	C&J Farmer	R&J Farmer
P&F Ralls	K&D Gordon	J Lawrence
J Wallace	M Turner	J Clerke
R Sivel	N Robertson	T Rowlands
R Flynn	J&F Williams	N Hoffman
J Bennett	A Harding Smith	John Holland Group

### ROTARY CLUB - ACACIA RIDGE



The Acacia Ridge Rotarians have a long history of supporting Huntingtons Queensland through their tireless efforts, in particular their recent art union which yielded Huntingtons Queensland \$480, with the Rotary Club rounding off their cheque to us for \$1,000.

In addition they very kindly presented Huntingtons Queensland with a cheque for \$10,000 which has become the seed money for the Rotary Club of Acacia Ridge Scholarship to provide support to school aged children.

*We sincerely thank them for their ongoing support.*

### BRISBANE CITY COUNCIL

#### Lord Mayor's Sustainability Grants Programme



We have been granted \$2,288 to conduct an Energy Audit with a view to minimising our energy usage. Depending upon the outcome of this audit we may apply for further funding under this Programme.

### SUNNYBANK COMMUNITY & SPORTS CLUB

The Club has recently committed to a grant of \$10,000 per year for the next three years to support the Huntingtons Queensland Youth Support Programme. The main focus of the programme is to provide support and opportunities to young family members.



*We thank them for their wonderful generosity.*

### DEPARTMENT OF DISABILITY SERVICES

#### Funding Programme – Building Supportive Communities

Through their Funding Programme, the Department has granted Huntingtons Queensland \$1,175 for production of a DVD to be presented at the National Conference in September. It will also be used for other awareness and support purposes.

### MULTI-DIRECT



Dave Miller of Multi-Direct, our telemarketing company, has committed \$10,000 toward the costs of the National Conference in September.

*Dave's ongoing support is much appreciated.*

### DONATIONS

If you would like to donate to Huntingtons Queensland and have internet access – just go to our website [www.huntingtonsqld.com](http://www.huntingtonsqld.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.

### PATCHWORK QUILT RAFFLE

Valued at approximately \$600 – this beautiful quilt has been very kindly donated by Crazy Quilters Caboolture Inc. It is suitable for either a double or queen size bed.

*Books of 10 tickets - \$2/ticket. Drawn 8<sup>th</sup> October 2010.*

If you would like a book of tickets to sell please phone on 3391 8833 or email [anne@huntingtonsqld.com](mailto:anne@huntingtonsqld.com)



## HUNTINGTONS QUEENSLAND

Florence Dannell House  
385 Ipswich Road  
Annerley Q 4103

All Correspondence to  
PO Box 635  
Annerley Q 4103

Phone: (07) 3391 8833  
Fax: (07) 3391 0443

Email: [admin@huntingtonsqld.com](mailto:admin@huntingtonsqld.com)

Website: [www.huntingtonsqld.com](http://www.huntingtonsqld.com)



**Huntingtons Queensland**  
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
Members	Nadia Farha
	Cliff Farmer
	Denis Kelly
	Jan Mealy
	Jan Szlapak

### Staff Members:

Operations Manager	Barbara Gray
Senior Welfare Officer	Christine Parfitt
Welfare Officer	Lesley Frazer
Welfare Officer	Theresa Byrne
Day Respite Assistant	Lydia Hudson
Telemarketing Officer	Helen Johnston
Administration Officer	Anne Stanfield

## CONTRIBUTIONS

Please feel free to submit articles or photographs for selection for publication in this Newsletter. The deadline for the next issue is 1<sup>st</sup> October 2010. Please email or post articles, details above. *Please be aware that the Newsletter is published on [www.huntingtonsqld.com](http://www.huntingtonsqld.com)*

