



# NEWSLETTER

## HUNTINGTONS QUEENSLAND

October 2010

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### FROM THE PRESIDENT

#### Dear Friends

The National Huntington's Disease Conference was a great success with approximately 140 delegates attending and 85 attending the associated dinner. There is more on the Conference later in the Newsletter. The next Australian HD Conference will be held in Sydney in 2012; however next September, Melbourne will be hosting the combined International Huntington Disease and WFN Conference.

The 34<sup>th</sup> Annual General Meeting of Huntingtons Queensland was held on Wednesday 22<sup>nd</sup> September and we had seventeen in attendance, fewer than we had hoped for but not surprising given the recent Conference. We warmly welcome Trish Flitcroft and Alan McKinless who have joined the committee. This year has seen the retirement of four members of your committee, namely, Jan Mealy, Nadia Farha, Cliff Farmer and Ray Bellert.

The Association thanks them all for their hard work and commitment. We owe a large debt of gratitude to Cliff and Ray who between them have over 60 years of service on the HD committee. Cliff was the instigator of the initial HD meeting in 1976, and his inspiration, dedication and drive has been instrumental in the success of the Association today. He has served on the committee since 1976 including thirteen years as President. Ray's first involvement over 20 years ago was donating a vacuum cleaner as a raffle prize and he has been on the committee since then including some years as president.

We still have a couple of committee vacancies, so if you're interested please call Barb or me.

**Gerry Doyle, President**

### DIARY DATES

#### November

- 16-18 Cairns regional visit
- 24 Caboolture Christmas Party
- 26 Toowoomba Christmas Party

#### December

- |       |                                 |    |                                    |
|-------|---------------------------------|----|------------------------------------|
| 1     | Burnett Christmas Party         | 20 | Sunshine Coast Christmas Party     |
| 6     | Gold Coast Christmas Party      | 21 | Day Respite Centre Christmas Party |
| 8     | Brisbane Carers Christmas Party | 22 | Eastern Suburbs Christmas Party    |
| 12-15 | Family Holiday                  |    |                                    |

## FROM THE OPERATIONS MANAGER

The recent National Conference Dinner was a very special evening with over 80 people from all walks of the Huntington's community coming together to celebrate the hosting of the National Conference in Queensland and to also pay tribute to some very special people who have made a unique contribution to the Association.



**Associate Professor John Rowell** who is Director of Haematology at Queensland Health Pathology Service, Royal Brisbane & Women's Hospital received an Honorary Membership. Early in the development of genetic testing Dr Rowell approached the Association to seek our agreement and support of his proposal to commence the analysis of blood specimens in Brisbane. Since that time his laboratory has been providing testing not only for Queenslanders, but for Huntington's families in other parts of Australia and New Zealand. We thank him for his special contribution, his skill and dedication.



**Associate Professor John O'Sullivan** is the leader of the multi-disciplinary Huntington's Disease Clinic based at the Royal Brisbane and Women's Hospital. The Clinic is highly valued by both patients and carers and makes a unique and valuable contribution to Queensland families affected by HD. John is also a regular contributor to the Huntingtons Queensland Professional Committee and his knowledge of support organisations as well as his clinical knowledge and expertise make a valuable contribution to the Association's functioning. We are grateful to him for his dedication, skill and ongoing support of Queensland families and awarded him an Honorary Membership.



**Gerry Doyle** – We were thrilled to present Gerry with Life Membership of the Association – the occasion even more special with the attendance of his family at the dinner. Gerry joined the Management Committee in 1994 and served as both Vice President and President until 2003 when his responsibilities as carer to his wife Alison required his full attention. He was again elected President in 2007 and still serves in that role.

Gerry has brought his own experiences of caring for a loved one and a great deal of energy to his appointment as President. He has overseen the transition of the Association towards a more professionally managed organisation, with sound judgment and sensitivity to the business needs of the Association, the welfare of its staff and families.

Gerry has also taken a leading role in ensuring the availability of suitable accommodation for young people requiring care and is a member of the State Younger People in Residential Care Reference Group.

Congratulations Gerry – it was with great pleasure that we have paid you this recognition.

**Barb Gray, Operations Manager**



## WELFARE NEWS

This past few months has been extremely busy here at Huntingtons Queensland for the Welfare Team and we are so very happy that Lesley has now joined our team to help us out with this workload. As most of you will know, Lesley joined our team as the new full-time Welfare Officer back in August and I (Christine) moved into the Senior Welfare Officer position. Thanks to all our lovely families for welcoming Lesley to the Team. Over the recent months Lesley has been out and about meeting with families from the Sunshine Coast, Pine Rivers, Peninsula, Brisbane North and Gold Coast Regions and is making her way to Cairns during November to visit with families there. Please feel free to call anytime to say hello to Lesley if you've not heard from her yet – rest assured she will get around to meeting you all in the next couple of months. As a reminder, with the changes to staffing we also made some changes to the regions our staff visit. They are as follows:

**Christine:** Brisbane West, West Moreton / Logan, Toowoomba, Scenic Rim, Mackay, Bundaberg / Fraser Coast, and Burnett (shared with Theresa).

**Lesley:** Brisbane North, Pine Rivers / Peninsula, Gold Coast, Sunshine Coast, Cairns and Townsville.

**Theresa:** Brisbane South, Brisbane East, Gladstone / Rockhampton and Burnett (shared with Christine).

**So what else has the Welfare Team been up to?** Well, taking it back to August, Christine visited the **Mackay region** and met up with some of the local families for a lovely lunch at the Leagues Club. Also in August, Christine and Theresa ran a **respite holiday to Hervey Bay** which included a **whale watching tour** and an opportunity for the local families to meet other families from Brisbane. There's a write-up and some photos about the holiday on the next page. We'd like to take this opportunity to thank the following organisations and people for helping us plan and run this holiday:

- Hervey Bay Meals-on-Wheels – for a fantastic dinner;
- Rob and the team from Emeraldene Eco Lodge – for great accommodation and being fabulous hosts;
- Whale Song Whale Watching tours;
- Carer Respite and Carelink Offices from Brisbane South and Wide Bay Burnett Regions;
- And finally to Bill Wilson for helping transport families on this holiday. Thanks Bill!

Following the respite holiday Christine travelled to **Bundaberg** to catch up with families. Jumping forward to the September school holidays and we had a fun day of **min-golf** with our **Young Families Group** followed by a **sausage sizzle in the park**. Thanks to the Victoria Park Golf Complex & Function Venue for the free passes!

In between all this we've had carer and family support groups, school holiday activities and visits to nursing homes to register our under 65 clients for the YPIRAC initiative. PHEW! And now it's only a couple of month until Christmas and all those Christmas parties – be sure to check the diary dates on the front page to see when we are coming to your town!

One more thing I'd like to mention is that from December 12<sup>th</sup> to 15<sup>th</sup> we will be hosting our annual Young Families Respite Holiday. This year we are going to Hervey Bay (we can't get enough of that town now that we've been) and we think the kids are going to just love all the activities on offer including the new FREE water park on the Bay, as well as swimming, fishing, swimming, walking out on the flats at low tide, swimming, exploring the jetties and piers and did we mention swimming? A letter will go out soon looking for interested families, so if you'd like to come (or don't get your letter in the mail) be sure to phone or email us (emails on back page). So with all that's been going on, you can see we have been pretty busy – but we're never too busy for a chat, so please feel free to contact us. Take Care and Keep Safe.

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



## 2010 RESPITE HOLIDAY HERVEY BAY WHALE WATCHING CRUISE

From August 23<sup>rd</sup> to 25<sup>th</sup>, Christine and Theresa accompanied some of our families to Hervey Bay for a respite holiday and whale watching cruise – and what a couple of days it was!

Leaving from our Annerley office on the Monday at around 11am with seven family members and carers from all around Brisbane as well as the Gold Coast and Ipswich, we made a quick stopover in Caboolture to pick up a couple more people (and promptly lost Theresa along the way but we won't mention that). Eventually, we caught up again at a road side rest area for lunch before driving on to Hervey Bay.



Arriving in Hervey Bay we were met by another family from Nanango and were shown to our rooms at the Emeraldene Eco Lodge. Rob the manager was an exceptional host and the rooms were spacious and well equipped.

After a couple of hours rest after the long drive we made our way to the Hervey bay RSL Club where we met up with six more family and carers from the Maryborough and Hervey Bay region for a fantastic three course dinner that was accompanied by great banter and a few drinks. It was a great opportunity for people from other regions to be able to meet with others from the Huntington's Community.

Tuesday morning came with a few ominous clouds looming along with some fairly breezy winds, but nothing was going to dampen our spirits for the whale watching cruise this afternoon. (Plus Rob our host at the motel promised he'd send up a few prayers for us.) Joining us on the whale watching cruise were another six people from the local area including a family who weren't able to make it to the dinner the evening before. It was a little tricky getting a wheelchair down the ramp at the harbour to board the boat as the tide was out, but we managed. The boat, *Whalesong*, was well-equipped for people with disabilities and we enjoyed an afternoon of not only whale watching (we saw a good 20 or so different whales the captain tells us) but also a



sumptuous smorgasbord lunch followed by cheese and fruit platters for afternoon tea. Many of us managed to get some good photos of the whales breaching and they also gave good commentary on board the boat. In total we spent about five hours out on the boat.

After a lovely (quite ample) dinner from the local Meals on Wheels, everyone was ready for an early night. The next morning we were up bright and early for the return trip, except for Christine who left Hervey Bay to go north to Bundaberg to visit with families in that region. We hope everyone had a wonderful holiday! Now the challenge is to come up with as good a holiday next year.





National Conference  
on Huntington's Disease  
Brisbane • 9-10 September 2010

## A VERY CONNECTED CONFERENCE.....

Those affected with HD, their families and carers, health and allied health care workers, researchers and interstate HD association staff members and committee members all had the wonderful opportunity in September to connect and network at our recent National Conference. It was a chance to hear about the sophisticated research into HD that's taking place in Australia and in particular right here in Brisbane at The Queensland Brain Institute at The University of Queensland. The QBI is a wonderful state-of-the-art research facility that was kind enough to make their excellent conferencing facility available for our Conference...we thank them for their generosity and assistance. We'd also like to express our gratitude to our key note speakers researcher, Professor Gary Egan and Jimmy Pollard from the US and other researchers Dr Trent Woodruff, Associate Professor Helen Cooper, Dr Valentine Hyland, Associate Professor Nellie Georgiou-Karistianis and Dr Jennifer Thompson for their excellent presentations. It is encouraging to know that so many great researchers are working on behalf of the Huntington's community.

In addition to research updates we heard personal stories from Michelle O'Brien and Naomi Van Dijk who have developed [www.ourhdspace.org](http://www.ourhdspace.org) a wonderful website to connect and assist those affected with HD. Therese Alting reported on the history of HD in Australia and Jimmy Pollard shared his considerable wisdom and practical insights into caring for those with HD. Dr John O'Sullivan (Neurologist) and Cate Barrett (Speech Pathologist / Psychologist) revealed the services and advice being offered to Queenslanders by the HD Clinic at the Royal Brisbane and Women's Hospital. Our thanks also go to the panel members (including Pam Cummings and Robert Westley) for their valuable contributions.

Feedback received about the Conference overwhelmingly indicated a very successful event that provided information, education, knowledge and networking. Delegates were generally highly satisfied...they said "Something for everyone – professionals, family and carers!" and "Thanks so much for a fantastic conference. It was well run, interesting, informative and really inspiring." One of our founding members, Cliff Farmer extended his congratulations to the Committee, the National Conference Working Party, staff and volunteers on the running of the Conference. He acknowledged the planning and hard work prior to the Conference, the variety of speakers, a programme that held something for all attendees and said that he was proud to be a member of Huntingtons Queensland.



Conference key note speakers  
Gary Egan & Jimmy Pollard



Morning tea on the terrace at the Queensland Brain Institute



State-of-the-art research facility at the QBI



Mingling at lunch in  
the QBI grounds



## **SLEEP PROBLEMS & WEIGHT LOSS**

*Why do Huntington's patients suffer from sleeplessness, and why do they lose so much weight?*

This was the question which Ahmad Aziz sought to answer in the research which he undertook toward his PhD. Dr Aziz obtained his PhD from Leiden University in the Netherlands on Wednesday 31 March 2010. He was the first Leiden PhD researcher to obtain his doctorate funded by a Mosaic subsidy. Mosaic is a grant program for students from ethnic minorities so that they can complete a PhD research program.

An aggregating protein causes many of the symptoms of Huntington's Disease, an incurable and frequently fatal brain disorder. Mosaic winner Ahmad Aziz discovered that the abnormal protein also aggregates in the hypothalamus, the part of the brain that regulates the autonomic nervous system and the endocrine system. Ahmad Aziz investigated the severity and causes of a number of less well-known symptoms of HD: weight loss, sleep disturbances and a poorly functioning autonomic nervous system. He established that many patients suffer from weight loss and sleeping problems.

Abnormalities in the hypothalamus appear to account for some of these symptoms. The hypothalamus was an obvious suspect for Aziz, as it regulates the autonomic nervous system and the endocrine system. Aziz established that certain nerve cells are lost in a part of the hypothalamus. In this part as well as in other parts of the hypothalamus abnormal protein aggregates were found. These hypothalamic nerve cells play an important role in the maintenance of body weight and a normal sleeping pattern.

### **SLEEP AND DEPRESSION**

Many of the patients investigated by Aziz get to sleep too late and wake up later in the morning than healthy people. Moreover, it appeared that the further the sleep rhythm is displaced, the more depressive the patients are. These patients also suffer from more cognitive abnormalities.

The disruption of the sleeping rhythm could partly be due to a shift in the rhythm of the 'sleeping hormone' melatonin. That rhythm is regulated by the biological clock in the hypothalamus. Many Alzheimer's patients also have an abnormal sleep/wake rhythm. This can partially be corrected by light therapy and the administration of melatonin. Huntington patients might also benefit from such an approach.

### **WEIGHT LOSS**

Although the mutated HD gene mainly causes damage in the brain, it is expressed in virtually all tissues, even though it does not cause damage everywhere. However, Aziz demonstrated that weight



loss in the initial stages of HD is not the consequence of other symptoms, such as hyperactivity, but is directly related to the mutation. This indicates that the cause must partly lie in the peripheral tissues, such as muscle and fat tissue. The defective gene probably causes damage there as well.

Influence of the normal gene HD is caused by a mutation in the huntingtin gene. In the mutated gene the DNA sequence C–A–G is repeated too often. Aziz's research reveals that weight loss and the number of CAG repeats are directly correlated: the greater the number of repeats, the greater the loss of weight.

The number of CAG repeats in the normal huntingtin gene can also influence the symptoms of the disease. This is because each person carries two copies of the huntingtin gene. In a normal gene there are 35 or less CAG repeats. Huntington patients have one normal gene and one defective gene with 36 or more repeats. Aziz discovered that the number of CAG repeats in both the normal gene and the defective gene is important for the rate at which the disease progresses. However, the effect of the normal gene is small and is mainly important for understanding how the disease develops and for a correct interpretation of future drug studies. It follows that such studies must take into account the differences in the number of CAG repeats in both genes.

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Acknowledgement: Ahmad Aziz Leiden University Netherlands



### **TRANSLINK ACCESS PASS**

The Access Pass gives you unlimited travel on all Translink services except Airtrain, until it expires.

You don't need to touch on and off like a 'go card'. You just need to carry your Access Pass with you at all times while travelling in case you're asked to show it.

#### **You can apply if all these things refer to you:**

- you are a permanent Queensland resident
- you have a significant permanent physical or intellectual disability
- you can travel independently on TransLink services
- you've been assessed by a qualified health care professional as being unable to touch on or touch off with a Translink 'go card'. This includes if you're in a wheelchair and have limited fine hand movement.

#### **For detailed information contact:**

TransLink Access Pass  
GPO Box 50  
Brisbane Qld 4001  
Phone: **13 12 30** (24 hrs a day, seven dys / week)  
Website: [www.translink.com.au](http://www.translink.com.au)

**PLEASE REMEMBER!!!**

**2010 / 2011 Huntingtons Queensland  
membership renewals are due now!**



**SOME USEFUL WEBSITES.....**

Huntingtons Queensland	<a href="http://www.huntingtonsqld.com">www.huntingtonsqld.com</a>
Australian Forum	<a href="http://www.hdaustralia.org">www.hdaustralia.org</a>
Website for young people	<a href="http://www.ourhdspace.org">www.ourhdspace.org</a>
HD Advocacy Centre	<a href="http://www.hdac.org">www.hdac.org</a>
HD drugs	<a href="http://hddrugworks.org/">http://hddrugworks.org/</a>
Juveniles HD family site	<a href="http://www.jhdfamilies.co.uk/">www.jhdfamilies.co.uk/</a>
HOPES (Huntington's Outreach Program for Education at Stanford)	<a href="http://hopes.stanford.edu/">http://hopes.stanford.edu/</a>
Huntington Study Group	<a href="http://www.huntington-study-group.org/">www.huntington-study-group.org/</a>
Huntington's Disease Lighthouse	<a href="http://hdlighthouse.org/">http://hdlighthouse.org/</a>
European HD Network	<a href="http://www.euro-hd.net/">www.euro-hd.net/</a>

**TOMMY'S LISTENING LESSON**

*By Jimmy Pollard, written for HOPE, the annual magazine of the Huntington's Disease Association of Ireland, Spring 2008.*

A popular book calls listening a "sacred art." It certainly is! Listening is active, or so I've learned. For some of us, myself included, it's a skill that needs lots of practice to achieve mastery. I'm a person who has an answer on the tip of his tongue before a question is completed. I need to make a conscious effort to wait until my family and friends finish their sentences. While they're speaking to me, I'm looking into their eyes and struggling to impede my impulsive response to them. Not surprisingly, what I assumed that they were going to say was often different from what they actually said.

By nature I'm not a good listener. I'm not alone. There are others just like me. We tend to be one step ahead in our conversations with others. Moments of silence during discussions unsettle us. We feel compelled to fill silence with words. They often don't have to be relevant to the conversation! But they relieve our discomfort with silence. Huntington's Disease challenges people like us.

Actually, though, it challenges people with HD to an even greater degree. They have to interact with us! Some of them may depend on us for assistance in their daily lives. From moment to moment they live with the cognitive challenges of HD. These changes affect how well they can deal with those of us who cannot actively listen and can't wait to take our turn in a conversation.

HD impairs the efficient function of thousands of brain cells. This accounts for slower processing of information. It takes longer to take it all in, to think about what you want to say and then to actually say it. Before their HD began to show itself, folks did this instantly and unconsciously. Now the same thought processes take longer. It



may take one second or several seconds to respond to a question. In an ideal world their families and communities would be made up of people **not** like me. Their worlds are better populated with spouses, children, parents and neighbors who do listen and can wait for an answer better than I can.

Tommy was a dear friend. I met him after HD had begun to affect his speech and thinking. Even then, he was a master teacher to me as he explained some of the ways that HD challenged his thinking. One evening he was reminiscing about his family with me. He told me about his daughter's childhood. He spoke one sentence at a time with extended pauses before he'd share his next thought. It was a warm conversation, just Tommy and me. I was fascinated by the details of his life.

As tactfully as I tried to keep the conversation going, I sensed that Tommy was becoming increasingly exasperated with me. Increasingly unnerving tension began to replace the warmth of his reminiscences. I wasn't sure what was happening between us. He told me about his daughter's first day of school decades ago now. He paused. I waited for his next thought. I waited a bit longer but not long enough. At the moment that he began speaking again, so did I. As soon as he heard me speak, he stopped. I apologized for stepping on his words and waited for him to begin speaking again.

I waited again. As if we had choreographed it, we both began speaking at precisely the same second. I apologized one more time. I sensed Tommy was a bit more annoyed. I felt that a greater apology was in order. "Tommy, I'm sorry that I keep tripping over your words. I am trying to listen but I'm not doing a very good job of it. Again, I'm sorry, Tommy."

He looked at me and said nothing for several seconds. Hoping that he would, I waited a few moments longer. Not wanting to make the same mistake yet again, I waited even longer. Tommy began to speak. "Every time that you do that it sets my timer back to the beginning."

Without missing a beat, I asked, "You mean every time I step on your words you have to start over again?" I realized immediately that I had done it again! I failed to wait. Too embarrassed to apologize again, I waited for his answer. I waited so many seconds that I was sure he had given up on me and wasn't going to say anything else.

Just then, I was silently lamenting that my impatience had ruined our warm moments of reminiscing, he said, "Yes."

I said, "Tommy, tell me if I understand this now? Every time that I don't wait long enough to let you speak, you have to start thinking all over again about what you're going to say, right?"

I waited again. Those twenty to thirty seconds of silence seemed like a lifetime to me. Then, just when I thought he would say nothing further, he said, "It's annoying." I finally understood that every time that I stepped on his words or asked the same question again because I thought he didn't understand me, he had to begin to formulate his idea and plan his answer all over again. How annoying it must have been to think and rethink his answer simply because I wasn't giving him enough time! Suddenly it dawned on me that I had been



doing this for years in our conversations. I recalled the many times that I believed he was irritable or just didn't want to speak with me.

I was well aware that many people with HD had difficulty organizing their thoughts and expressing them. I was unaware, though, of my role in making it even more difficult for him. I waited for a few moments to pass. I simply said, "I'm sorry, man."

Tommy looked up at me for a few seconds. "That's OK, Jim." I let a few more moments pass. "My wife dressed my daughter so cute." He paused a few more seconds. "She put ribbons in her hair." I listened, smiled and waited. "She's twenty-three now." The reminiscing continued.

I still have difficulty waiting through silent pauses in conversations. Sometimes I have to repeat silently to myself over and over, "Silence is golden." Or "Listening is a sacred art." I've learned that I have to sit down, turn off the TV, close the door and actively listen. I still have to remind myself to not set his ticker back to start. I'm getting better at it, though.

Thanks, Tommy! Lesson learned. Thank you, teacher, for patiently enduring my impatience. Had I only understood earlier.

### ARE YOU A CARER OR FORMER CARER WHO WANTS TO UPSKILL?



Do you want a job but can't afford to upskill? Carers Qld may be able to help you.

Carers Qld's Training & Education Unit is offering Certificate III in both Community Services Work and Aged Care in 2011, to be held at their offices on Brisbane's northside and southside.

Act now and you could have a nationally recognised qualification by the end of 2011. If you are interested talk to one of their friendly staff about eligibility.

Contact Details:

Carers Qld's Training & Education Unit

Phone: **1800 242 636**

Email: [rtoenquiries@carersqld.asn.au](mailto:rtoenquiries@carersqld.asn.au)



### NO INTEREST LOAN SCHEME (NILS)

Carers Qld runs a No Interest Loan Scheme (NILS), a community based programme to assists carers to access fair, safe and equitable credit for the purchase of essential household goods eg fridge, washing machine, TV, bed and to also fund the cost of other essential needs like health aids and motor vehicle repairs.

NILS is not for emergency relief, bond or rent money, living expenses or debt repayment. Borrowers must meet certain eligibility criteria to participate and can borrow between \$200 and \$1,200 with repayment period being between 12 and 24 months. For detailed information, contact your local Carers Qld office.



## POWER OF ATTORNEY ARRANGEMENTS – ADVICE FROM CENTRELINK

A Power of Attorney entitles a person to act on behalf of another and may include the power to make financial, personal or medical decisions. The purpose of a Power of Attorney is to make sure that a trusted person attends to essential matters at the right time.

A standard Power of Attorney can remain in place until it is revoked by the person who made the appointment, or until he or she loses their legal power. This is in contrast to an enduring Power of Attorney, which will continue after the loss of the legal capacity to make decisions.

Power of Attorney legislation is different in each state and territory so it is important to understand the process and obtain sound advice and information.

For detailed information, visit [www.centrelink.gov.au](http://www.centrelink.gov.au) or call the Centrelink Retirement Line on **13 23 00** or visit your nearest Centrelink Customer Service Centre.

## FUND RAISING

### FINANCIAL ASSISTANCE

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

P Jinks	Despa Sendra	William van Heel
John Gauci	Sinah Hoskings	Cindy Benjamin
	Mark White	

### VICTORIA PARK GOLF CLUB

Our kind thanks go to Trent and Bryony at the Victoria Park Golf Complex & Function Venue for kindly donating Conference speaker gifts of Queensland wine and also for providing free admission to their putt putt course for our recent young family outing.

*We thank them for their generosity.*



### DONATIONS

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

The raffle of the beautiful quilt kindly donated by Crazy Quilters Caboolture Inc raised just over \$1,400 – so our very sincere thanks to them for their generosity.

Congratulations to the holder of the winning ticket number 0275, Brook Keune!



# World Congress on Huntington's Disease



Melbourne Convention and Exhibition Centre  
Australia  
11-14 September 2011

For information go to [www.worldcongress-hd2011.org](http://www.worldcongress-hd2011.org)



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**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 2010/11:**

President	Gerry Doyle
Vice President	Position Vacant
Secretary	Pam Cummings
Treasurer	Darren Careless
Members	Jan Szlapak
	Trish Flitcroft
	Alan McKinless

**Staff Members:**

Operations Manager	Barbara Gray
Senior Welfare Officer	Christine Parfitt
Welfare Officer	Lesley Frazer
Welfare Officer	Theressa 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> December 2010. Please email or post articles, details above. *Please be aware that the Newsletter is published on [www.huntingtonsqld.com](http://www.huntingtonsqld.com)*

