



October 2012

# NEWSLETTER

## HUNTINGTONS QUEENSLAND

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### FROM THE PRESIDENT

Dear Friends

With this Newsletter I am pleased to advise you all that in September Cheryl Miller joined Huntingtons Queensland in the role of Executive Officer. Cheryl has had considerable experience with not-for-profits as well as with commercial organisations. I am sure that over the next few months Cheryl will be meeting many of our families and supporters and would be more than happy to receive a phone call if you have issues that you would like to discuss with her.

Fiona Kerr also joined us as a part time Welfare Officer in October and has had a lot of experience with organisations similar to ours.

The Annual General Meeting was held on September 26<sup>th</sup> and I am pleased to announce two new members to our management committee, Emma Kyle and Gwen Pratten. Gwen will be familiar to you all and Emma is a lawyer working in Redcliffe. Kerry Stewart and Esther Elliott have retired from the committee.

At the AGM our guest speaker Dr Trent Woodruff provided an excellent talk on his research project into anti-inflammatory drug PMX205 into the HD mouse model. A paper prepared by Trent appears on page five of this Newsletter.

It is worth recalling this project's history. On 5<sup>th</sup> June 2008 the Courier Mail contained an article "Anti-inflammatory drug gives hope for patients with brain diseases" by the Health Reporter Janelle Miles. Following an approach by an HD family member I contacted the University of Queensland and met Trent and Dr Stephen Taylor. From this initial meeting our support for the research was developed and I would like to thank The John and Wendy Thorsen Foundation for their financial support that has made all of this possible. I am very proud of the support that Huntingtons Queensland has given this project as it means we have active research in Queensland using local researchers and our local HD families and clinicians.

The best to you all.

**Gerry Doyle, President**

### CALENDAR – NOVEMBER & DECEMBER 2012

Wed 21/11/12	Combined Brisbane East Support Group & Brisbane Carers' Xmas party
Mon 26/11/12	Pine Rivers Peninsula Family Support Group Xmas party
Wed 28/11/12	Burnett Family Support Group Xmas party
Fri 30/11/12	Toowoomba Family Support Group Xmas party
Mon 3/12/12	Gold Coast Family Support Group Xmas party
Wed 5/12/12	Coffee Catch Up Xmas party
Tue 11/12/12	Day Centre Xmas party
Wed 12/12/12	Sunshine Coast Family Support Group Xmas party
Sun 16 - Wed 19/12/12	Family respite holiday – Hervey Bay
To be advised	Ipswich Family Support Group Xmas party

## FROM THE EXECUTIVE OFFICER

Yes there is a new person at the 'helm' and yes it is a 'new title'. I hope I can bring to Huntingtons Queensland the dedication, caring and inspiration which precedes me.

Rather than re-invent the wheel I have inserted here a biography which was written about me by an obviously biased person, but which will give you a bit of my history.

*Prior to joining Huntingtons Queensland, Cheryl held a number of positions in the not-for-profit, charities and communities sector with organisations such as Royal Queensland Bush Children's Health Scheme and Lifeline Community Care in Queensland.*

*An ebullient and tireless leader, Cheryl takes a collegial approach to management and is widely respected for her direct and equitable approach and strategic vision.*

*During her tenures, she has overseen the consistent performance of staff retention and increased staff morale in the organisations she has worked with. She has been instrumental in significant increases in organisational profiles and has overseen substantial growth in donor contributions.*

*Prior to moving to Queensland Cheryl had a successful and expansive career spanning international sales and marketing, tourism and many years serving as a volunteer board/committee member for a number charities and organisations including Red Cross, Shepherd Foundation, Royal Blind Society and Australian Business Limited. She was Chairman of the Illawarra Export Corporation and holds an Australian Institute of Company Directors Diploma and is a Fellow of the Australian Institute of Company Directors.*

*Cheryl has lived and worked not only throughout Australia but also in areas such as Iraq, Kuwait, United Arab Emirates, Jordan, Algeria, Tunisia, Taiwan, South East Asia and Europe and as such has a sensitivity to diverse cultures, etiquettes and social protocols among widely differing cultures and nations. She has been widely recognised by all forms of media for her work in not only varying cultures but in what would once have been called male dominated work place environments.*

*Cheryl was born in Seymour, Victoria and completed her education in Melbourne prior to moving to Adelaide, South Australia from where she actively pursued her international career.*

*Michael, a mining engineer, met Cheryl whilst they were both working in Tennant Creek, in the Northern Territory. They now reside in Cheryl's adored Paddington, Queensland.*

So that is all there is to me other than as said I live in Paddington with my husband Michael and I just absolutely love where we live and our community.

I have been in my role here for approximately six weeks and know that this is an organisation that I am proud to be associated with. The dedication and inspiration which is so evident in the staff and volunteers is a joy to be enveloped in. I have had the opportunity to meet a few of the day centre participants and will be making my presence known by visiting support groups around the State given time. I welcome the opportunity to meet with anyone who wishes to call into the office or give me a telephone call. If there are any ideas which I could put into place to help me to help you I would be grateful to hear from you.

Finally, my thought for this Newsletter...

*A good decision is the result of experience and experience is the result of many wrong decisions. Aesop*

**Cheryl Miller, Executive Officer**

## FROM THE WELFARE DESK...

**Day Respite** Bowling continues to be a popular activity with much good natured competition to achieve the best score of the day. A visit to the Museum at Southbank to view the Mummy (Secrets of the Tomb) Exhibition followed by a picnic by the River was a popular outing; all clients appeared to enjoy the day.



**Coffee Catch-Up (CCU)** CCU Brisbane ladies and some of our Toowoomba ladies met with Christine, Tressa and a genetic counselling student for the Carnival of Flowers ‘Flowers, Food and Wine Festival’ in Queens Park in the leafy heart of Toowoomba. Some of the ladies had met previously on respite holidays and recognised one another whilst others made friends for the first time. The CCU group is becoming a very cohesive and supportive group.

**HYPe (Brisbane)** Movies at Browns Plains followed by ‘all you can eat Pizza’ for lunch was a great success with our young HYPe members. Six families joined Christine, Tressa and André McDuling. Our families really take pleasure in these activities and all ages enjoy the chance to socialise with new friends. Some of our ladies were interviewed by a journalist and had their photos appear the following day in the Toowoomba Chronicle. Superstars!!!

**HYPe (Toowoomba)** Bowling followed by lunch is a regular and very popular school holiday activity for our young Toowoomba HYPe members. Five families enjoyed socialising as well as the fun of the games which are becoming increasingly competitive.

**Family Support Group Activity** Our Brisbane East Family Support Group voted a recent barbecue by the bay a success and have requested another in the months to come. It’s been a great opportunity to enjoy beautiful Brisbane before the weather heats up too much.

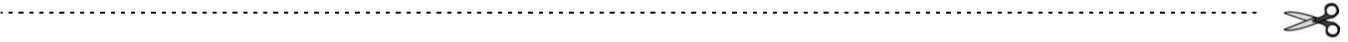
**Cairns** In August Christine travelled to Cairns (with her mother in tow to look after little Lauren) to visit with families from Port Douglas to Tully. It was a busy but enjoyable trip and it was good to finally meet up with some new families.

The welfare team is delighted to welcome Fiona Kerr to its ranks and looks forward to introducing her to our clients and their families. More about Fiona on page nine.

**Christine Fox (Senior Welfare Officer) along with Theresa Byrne (Welfare Officer & Day Centre Facilitator)**

## DONATIONS TO HUNTINGTONS QUEENSLAND

If you would like to donate to Huntingtons Queensland, please cut off the slip below and return it to our office with your payment. Alternatively you can donate online – directions on page ??? of this Newsletter. All donations over \$2 are tax deductible and we will send you a receipt for taxation purposes.



### Personal Details:

Title..... Name.....

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.....Postcode.....

Telephone..... Mobile..... Fax.....

Email (please print clearly).....

### PTO for Payment Options

### SUPPORT FROM THE NORTH

On Tuesday the 2<sup>nd</sup> of October Karen and Bedford Astley presented our Association with a cheque for \$2000 generously raised by members of the North Queensland District Grand Chapter of the Order of the Eastern Star. We sincerely thank the Order for their wonderful support.

The Order of the Eastern Star is part of the Freemason (Masonic) family of orders. It is the largest fraternal organisation in the world to which both men and women can join. It is a non-denominational order with the main requirement for membership being a belief in a supreme being. The order centres around the lessons learned from five heroines named in the bible with each representing an important woman and virtue in our lives. These are:

- Ada, Jephthah’s daughter, representing a daughter and fidelity;
- Ruth, representing a widow and constancy;
- Esther, representing a wife and purity;
- Martha representing a sister and faith;
- Electa, representing a mother and love.



Cheque presentation — from left Cheryl Miller (Executive Officer, Huntingtons Queensland), Bedford Astley (Worthy District Grand Patron), Karen Astley (Worthy District Grand Matron) both from North Queensland District Grand Chapter, Order of the Eastern Star and Gerry Doyle (President, Huntingtons Queensland)

While men can join the order, women are the chief officers, and men take second place. The Order is found in all parts of the world and has raised millions of dollars to support national and local charities. In Australia members have donated thousands of dollars each year to various charities, with the Star Gardens Homes for the Aged in Beaudesert being a project of the Order here in Queensland.

If you are interested, more information can be found on the website at [www.oesqld.com.au](http://www.oesqld.com.au)

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Name on Card ..... Signature ..... Date.....

*Thank you so much for your very kind donation to Huntingtons Queensland! We will post you a tax receipt. Please retain a copy of your completed slip for your records and mail, fax or scan & email a copy to:*

Huntingtons Queensland PO Box 635 Annerley Qld 4103  
Tel: (07) 3391 8833 Fax: (07) 3391 0443 Email: [admin@huntingtonsqld.com](mailto:admin@huntingtonsqld.com)

## TERMITES NOW WRAPPED UP AND GONE

To our consternation, in January this year we discovered we had termites living in the wall above the fireplace in the upstairs office at Florence Dannell House (our HD centre in Annerley). The building was fully inspected and a sample sent to DAFF (Qld Department of Agriculture, Fisheries and Forestry).

DAFF identified West Indian drywood termites (*Cryptotermes brevis*), native to northern South America, which have now spread throughout the world. It was first recorded in Australia in the 1960s and is established in Brisbane, Maryborough, Bundaberg and Rockhampton; it has also been found in Sydney and Canberra.

Colonies may last for more than ten years. They are small – usually no more than 1,000 specimens - but a large number of these colonies may co-exist adjacent to one another in the same building or in the same piece of timber. Twenty colonies have been recorded in a single wooden door. It is one of the world's most destructive termites, its presence is usually not noticed until the timber it is infesting collapses. In Australia, it attacks structural timber only - furniture, house stumps etc – but has not been recorded in dead trees or shrubs. The species has only relatively recently been found attacking such resources in northern South America.

Thankfully, DAFF funded the expensive treatment of our building. Over the last weekend in September the entire building was enshrouded in tarpaulins and gas was pumped into both floors of the building. Repair work will be carried as soon as possible. If you'd like to contribute to our repair fund, please use the slip on page three of this Newsletter.



## MEETING ROOM FOR HIRE

The ground floor of Florence Dannell House makes for the perfect venue hire. It's suitable for meetings, educational courses and small business seminars. Its features include air con, seats 60, disability access, kitchen and amenities, car park, close to bus and train. Rates are reasonable at \$100/day Mon-Thu, \$155/day Fri-Sun, \$40/hour Mon-Thu and \$60/hour Fri-Sun. Video, PA system, data projector and screen \$20/item. The bond is \$150.

Please pass the word around to your friends and associates. Brochures are available should you wish to place one in your local supermarket or corner store. Please contact Anne on 3391 8833 or [anne@huntingtonsqld.com](mailto:anne@huntingtonsqld.com) if you'd like more information.

## REPORT ON UQ HUNTINGTON'S DISEASE STUDY

Presented by Dr Trent Woodruff to Huntingtons Queensland AGM 26<sup>th</sup> September 2012

### Overview

Our group is researching the role of the innate immune system, and inflammation, in the development of disease symptoms and pathology in rodent models of Huntington's disease (HD). Specifically we are focussing on a major component of our immune system called the complement system. Our group has developed a potent and orally active drug which inhibits a major inflammatory product of the complement pathway, the complement factor C5a. We aim to test this therapeutic in established animal models of HD, to see if targeting this complement factor, maybe a useful future therapeutic option to treat HD. These studies are therefore primarily pre-clinical studies to determine the efficacy of this class of novel drugs at treating symptoms and the disease process in an animal model



of HD. If successful, our results will lead the way for future clinical trials with this compound, or related derivatives in HD. We are also exploring the role of this inflammatory system in patients with HD. We aim to collect blood from patients, and healthy partners/carers to identify if these complement pathways are increased in patients with Huntington's.

### July 2012 Research Update

We have now a well-established R6/1 transgenic Huntington's mouse colony in the Queensland Brain Institute animal facilities at UQ, which was sourced from A/Prof Anthony Hannon (University of Melbourne). We are using these mice in our studies exploring the role of complement in HD. In addition, during the 2011 World Congress on Huntington's Disease held in November in Melbourne, Dr Woodruff met with Prof William Yang (UCLA) who is using a new mouse model of HD. These mice, termed BACHD mice, express the full-length mutant human huntingtin gene, and are thus to date, the most relevant animal model for HD. In December 2011, Dr Woodruff visited Prof Yang, to arrange shipment of these mice to our Brisbane laboratories. In May 2012, we obtained these mice, and are now establishing a colony of these mice within the Queensland Brain Institute animal facilities at UQ. These mice will be a great boon to our research, and they are the first BACHD mice to enter Australia. We hope to share these mice with other HD researchers throughout Australia, to increase our knowledge about this disease.

Using the R6/1 mouse model, we have now confirmed that brain tissue from diseased show a large upregulation in inflammatory factor biosynthesis, in line with our hypothesis that this innate immune system is involved in the disease process of HD. We are continuing research into this, and are examining the expression of a wide variety of complement system markers to determine which specific factors are involved in disease pathology. We aim to extend these studies to the BACHD mouse, to determine if this is a shared pathology across multiple models of HD. Furthermore, this expression correlates with our data obtained in the laboratories of Prof Richard 'Faull and Dr Henry Waldvogel at the Neurological Foundation Human Brain Bank, Auckland, New Zealand. In 2011, we showed that complement factors were expressed and increased in post-mortem HD brains, compared to non-diseased post-mortem brains.

We are continuing our drug dosing experiments in the R6/1 transgenic mouse Huntington's line, we have established at UQ. Mice are receiving the orally active complement C5a receptor antagonist, PMX205, in the drinking water daily from 6 weeks of age, until the end-stage of disease in these mice (~32 weeks of age). We are examining these drug-treated mice using standardized motor and cognitive behavioral tests, and determining the effects of drug treatment on mice survival. Importantly, we will also examine the brains of these mice post-mortem, to determine the mechanisms of any disease protection we may see. These drug experiments are time-consuming and extensive projects, which will continue into 2012 and 2013. In addition, we aim to drug-treat the BACHD mice, again to see if protection can be seen in multiple HD models, and in order to build up our tissue samples and obtain strong supportive pre-clinical data.

### Clinical Studies

We have now obtained full approval from Human Research Ethics Committees (Royal Women's and Brisbane Hospital, and University of Queensland), to obtain blood samples from HD, and healthy volunteers, to examine the expression of inflammatory markers. Our hypothesis is that HD patients will have increased levels of complement and other inflammatory factors, which contributes to disease progression. These bloods will be collected in the HD clinics run by Dr O'Sullivan. Please see the end of this report for information on this clinical study.

Presentation of our work at National and International Meetings:

Mr John Lee and Dr Trent Woodruff attended the World Congress on Huntington's Disease in Sep 2011, and presented posters of their work supported by the Australian Huntington's Disease Association (Qld) Inc. In addition, Dr Woodruff presented his work in the renowned HD laboratories of Prof William Yang (UCLA), and Prof Paul Muchowski (UCSF) in 2011, which was well received. These collaborations strengthen the international link between our groups.

### Summary

We are continuing our research into the role of complement in Huntington's disease and are undertaking animal trials with our complement inhibitor. The funding provided by the Australian Huntington's Disease Association (Qld) Inc, has allowed us to gather important preliminary data, which was essential for the success of our NHMRC grant in 2011. We are sincerely thankful for this funding, and aim to increase the knowledge of the causes and progression of this disease, in the hope that future therapies can be identified. The continued funding from Huntington's Queensland will enable our continuing research into this devastating disease.



**Our HD Team**

Dr Trent Woodruff (HD Group leader)  
 A/Prof Peter Noakes  
 Prof Steve Taylor  
 Dr Susanna Mantovani (HD Post-doctoral fellow)  
 Mr John Lee (recipient of the Huntington's Qld Scholarship)

**HD Study – HD Patients and Healthy Volunteers Needed**

What is required: A single 20ml blood sample collection (ie approximately one tablespoon)  
 Signed consent  
 Brief questionnaire and examination for HD patients

Who can participate: Males and females over 18 years of age  
 HD patients and healthy volunteers

For details please contact Dr Susanna Mantovani on 0468 753 805 or [s.mantovani@uq.edu.au](mailto:s.mantovani@uq.edu.au)

**Shooting the messenger with single-stranded RNA gene silencing**

New 'single-stranded RNA' gene silencing drugs could be safer & more effective to treat Huntington's disease

By Dr Nayana Lahiri on September 24 2012. Edited by Dr Ed Wild. Courtesy <http://en.hdbuzz.net>

*After huge leaps forward in recent years, we're edging ever closer to human trials of huntingtin lowering or 'gene silencing' as a potential treatment for Huntington's Disease. Newer, better and safer techniques are always welcome and the announcement of 'single-stranded RNA' silencing is causing quite a hubbub. What's it all about?*

Gene silencing drugs work by telling cells not to make the huntingtin protein, the cause of damage in Huntington's disease. They do this by interfering with the cells' protein-making systems.

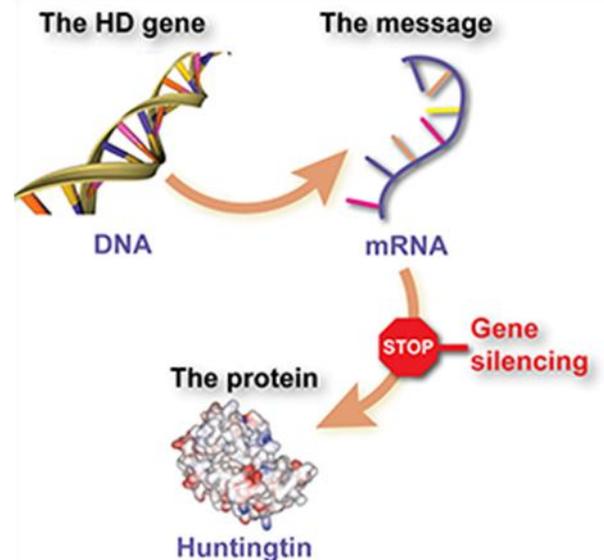
There are two main types of gene silencing drug: **anti-sense oligonucleotides (ASOs)** and **RNA interference (RNAi)**. This article is about RNA interference.

While pushing towards clinical trials as rapidly as possible, scientists have also been working on developing a new, and hopefully improved, RNA interference technique. To explain the differences from existing techniques we need to explain a bit about how genes are read to make proteins. Stick with us — it'll be worth it!

**What are DNA and RNA?**

DNA is the blueprint for making humans. It is a long molecule made up of stuck-together bits called **bases** which come in 4 'flavours' — C A G and T. These are the letters in which our genetic code is written.

The DNA 'double helix' is made up of two strands that line up side by side. Each strand is a string of bases, and the two strands are held together by chemical bonds between the bases on opposite strands. A pairs with T, and C pairs with G.



Gene silencing reduces the manufacture of a chosen protein, by preventing the mRNA message being read by cells



To get from DNA to a protein, a ‘working copy’ of the DNA needs to be made. The copy is called ‘messenger’ RNA, or mRNA. RNA is closely related to DNA but looks a little different. mRNA is the template which tells a cell how to put a protein together. Whenever a cell makes any protein — including the huntingtin protein — it does so by reading the instructions in the mRNA that corresponds to that protein. Interfering with huntingtin mRNA — or ‘shooting the messenger’ — prevents the huntingtin protein from being put together, and is the basis of gene silencing in RNA interference.

**OK — back to gene silencing**

So far, RNA-based gene silencing techniques have used double-stranded RNA molecules, called **siRNA**. Double-stranded RNA was needed until now, because single-stranded RNA is destroyed by the cells’ own garbage-clearing mechanisms before it can do any silencing.

Once inside cells, the double-stranded RNA needs to separate into single strands to let it bind to the huntingtin mRNA message molecule. Then an enzyme in cells chews up the mRNA, so that the mutant protein never gets made.

We know that this way of doing things can dramatically decrease the amount of the mutant HD protein made in cells. What we are less sure about is whether the unwanted strand that separates off has any bad side effects on cells. There is a possibility that the body might launch an attack on the leftover strand and cause harm. Another possibility is that the leftover strand might bind to other mRNA, and prevent other important proteins from being made.

Single-stranded siRNA drugs could combine the silencing power of double-stranded RNA with the ability of single-stranded molecules to spread throughout the brain.

Double-stranded siRNA molecules don’t spread very far within the brain, making treating large brain areas difficult.

A final difficulty of double-stranded siRNAs is that they need to be packaged up in a complicated way in order to get them to the right tissues for them to do their job.

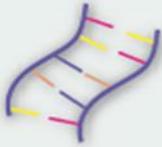
There have been studies in mice and monkey animal models of Huntington’s disease which showed that siRNAs are safe and effective, but scientists are a cautious bunch because we have to be really sure about safety before giving any treatments to precious humans. The last thing we want to do is make HD worse.

**Single-stranded siRNA**

One idea for reducing the risk of bad effects of RNA interference is to produce a single-stranded siRNA. But how could we overcome the stability problem — that annoying habit of cells of chopping up the single-stranded RNA drug?

After a lot of hard work, a group of researchers headed by David Corey in Dallas, in collaboration with ISIS pharmaceuticals have just announced they’ve finally cracked it. To give you an idea of the excitement this has caused, it was announced in not one, but two ‘back-to-back’ articles in the same edition of top journal Cell. Quite a scoop!

By making some chemical modifications to previous attempts, Corey’s team have made a single-stranded siRNA, and were able to

	Stable in cells?	Good silencing?	Spreads far?
 Double-stranded siRNA	✓	✓	✗
 Single-stranded siRNA	✗	✗	✓
 Modified Single-stranded siRNA	✓	✓	✓

Single-stranded siRNA drugs could combine the silencing power of double-stranded RNA with the ability of single-stranded molecules to spread throughout the brain.



package it in a simple salt water solution. They successfully injected the single-stranded siRNA into the fluid spaces which surround the brain in a mouse model of HD, and were able to show that it binds to huntingtin mRNA and prevents the HD protein from being made.

### **Win-win-win?**

What's more, unlike double-stranded siRNA drugs that have been tested before, the effects of single-stranded siRNA spread throughout the brain rather than being confined to the small area near the injection. In these mice at least, single-stranded siRNA produced a win-win: it was stable and it spread further.

Not content with that, they took things further. By slightly altering the structure of their molecule, they could also create a single-stranded siRNA which only blocked production of the **mutant** HD protein and didn't prevent the normal version of the HD protein from being made. They did this by targeting the siRNA to the abnormally long 'CAG' stretch in the HD gene. With a single-stranded siRNA we don't need to worry about what a second strand might be doing, and by targeting just the mutant huntingtin mRNA there's less concern about the possible effects of stopping production of the normal HD protein.

### **What next?**

So this new method looks safe and effective in mouse models. Now we need to make sure it is safe and effective in other, larger animal models before even considering going into human trials. That's happening now!

### **Remaining questions**

A few questions will need to be answered before single-stranded RNA interference can be tested in people. First, there are some other genes with a stretch of CAGs in them. We don't yet know if introducing single-stranded siRNAs targeting those CAG stretches might inadvertently switch off other important genes. Second, the delivery problem. How are we going to reach the important parts of the brain of Huntington's disease patients? Luckily, researchers in HD and other diseases are already working on this. A trial of a similar drug made from single-stranded DNA is being trialled in motor neuron disease (ALS) right now.

Finally, how are we going to measure and monitor the effectiveness of treatment? In animal models, we can do this by looking at brain tissue and measure how much huntingtin protein is made. This is a lot more tricky to do in humans, but top scientists are working on it and we think we're ready to start trials in Huntington's disease patients.

### **More potential uses for single-stranded siRNA**

A final sneak preview of another possible use of single-stranded siRNA. Researchers are also looking at using it in combination with stem cell research. Basically, they are working on taking skin cells from individuals with Huntington's disease, and turning those skin cells into neurons. Those neurons could then be treated with single-stranded siRNAs to reduce the levels of harmful HD protein before transplanting them back into the brain.

It'll be many years before the combination of single-stranded siRNA with patient-derived stem cells might be used as a treatment, but it's a neat idea and good to know all avenues are being explored. Meanwhile we expect single-stranded siRNA to progress fairly rapidly towards clinical trials.

## **HELLO FROM FIONA KERR**

This is just a brief note to introduce myself as the new part time Welfare Officer. I'll be supporting individuals and families on Brisbane's Southside, the Gold Coast, Cairns and Townsville.

Many years ago I trained as a nurse in my native UK and then moved into the community sector. My dad is Australian so in 1996 I came out for the whole backpacker experience and I haven't made it back yet. Here I've worked in a variety of settings: disability sector, specialised employment services, child protection and most recently in housing with families in crisis. Outside of work, my hobby is to do as little as possible but that's proving difficult with a couple of very active kids.

I started with Huntingtons Queensland on October 9<sup>th</sup> and so far it has been an extremely interesting experience. I look forward to meeting as many of you as possible.



## INAUGURAL HIGH TEA SUCCESS



On Sunday the 16<sup>th</sup> of September a small group of ladies gathered together to raise funds for our Association. The afternoon tea was hosted by florist, Merrilyn Brown, who owns the lovely florist shop, Flowers by the Bay, at Gumdale. Merrilyn has a dear friend who is affected by HD and she wanted to help...to make a 'little bit of difference'. So Merrilyn invited her friends, baked some delicious goodies (by the way, this lady hates cooking) and set out her Grandmother's beautiful Royal Albert 'Country Roses' tea set. Her friends arrived, many of them bringing yet more goodies and one friend brought her coffee machine. From just this small gathering and a few people who could not attend, Merrilyn raised \$500...that's a very nice 'little bit of difference' to our Association. Thanks so much to Merrilyn and her generous friends.

If you would like to hold your own high tea, or perhaps a wine and cheese night or cocktail party in aid of our Association, please contact Anne on 3391 8833 or [anne@huntingtonsqld.com](mailto:anne@huntingtonsqld.com) for more information.



Merrilyn in the middle with two of her guests

## STORY

Whilst on the subject of making a difference, our Senior Welfare Officer, Christine Fox chose the following story for this edition. We would like to definitively state the author's name, but we can't. Perhaps it is Loren Easley who refers to it as 'The Starfish Poem' or perhaps it's Jack Canfield and Mark Hansen who wrote "Chicken Soup for the Soul" where they relate this story in reference to a friend of theirs who was walking on the beach. Nonetheless, it is a fine notion.

### One at a Time...

*Early one morning a man was walking down a deserted beach. As he walked along, he saw a little girl in the distance. As he came near he saw that she kept picking up something and throwing it out into the water. Time and time again the little girl kept hurling things into the ocean.*

*As the man came even closer, he noticed that she was picking up starfish that had been washed up on the beach and, one at a time, she was throwing them back into the water. The man was puzzled and approached the little girl and said, "hello, I am just wondering what you are doing".*

*"I'm throwing these starfish back into the ocean. Last night's storm washed them up onto the shore and if I don't throw them back into the sea they will all die."*

*"I understand" the man replied "but there must be thousands of starfish on this beach. You can't possibly get to all of them, there are simply too many. And don't you realise that this is probably happening on hundreds of beaches all up and down this coast. Can't you see that you can't possibly make a difference?"*

*The little girl smiled, bent down and picked up yet another starfish and as she threw it back into the sea she replied, "made a difference to that one!"*



## LAUNCHING ENROLL-HD

Over the past year, Enroll-HD's Project Management Team, Steering Committee and a series of Working Groups have been planning, consulting, and working together to launch Enroll-HD, a worldwide observational study for Huntington's Disease families. This new study will combine the existing REGISTRY and COHORT longitudinal clinical observation studies of HD

and also add new clinical sites in Latin America and other regions of the world.



The first set of clinical sites to join Enroll-HD will be those that participated in COHORT. However, the transition from COHORT over to Enroll-HD has not been as smooth as originally hoped with the study start-up process-drafting of the study protocol, development of trial procedures, institutional review board approval-causing an interruption in the study visit schedule. Despite these start-up complexities that the project team is actively addressing, Enroll-HD attained its "First Patient In" milestone on July 26, 2012, and has enrolled 35 patients as of September 12, 2012.

The University of Tennessee Health Science Center located in Memphis, Tennessee, USA was the first site initiated into Enroll-HD and also the first to recruit a patient into the study. Study Coordinator Kate Marshall has been heavily involved in getting their site established within the new study and transitioning patients from COHORT to Enroll-HD. "For the most part, our previous [COHORT] patients are excited to be part of the new study," says Kate, "if they can help in any way, most of them are willing to do that." She went on to mention that families are excited to participate together, and those who live outside of the Memphis area generally plan a day trip to do so. According to Kate, being part of the study "really gives people something to look forward to" and the convenience of flexible visit types and assessments helps the study run smoothly.

Kate Marshall and Dr. Mark Ledoux, the site's Principal Investigator, have been working closely with the Enroll-HD study team to test the overall study processes, assessment trainings and systems. Kate feels that one of the most important factors in this and any study is compliance. "Making sure everyone is doing the same thing is a big factor in making this successful."

Enroll-HD uses a customized user friendly and flexible online system for electronic data capture (EDC). Kate finds that having a global data entry portal and the ability to choose basic visits or add additional assessments is very convenient for the progress of the study. "The EDC is a great system with a user-friendly interface. Having a worldwide database of information will help us better understand the disease and explore new treatment options." Kate is enthusiastic about the study and feels that her patients are as well.

The University of Tennessee Health Science Center has been making a huge difference in the lives of patients and families with Huntington's disease and is a highly valued contributor to the study. On behalf of the entire Enroll-HD staff, we would like to thank Kate and everyone at her site for their participation in making Enroll-HD a success.

### Enroll-HD at the EHDN Plenary Meeting

The 7th European Huntington's Disease Network (EHDN) Plenary Meeting was held in Stockholm, Sweden from September 14-16, 2012. Two posters were presented by representatives from EHDN and CHDI to clinicians, scientists, EHA delegates and members of families affected by HD that were in attendance. The joint team



presentations included an overview of the Enroll-HD study as well as guidelines for "Developing Strategies for Global Compliance to Data Privacy and Data Protection in an Observational Non-Interventional Study of Huntington's Disease".

Olivia Handley, Global Project Manager for Enroll-HD, presented an overview of Enroll-HD during the plenary session on the last morning of the conference. In addition, Olivia made a special Enroll-HD presentation to the EHDN Young Adults Working Group providing an overview of the study procedures and suggesting reasons why young adults should become involved in Enroll-HD.

### **Tiago Mestre MD – Enroll-HD's Medical Resource**

The Enroll-HD team is very happy to announce that Tiago Mestre, MD, MSc has agreed to join the team as Enroll-HD's Medical Director. Tiago's responsibilities will include conducting the medical review of Enroll-HD data and consulting with team members on medical questions, safety issues and training optimization.

Dr Mestre is a movement disorder specialist working at the Movement Disorders Centre of the University of Toronto and has been involved in Huntington's Disease research throughout his career - he is the primary author of the Cochrane Systematic Reviews on Treatment for Huntington's Disease, was a co-investigator and language coordinator in Portugal for the REGISTRY study from 2006 to 2010 and a local co-investigator of the FuRST-pHD study. More recently he participated in the planning of Enroll-HD as a member of the Site Management Working Group. His interests include clinical trial design and improvement of the translational process from pre-clinical to clinical evaluation of new HD treatments.

### **A MESSAGE FROM CARERS QUEENSLAND**



We at Carers Queensland are passionate about looking after the unpaid carers who look after others.

A carer is a person who is providing, or who has provided, unpaid care and support to family members or friends who have a disability, mental illness, chronic condition, terminal illness or who are frail aged.

Carers are largely invisible outside the small but devoted carers' network and do their selfless work without expectation of financial reward. We believe they should be recognised for their contribution to society.

Can you assist us to get the word out to the carers that they are not alone and that we are here to help them? Carers Queensland assists carers through advocacy, counselling, training and a range of support services. We are a not-for-profit organisation.

With nearly 500,000 carers in Queensland, it is important that they are made aware of organisations, like Carers Queensland, that can assist them in their everyday living. Community, business and individual support goes a long way towards helping us achieve this goal.



Our Carer Advisory Service is available on **1800 242 636** Monday to Friday.

Thank you for your help

Carers Queensland



## FUND RAISING

### FINANCIAL ASSISTANCE TO HUNTINGTONS QUEENSLAND

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

<i>Pam Webb</i>	<i>John Stride</i>
<i>Ross Craig</i>	<i>Patricia Barnes</i>
<i>Jean Farmer</i>	<i>Elsa &amp; Scott Wood</i>
<i>Kate Fitzpatrick</i>	

### HUNTINGTONS QUEENSLAND NOMINATED AS BENEFICIARY

Our sincere thanks continue to **Beecham Holden Caboolture** who has kindly nominated Huntingtons Queensland as the beneficiary for a charitable donation by way of CTP on first time registered vehicles sold through them.

You can contact them on:

**Ph: 1300 661 958**  
**29 Bribie Island Road Caboolture**



### DONATIONS TO HUNTINGTONS QUEENSLAND



If you would like to donate to Huntingtons Queensland and have internet access, go to our website [www.huntingtonsqld.com](http://www.huntingtonsqld.com). Scroll down to the 'Please Make a Donation' section on the bottom left, click on the button <CLICK HERE> and follow the instructions.

Alternately you can cut off the **slip on page 9** of this Newsletter and return to us with your donation – cheque, money order or credit card.

All donations over \$2 are tax deductible and we will send you a receipt for taxation purposes.

### RAFFLE WINNERS

The LG 50" Plasma TV and the beautiful queen sized quilt, hand stitched and kindly donated by the Little Mountain Quilters were raffled at the AGM on 26<sup>th</sup> September 2012.



Congratulations to the lucky winners of the TV with ticket # 652, Cameron Smith and Richard Gerlagh from Espresso & Collectables in Annerley and 2<sup>nd</sup> prize with ticket # 489, Kylie Marshall. Thanks to everyone who supported this raffle –nearly \$2000 was raised.

### IOOF



Thanks to the generous support of the IOOF, the Association's new Coffee Catch Up (CCU) Group has seen its first successful year.



The CCU Group is a great social outlet to catch up with others with HD in similar circumstances who know and understand, possibly better than any others, exactly what everyone is going through. The CCU Group provides a great opportunity to discuss common issues and share real experiences. Call us for information if you'd like to attend.

### SUNNYBANK COMMUNITY & SPORTS CLUB

For the third consecutive year the kind members of the Sunnybank Community & Sports Club have donated funds to support Huntingtons Queensland's Youth Program (Southside).

In all there are nine separate families with twenty-one children among them in the Southside catchment area who have benefited from their generosity during this past year.



The Association would like to sincerely thank Bedford and Karen Astley for their wonderful fundraising work with the North Queensland District Grand Chapter, Order of the Eastern Star. Through their tireless efforts the Chapter raised \$2000 which was presented by Bedford and Karen to Gerry Doyle and Staff at a morning tea held at Florence Dannel House on Tuesday 2<sup>nd</sup> October. Their support for Huntingtons Queensland is greatly appreciated.



**Huntingtons Queensland**  
is a not-for-profit service organisation.  
Established in 1976.

### HUNTINGTONS QUEENSLAND

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#### **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 2012/2013:**

- |                      |                  |
|----------------------|------------------|
| ➤ President          | Gerry Doyle      |
| ➤ Vice President     | Robert Westley   |
| ➤ Secretary          | Pam Cummings     |
| ➤ Treasurer          | Heather Whye     |
| ➤ Committee Members: | Jan Szlapak      |
|                      | Alan McKinless   |
|                      | Marty Harmsworth |
|                      | Shirley Ross     |
|                      | Emma Kyle        |
|                      | Gwen Pratten     |

#### **Staff Members:**

- |                              |                |
|------------------------------|----------------|
| ➤ Executive officer          | Cheryl Miller  |
| ➤ Senior Welfare Officer     | Christine Fox  |
| ➤ Welfare Officer            | Theressa Byrne |
| ➤ Welfare Officer            | Fiona Kerr     |
| ➤ Administration Manager     | Anne Stanfield |
| ➤ Telemktg / Admin Assistant | Helen Johnston |
| ➤ Bookkeeper                 | Jan Mealy      |

### CONTRIBUTIONS & DISTRIBUTION

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 2012. Please email or post articles, details above. Please be aware that the Newsletter is published on [www.huntingtonsqld.com](http://www.huntingtonsqld.com) in addition to postal and email distribution.

*This Newsletter has been printed free of charge by the office of Graham Perrett, Federal Member for Moreton. Our kind thanks to Graham & Staff.*

