NEWSLETTER

HUNTINGTONS QUEENSLAND

March 2014

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FROM THE PRESIDENT

As I advised in the December Newsletter it was a great result to report to you all that Queensland Health would be continuing our current funding arrangements until 30th June 2014 and that they would work with us to develop a Transition Plan for a sustainable business model through to 31st December 2015 and beyond.

This timeframe has placed a great deal of pressure on Huntingtons Queensland (HQ) as we will need to have finalised our Transition Plan by 30th June 2014.

Your Opinion - Important Survey of Clients, Families and Carers

To assist in the transition process we have prepared a Survey that we will be sending out in the next couple of weeks. The purpose of the Survey is to obtain your feedback from clients, families and carers on the services provided by HQ, the priority that you place of these services and most importantly, what are your expectations and other services that you would like HQ to provide.

An important part of future planning for HQ is supporting people living in regional areas of Queensland so feedback from clients, families and carers living in regional areas of Queensland is of particular importance.

Included in our planning is consideration and establishment of partnerships as we move to the NDIS (National Disability Insurance Scheme). I ask you all to please take the time to complete and return the Survey.

Although I am confident of HQ providing a suitable Transition Plan that meets the requirements for funding through to 31st December 2015, the future beyond this time is not clear. Going forward we need committed families and friends to get involved in helping HQ so we can help those affected by HD. You can help by organising fundraising activities and/or becoming members of the Committee of Management of Huntingtons Queensland.

Gerry Doyle

President

UPCOMING SUPPORT GROUP MEETINGS

Bris Carers	Mon Apr 7	Toowoomba FSG	Fri May 30
Bris HYPe	Tue Apr 15	Bris Carers	Mon Jun 2
Bris East FSG	Wed Apr 16	Gold Coast FSG	Mon Jun 2
Gold Coast HYPe	Thu Apr 17	Ipswich FSG	Wed Jun 11
Sunshine Coast FSG	Mon Apr 28	Bris East FSG	Wed Jun 18
Ipswich FSG	Wed Apr 30	Sunshine Coast FSG	Mon Jun 23
Caboolture FSG	Thu May 1	Cairns Regional Trip	Mon-Fri Jun 23-27
Townsville Regional Trip	Mon-Fri May 26-30		

FROM THE WELFARE DESK…

Hello Families and Friends,

From the 15th to the 19th of January, 2014 we held our 7th Annual HYPe Family Holiday. For those of you not familiar with our HYPe initiative, HYPe stands for **H**untington's **Y**outh **P**rogram **e**tc and its objective is to engage children from families affected by HD. Many families, of all ages, feel alone because they do not think there is anyone else out there going through the same experiences or having the same thoughts and questions as they do. I'm sure there are many people reading this now who were feeling exactly the same way. People are often surprised to learn just how many people, families and carers there are who are affected by HD, not only in Queensland but in their own town. With this is mind, the HYPe initiative was created to bring kids together, with their family, so they can see there are other kids out there living in HD families, but also giving an opportunity for parents to share experiences and feel supported by others who know what it is like to either be a parent with HD, or the partner of someone with HD.

Theressa and I were joined by 37 mums, dads and kids making up ten families from towns including Brisbane, Ipswich, Toowoomba, Sunshine Coast, Bundaberg and Townsville who came to the Emeraldene Inn and Ecolodge in the beautiful town of Hervey Bay. This was our fourth year back to this venue and Rob, the manager, is an incredible host. All the families arrived safe and sound and we all sat down to a big BBQ beside the pool on the first night to renew old friendships and to meet new friends. Kids are amazing – it doesn't take them long to make friends (or get into their swimmers as soon as they arrive)! It was a relaxed atmosphere and set the scene for a great holiday.

On Thursday morning, some of the families went to the waterpark on the bay, always a favourite place to visit, whilst other families enjoyed a leisurely swim in the motel pool. In the afternoon, Sergeant Steve Webb came to visit with his Forensic Unit truck and gave us a chat about safety on the roads. We learnt some amazing things from Sergeant Steve and afterwards we all had a photo taken with him in front of his truck. I think we were all a little awestruck, because Sergeant Steve is also on a lot of billboards advertising road safety from Maryborough to Bundaberg. It was like meeting a rock star! What's more, Sergeant Steve has family members who are at risk of HD, so he is like one of us too.

Thursday night we all went up to the Hervey Bay RSL for dinner and it was amazing! The Hervey Bay RSL has undergone some renovations since the last time we came, and we were lucky to all be seated on the new deck – right beside the kid's room. Heaven! The staff were so friendly and helpful AND the RSL kindly donated $250 credit towards our dinner. We all felt special that night.

Friday morning we were all up at 5am to drive to Tin Can Bay in a convoy to see the dolphins that come in every morning for feeding. We arrived on time (that doesn't happen too often so you know everyone must have been super excited!) and were treated like royalty by Les and his team at Barnacles. When they found out we were from Huntingtons Qld, they let each and every family member come down to the water and feed the dolphins at no cost. This was truly an amazing, even spiritual encounter for everyone. Little kids excited and nervous, older kids squirming about holding the fish and parents absolutely thrilled to be doing something they possibly never thought they would ever have the opportunity to do. Les and his amazing team of volunteers helped some of our parents get to the water and were so patient and happy to be a part of our experience as well.

Sergeant Steve, who happens to live near Tin Can Bay, came and joined us again this morning and as a surprise, he introduced us to Stainless (yep, that was the man's name!) who runs the Sailability program out of Tin Can Bay. Sailability is an organisation that operates around Queensland and has special 2-person sailing boats for people with a disability. Stainless gave us a great talk about the program and even brought one of the sailing boats out for us to see. Apparently these boats are 'untippable' – all the parents, Theressa and I included, had a bit of a giggle and wondered if they'd had anyone with HD on the boats before, because we reckon we could give that

theory a run for its money. Guess what – they have had people on them with HD and they stay afloat. AMAZING! Stainless invited us all to come back on our next holiday for a sail. We'll be there with bells on, Stainless!

After the dolphin feeding, we made our way back to Maryborough where we went to the Fraser Coast Wildlife Sanctuary. We had a very informative guided tour of the sanctuary with its dingo enclosure, kangaroos, wallabies, emus and the great big aviaries you could walk through (and cool off in!) all featuring native Australian animals and wildlife. After a BBQ lunch, we all headed back to the motel to rest. That was a BIG day!

On Saturday morning we went to the Fraser Coast Discovery Sphere, where the volunteers gave us a tour and we learnt about the humpback whales who visit Hervey Bay every year. Apart from learning about other flora and fauna in the Hervey Bay region, we also learnt much about the Butchulla people who are the traditional owners of Fraser Island and much of the Fraser Coast region. We learnt about their traditions, customs and totem. This was a wonderful education experience mixed with interactive games and activities. Whilst we were there, some of the rangers from the Fraser Coast Wildlife Centre came along with some of the animals and wildlife for a "show and tell" morning. We were able to hold, pat and touch so many animals, including the dingoes, lizards, and even snakes. Rumour has it that there is a photo of Theressa and I holding a snake – sorry but THAT one isn't going in the Newsletter!

That afternoon we headed back for a relaxing time by the pool and to socialise with one another. For dinner, we all headed down to the big Urangan pier, where we had pizza (lots and lots of pizza!) and drinks as the sun set. Some people went fishing, some went for a walk on the tidal flats to find shells and starfish and some just sat back and soaked up the beautiful sunset. The final night was a late night, as everyone sat around telling stories and sharing in laughs from the holiday.

Sunday came and it was time to pack up to say goodbye. It is always sad to say goodbye to friends, but plenty of email addresses, phone numbers, addresses and Facebook details were exchanged and we're sure people will keep in touch. So many of the kids wrote us beautiful letters of thanks and did some drawings of their holiday. This was goodbye, but only for now, as we hope to come together again at the next holiday or school holiday event and rekindle those friendships. This holiday is such an enjoyable experience for not only the families, but for Theressa and I. We would like to thank all our families for sharing this experience. But most of all, we would like to thank the Sunnybank Community & Sports Club for their very generous donation to the HYPe initiative, without which we would not be able to have this holiday every year. We appreciate their continued support and look forward to many more HYPe holidays and events for our families to join in. If you'd like to learn more about our HYPe initiative, or maybe join in one of our events, please give me (Christine) a call on 3391 8833.

Christine Fox and Tressa Byrne - the Welfare Team

FROM THE EXECUTIVE OFFICER…

It never ceases to amaze me how the year seems to progress and one never seems to realise how far it has gone until we look to how little time we have until the next milestone.

A year ago we were having discussions with Cam Wilson and his team about Cam contesting the Guinness World Record for "Karting, greatest distance travelled in 24hrs indoors (individual)". Not long after those discussions, Cam was involved in a major accident at the Gold Coast 600 which delayed his attempt for November 5th & 6th. The next thing we know it is February 4th 2014 and Cam is at the wheel for the Guinness World Record attempt. 20 hours later he has broken the record and a further 4 hours later he has annihilated it. I was there from start (I waved the flag) to finish. Cam Wilson broke that record, but so did his father (his inspiration), his brother Benn, his wife Tracey, his mother and father-in-law and his staff who supported him through the whole event. This is a team which works as a family and this family has not only raised valuable funds towards the continued support services provided by Huntingtons Queensland but has also raised the awareness of Huntington's Disease to many people around the world. To Cam and his team (family) we say "Thank You" and wish you all the best in your future endeavours.

COULD YOU HOST A FUNDRAISING EVENT? DO YOU HAVE ANY FUNDRAISING IDEAS OR COULD YOU VOLUNTEER AT HUNTINGTONS?

Hosting an event could be a high tea, wine and cheese tasting, dinner party or barbeque for HD. Perhaps you or some friends are having milestone birthdays and rather than gifts you could suggest a donation to Huntingtons Queensland. I am sure there are a myriad of ideas out there that we do not know about, but you do and we would love you to host an event for HD.

Volunteering We could use some help with preparing morning teas and sandwiches for Day Centre on the 2nd, 3rd and 4th Tuesday of each month. We are in particular need of some help at the moment as Helen our trusty Day Centre person is going on holidays in mid-May and then backing up with knee surgery in June. We wish Helen and her husband "bon voyage" and wish her well for her upcoming surgery and look forward to her return.

We are also looking for volunteers to help us fold our quarterly Newsletters and fill the envelopes. For many years Mary Stunden, Eunice Brooks and Maida White have faithfully performed this task (and many others tasks too). Unfortunately, Eunice and Maida have retired from their volunteer roles – we thank them sincerely for their long service and wonderful support of the Association. Mary continues to help with the Newsletters but some new volunteers for this task would be most welcome.

Alan McKinless is another of our wonderful volunteers. With his handyman duties around Florence Dannell House at Annerley, he is often seen on the end of the lawn mower, but Alan could do with some help to keep the weeds under control and the hedges trimmed. Alan is also a member of the Committee of Management.

Our **Committee of Management**, chaired by Gerry Doyle meets at 12 noon on the 3rd Thursday each month. Do you have skills which you could put into our Committee of Management? If so, please do not hesitate to contact me and we can discuss more about how we work and how you may be able to help.

Bequests If you have considered leaving a bequest to Huntingtons Queensland and need more information, please contact Anne Stanfield or myself. If you have already made a bequest to Huntington's Queensland we would love to know of this so we can say "thank you" - which we cannot do once you have passed.

As March comes to a close and Easter nears, I leave you with my Newsletter quote…

"We earn a living by what we get, but we make a life by what we give." – Winston Churchill

Cheryl Miller Executive Officer

DO YOU NEED TO SPEAK TO ONE OF OUR WELFARE OFFICERS?

Did you know that Christine and Theressa are the only two Welfare Officers and in fact the only two dedicated Welfare Officers in all of Queensland, who specifically provide support to people with HD and their families? Since the position held by Iris Simpson in Queensland Health was made redundant, we have seen a significant increase in the volume of calls for information, advice and support from HD families. This is together with a large increase in the number of new families we are now supporting.

This increase in demand means that our Welfare Officers are kept incredibly busy. They always try to return your calls as soon as they can. As this Newsletter goes to print, both Christine and Theressa are out of the office on regional trips covering towns from Mackay all the way down to Gympie. There are a few ways that you can get in touch with our Welfare Staff:

1) Call the office on (07) 3391 8833. Please leave a message if it goes to the answering machine. It could simply be that we are on another call with someone and cannot interrupt them to get to your call.
2) Send an email to Christine – christine@huntingtonsqld.com or to Theressa – theressa@huntingtonsqld.com
3) Write us a letter. Some people like to keep in touch this way. You can send mail to PO Box 635 Annerley 4103.

What about mobile phones? This is a question we are often asked. Both Christine and Theressa have mobile phones, however, when they are out visiting families, or in a meeting, they cannot always answer your call. If you want to call, the fastest and preferred way to do so is on the office number.

CAM WILSON SMASHES WORLD RECORD & RAISES MONEY FOR HD!

On the 5th of February V8 Ute driver, Cam Wilson, rocketed into the Guinness World Record Book, travelling 604kms in 24 hours and smashing the current record of 503kms for "Karting, greatest distance travelled in 24hrs indoors (individual)" by 101kms.

An exhausted but elated Cam said, "it was touch and go at some points, but the cause kept me motivated and I couldn't be happier about raising not only awareness of HD, but also much needed funds for Huntingtons Queensland". Referring to his spectacular V8 ute crash in the Gold Coast 600 last year, Cam joked, "I'm glad the only thing I smashed this time around was a world record and not my vehicle!"

As of this Newsletter going to print, Cam has raised nearly $10,000 and we are urging everyone to head to our website www.huntingtonsqld.com and give generously to this very worthwhile cause.

The event took place at one of Cam's Go Karting tracks at Eagle Farm in Brisbane. Cam, his family, dedicated track staff, local businesses and members of the public enjoyed the after celebrations which included Eagle Boys pizzas, an auction of parts from Cam's smashed V8 ute and hot laps. All proceeds went towards to Huntingtons Queensland.

Everyone at Huntingtons Queensland congratulates Cam on his wonderful dedication and courage in completing 24 grueling hours on the track.

SLIDEWAYS GO KARTING Brisbane EAGLE FARM

For Go Karting info at Eagle Farm or Nerang

Phone	Eagle Farm – (07) 3868 2225	Nerang – (07) 5596 3663
Website	www.gokartingbrisbane.com.au	

DONATIONS TO HUNTINGTONS QUEENSLAND

If you or a friend would like to make a donation to Huntingtons Queensland, please return the slip below to our office with your payment. Alternatively you can donate online – go to www.huntingtonsqld.com. All donations over $2 are tax deductible. We will send you a receipt for taxation purposes.

Personal Details:

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Please see bottom of next page for payment options...

Announcing the 2014 Australian HD conference…..

"Embracing Opportunities with HD"

National HD Conference 2014

Perth, Western Australia 11th - 12th September 2014

As part of its 40th anniversary celebrations, Huntington's WA invites you to the National Huntington's Conference at the UWA Club, University of Western Australia, Perth. It will bring together family members, researchers, allied health professionals, care workers and members and supporters of all Huntington's Disease Associations across Australia.

An exciting line up of inspirational keynote speakers includes Richard Faull, Nellie Georgiou-Karistianis and Tony Mims as well as presentations around living well with HD, sharing best practice and translational research, engaging youth and exploring new boundaries.

Perth is a delight to experience in September as the wildflower season is in full swing. Why not extend your stay and experience the September Wildflower Festival held annually at Kings Park and Botanic Gardens, just 1.5kms from the City. The Park offers guided and self-guided walks including a tree top walk providing spectacular views across the City as far as the Darling Ranges. September is a popular time for tourists so be sure to book early.

Full programme and registration, including links to accommodation and popular tourist activities, will be available shortly from www.huntingtonswa.org.au

Contact Huntington's WA:

Phone: (08) 9346 7599 or Email: admin@huntingtonswa.org.au

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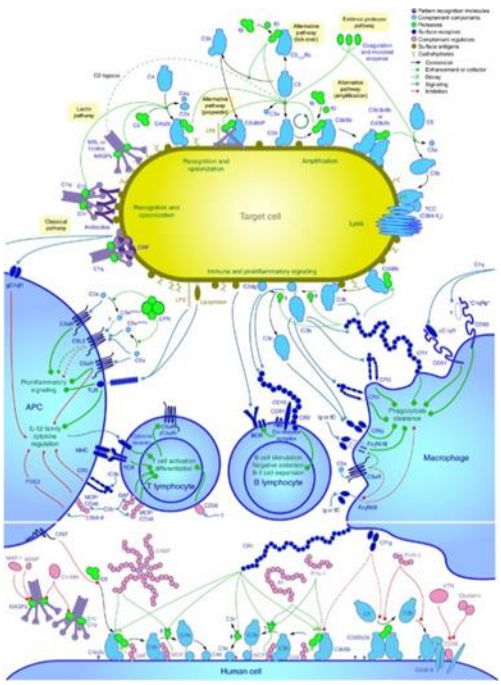
Tel: (07) 3391 8833 Email: admin@huntingtonsqld.com

Report from Associate Professor Trent Woodruff & Dr Susanna Mantovani

HD Report 2013

Our research team at the University of Queensland and the Royal Brisbane and Women's Hospital is studying the role of the immune system in the development and course of Huntington's disease (HD). Specifically we are focussing on a major component of our innate immune system called the complement system.

What is complement system and why is it important in Huntington's disease?



Complement, a very complex system. (Picture from Ricklin and Lambris, 2010; Nat Immunol.11:785-97).

The complement system is an ancient and powerful part of mammalian innate immune defence and it is a key mediator of inflammatory responses. Complement is a very complex system, composed by over 40 different proteins, which can activate a cascade of molecular events to recruit immune and inflammatory cells (white blood cells), stimulate the immune system and directly destroy bacteria. The picture to the left shows just how complex this system is.

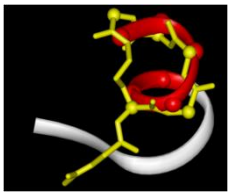
There are clear indications that the activation of the immune and inflammatory systems, and in particular complement system, play an important role in Huntington's pathology.

One of the very final and most powerful molecules produced by complement activation is called C5a. C5a is the strongest inflammatory mediator in our body and it is able to trigger inflammation when it activates its main receptor called the C5a receptor.

We do know that complement factors, and in particular the C5a receptor, are increased and activated in HD. We also know that in HD there is an overproduction of C5a. To the date however, no one has determined the function and the mechanism of action of complement C5a in Huntington's pathology.

What we can draw from the data presented is that the development a drug that blocks the action of C5a could be a promising future therapy to treat HD.

Our drug



A 3D model of our drug

In 1999, Professor Stephen Taylor from our group developed a specific antagonist to the C5a receptor. This antagonist has many favourable features: it's small, potent, stable and orally administrable. Importantly, this drug has been tested in early Phase I clinical trials and is considered safe for clinical usage.

How do we study complement in Huntington?

Scientists have many different ways of studying a disease. One possible way is to use animal models, such as transgenic mice. These mice are engineered in such a way that they carry in their genome the same mutation that HD people carry in their DNA. Many different transgenic models of Huntington's have been generated since the discovery of HD gene, but only in the last years investigators were able to insert precisely the full human HD gene in mice.

In our laboratory we use two different models of HD transgenic mice:

1. The R6/1 transgenic mouse model, which only contains a fragment of the HD gene, and recapitulates many of the features of human HD, including motor and cognitive symptoms.
2. The BACHD model, which expresses the full length version of the mutated human HD gene.

Very importantly, we do also work on human blood. You might have met our team at one of the HD clinics held at the

Royal Brisbane and Women's Hospital (RBWH). We study blood cells and soluble factors that are found in blood of both HD patients and healthy people, and we compare them to determine if there are any differences in the activation of complement system.

Our preliminary results with the human study

We started collecting blood from HD patients and healthy volunteers in February 2013, and since then, we kept on collecting blood every month, during the HD clinics coordinated by Dr John O'Sullivan at the RBWH. As you can imagine, it is pretty hard to obtain uniform and consistent data when working with human samples, and that's because of a simple reason: every one of us is different. Just think about the fact that different people might have different gender, age, ethnicity, weight and lifestyle. Some people might be taking certain medications, which can interfere with laboratory analysis. To the date we collected blood from 44 healthy donors and 36 HD patients. These are great numbers if you think that we could collect blood only once a month! This demonstrates the generous spirit of HD families and carers of HD patients.

Our initial analyses have found that the complement component C5a and also the levels of C5a receptor tend to be increased comparing blood from HD patients to healthy people. To consolidate our results, however, we do need a higher number of HD patients and healthy volunteers for comparison. Our goal for this year is to collect more blood samples and to be able to publish our data. Moreover, with the blood we collect, we are also setting up some experiments to look at white blood cells in the blood. This is done using a state of the art technology (called FACS, fluorescence-based flow cytometry), which is giving us some preliminary results on complement as well.

Altogether, our data indicate that complement C5a is increasing in HD patients and that the C5a receptor is activated during this pathology. This means that, in the future, we might be able to start designing a clinical trial using drugs which block complement C5aR activation.

Our results with the mouse study

To better understand all mechanisms underpinning complement involvement in HD, we also use mouse models of this pathology. As you can imagine, that gives us the possibility to study in depth what's happening in all different stages of HD and to take a look not only to what's happening in the blood, but also to what's going on in the brain and any other organ we might be interested in.

Of course, to obtain valuable results, we need to first establish that the mouse models we are using are mimicking human HD pathology in the best way.

As mentioned before, we used a mouse model of HD pathology called the BACHD mouse. The BACHD animals are a new generation of HD mouse models expressing the entire mutated human HD gene. For the first time in Australia, our group set up a colony of these mice and we first decided to extensively test if they were a good and reliable model to study complement in HD.

Unfortunately, after extensive investigation, we discovered that they cannot be considered a reliable model of HD. These mice do have clear motor symptoms similar to HD patients, but unlike HD, they do not show some of the main characteristics that are usually at the basis of this pathology. For example, they do not show a clear degeneration of the area of the brain called striatum, which is found deeply affected in human patients.

For all these reasons we decided not to keep on using the BACHD as a model for HD. Regrettably disappointing results can happen in scientific research, but the most important thing is that we determined what to do, to avoid any misleading results, since we want to make as sure as possible that our results can be translated to human patients.

Luckily, we have a second mouse model of HD, called R6/1. This model is a relatively older one and it has been used for many years and by dozens of different laboratories all around the world, so we are sure about its consistency, robustness and similarity to human HD. Importantly, we have also proved that in R6/1 animals the complement system is activated

during the course of the pathology and that complement factors C5a and C5a receptor are increased. We have started treating R6/1 animals with our drug, and are continuing to treat new mice as they become available. We now need to increase the number of treated animals and to look at what's happening in all the stages of the pathology during the treatment. This work is really important, because it will give us a clearer idea on how to design a clinical trial on HD patients.

Next goals

We aim to keep on studying in depth how the complement system is involved in HD and how we can stop, or at least slow down, the inflammatory process that feeds a vicious process of neuro-degeneration. We will do this with the best HD transgenic model available (the R6/1 mouse) and, most importantly, collecting samples from HD patients and healthy volunteers. The synergy of these two approaches will allow us to make sure that all our findings can be translated into the clinic. Our next goal is to define in great detail how, and why, complement is involved in HD pathology and, in the future, design a clinical trial using either our C5a receptor antagonist drug, or other clinical compounds which block C5a receptor activation.

Thanks to the contribution of Huntington's Queensland association, we recently presented our work at the World Huntington's Congress 2013, obtaining useful feedback from other HD researchers. We are also in the process of submitting journal article publications related to the research we described above.

As you could imagine from this description, researching to find new and reliable therapy for HD is a long process, and really hard work, but we are doing all we can to fight against this terrible disease. With the collaboration of many other researchers around the world, we hope that future therapies can be identified.

The funding provided by the Australian Huntington's Disease Association (Qld) Inc, has allowed us to reach important results. We are sincerely thankful for that, and we aim to increase the knowledge of the causes and progression of this devastating disease.

Dr Susanna Mantovani & Associate Professor Trent Woodruff
School of Biomedical Sciences
University of Queensland

HDBuzz – check out some of the recent articles…

Does high-dose creatine "slow the onset" of Huntington's Disease? http://en.hdbuzz.net/157

Prana announces results of Reach2HD trial of PBT2 for Huntington's Disease http://en.hdbuzz.net/158

Huntington's Disease Therapeutics Conference 2014: day 1 http://en.hdbuzz.net/159

Huntington's Disease Therapeutics Conference 2014: day 2 http://en.hdbuzz.net/160

Huntington's Disease Therapeutics Conference 2014: day 3 http://en.hdbuzz.net/161

Sleep, cilia and HD http://en.hdbuzz.net/162

HD blog – Hope of treatments getting 'really real'! www.curehd.blogspot.com

A message from Gene Veritas…

Dear friends in the fight against Huntington's Disease,

The decades of work of the HD community of affected families, doctors, researchers, and supporters is starting to pay off. Thanks to that massive effort, potential treatments are on the horizon, and the path there is becoming clearer.

"It's really getting real," Dr Robert Pacifici, one of the leaders of the quest for treatments, said at last month's Ninth Annual HD Therapeutics Conference in Palm Springs, California, USA.

Conscious of HD families' pressing need for treatments, the researchers are working to set up the best possible clinical trials in order to aid the community quickly and effectively.

I attended the conference, where I interviewed Dr Pacifici and heard four days of presentations on the latest news in the quest. I also learned more about Enroll-HD, the global registry of HD individuals and families that will serve as a platform for clinical trials.

The hope is tangible!

You can read my report on the conference in "'It's really getting real': payoffs in the effort to treat Huntington's Disease," the latest entry in my blog, **At Risk for Huntington's Disease**, which you can view at www.curehd.blogspot.com. The report includes a video my interview with Dr Pacifici and a link to my conference video album, which contains two dozen additional videos on numerous aspects of the conference.

As always, your feedback is welcome. You can post comments on the blog. You can also write me at curehdnow@earthlink.net. I'm on Facebook, too.

Yours in the struggle to cure diseases,

Gene Veritas

Jessica's Story

My name is Jessica, I am 24 years old and this is my story about having inherited Huntington's Disease.

Huntington's Disease is an inherited neurological disease. It is a disease of the brain which affects the nervous system and is passed down through a family line. There is a 50/50 chance of inheriting the HD gene for anybody with a parent with HD. At this point in time there is no known cure for the disease. There is however, a lot of hype surrounding new treatments, which may help to manage or cure this disease in the near future.

I should explain that I am gene positive for the disease. I am however pre-symptomatic. I will probably not start to show any symptoms for another ten years or so. However exactly when it will rear its ugly head, is anybody's guess. I often call HD a 'silent disease'. It lurks below the surface for so long and although you may not actually have any symptoms as of yet, it affects every single decision you make and controls every thought you have.

My mother inherited the disease from my grandmother (and so did seven of her nine siblings). She died at 46 after suffering from the disease for around twelve years. This is how the 50/50 chance was passed on to me. Yes that means that both of my beautiful children will face this same 'flip of the coin' chance as well. My sister has tested gene positive but my brother remains untested at this point.

I was tested at the age of 22. After having my first child, I felt a yearning desire to find out. I often felt as though there was a sword hanging above my head and it could drop at any time. I had to remove that uncertainty. People ask me why I got tested so young. I guess the simple answer is - I have grown up my entire life knowing that there was a chance I could inherit the disease. Therefore, I obviously knew I would at some point in my life be tested. Do I regret it? Yes and no. I do regret, on one hand, because I feel I limit myself not to enjoy the simple things in life and am always wondering when the symptoms will decide to appear.

I am, on the other hand, grateful I found out. Grateful because I appreciate everything in my life a lot more since the diagnosis and never take anything for granted. It has helped to form close bonds with others, which normally wouldn't have happened. I also have time to prepare and have plans in place for when I need them in the future. I have time to spend with my loved ones, treasuring each little moment together. I am well aware, that this is a luxury - one that a lot of people will never get.

Yes I do live every day with tremendous guilt, that I have possibly passed this dreadful gene on to my kids. There is nothing you can say to me, that I haven't already said to myself. It was an informed decision that my husband and I made together. We had already welcomed our beautiful baby girl into this world before the diagnosis. There was no way we were going to embark on IVF and other costly and invasive measures, to remove the bad gene (if present) from our second child, our handsome little boy. In our opinion, it would not have been fair to do it for one child and not the other. Let me emphasise the fact that my kids are definitely not a mistake nor a regret!

I guess I am writing this story, to remove the stigma I have attached to this disease. Since diagnosis, I have suffered overwhelming feelings of discouragement and shame. Shame that people will see me differently, or treat me with pity, or avoid me altogether, because it is too hard for them to understand or deal with.

For those of you wondering how to approach my situation, do so without pity. Please do not treat me any differently than before. I am after all, the exact same person I was before the diagnosis. I am still the eager, determined person, who is more than capable and will never give up. Please do not give up on me, as I have not yet given up on myself.

After one straight year of denial and keeping it all a secret and another year to come to terms with it all, I have finally found the courage to be open and speak up about my situation. I find courage in my children, my husband and my relatives. They inspire me every day, to be the best version of myself that I can be. I will never say I am perfect. But I am willing to stand up, acknowledge my mistakes and promise to learn from them. I endeavour to be the best mother, wife and friend that I can be.

I will do this through sharing my story and my courage. I will raise my children to be kind to themselves and to each other and to be there for each other, through thick and through thin. When the going gets tough, I will be here with them, to guide them through their darkest of days.

When the time comes for me to go, they will hold me close in their memories. I hope they can show the same courage that I have taught them, no matter what their futures hold.

Jessica (18th March 2014)

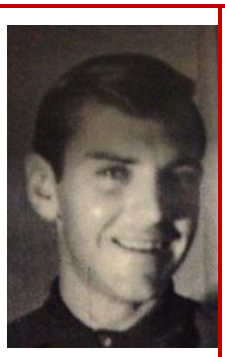
FUND RAISING

Raymond Grig Burnip Bequest

Sadly, late last year Ray Burnip passed away, having lived with the difficulties and challenges of Huntington's Disease.

Despite the many troubles he faced throughout his life, he and his family made arrangements for the very substantial bequest of $80,000 to be left to Huntingtons Queensland.

The Association acknowledge Ray and his family for their generosity and foresight in providing a legacy for those whose plight they well understood.



Ray Burnip 1968

Grill'd healthy burgers

Our thanks to the Management and Staff for allowing us to participate in their money raising Local Matters programme! Their contribution is much appreciated and valued.

You can pop in for a healthy burger at Southbank…

Grill'd healthy burgers

Shop 3 / 167 Grey Street

Southbank

ShareGift Australia

ShareGift Australia makes it easy and cost effective for people to support the community by donating shares to charity.

As the shareholder, you complete a Share Sale Donation Form to authorise the sale of your actively trading ASX listed securities. If the value of the sale exceeds AU$50, then you are also able to recommend Huntingtons Queensland to benefit from ShareGift Australia distributions. Donations over $2 are tax deductible.

For more information go to http://www.sharegiftaustralia.org.au/

Continued Support from BEECHAM HOLDEN Caboolture

In 2010 Chris Beecham of Beecham Holden at Caboolture initiated a program for QBE Insurance to make a charitable donation to Huntingtons Queensland by way of CTP on first time registered vehicles sold through Beecham Holden. Since 2010 the Association has received over $12,000 in donations from QBE.

We offer our ongoing thanks and gratitude to Chris, his son Lockie and all the team at Beecham Holden.

You can contact them on:

Sales: *1800 619 787* ***Service:*** *(07) 5322 4015*

29 Bribie Island Road Caboolture

IOOF Foundation

The IOOF first provided their financial support for our Coffee Catch Up (CCU) Group for 2012 and 2013. They have just annouced their further assistance for 2014 and 2015. We can't thank them enough for their generous ongoing help.

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 provides a great opportunity to discuss common issues and share real experiences. Call us for information if you'd like to attend.

DICK SMITH'S AUSSIE GROWN FOODS

Keeping Jobs in Australia

Simply text or email a photograph of any Dick Smith Foods product in your pantry to charity@dicksmithfoods.com.au as well as our name (ie Huntingtons Queensland). The charities with the most votes will share $1 million generously sponsored by Dick Smith Foods Foundation.

GENEROUS DONORS SUPPORTING HUNTINGTONS QUEENSLAND

A big thank you! We have received and gratefully acknowledge major financial assistance from the following kind donors:

Brian Clark
Cindy & Lawrence Benjamin
Christine Hammond
M Lupton

DONATIONS TO HUNTINGTONS QUEENSLAND

If you would like to donate to Huntingtons Queensland and have internet access, go to our website 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.

Alternatively you can return the slip on page 5 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.

HUNTINGTONS QUEENSLAND

Florence Dannell House
385 Ipswich Rd cnr Ponsonby St
Annerley Brisbane

All Correspondence to
PO Box 635
Annerley Q 4103

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

Emails:
cheryl@huntingtonsqld.com
christine@huntingtonsqld.com
theressa@huntingtonsqld.com
helen@huntingtonsqld.com
anne@huntingtonsqld.com

Website: 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 Centre 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

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Please feel free to submit articles or photographs for consideration for publication in this Newsletter. The deadline for the next issue is 15th July 2014. Please email or post articles, details above. Please be aware that the Newsletter is published on *www.huntingtonsqld.com* in addition to postal and email distribution.

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