



NEWSLETTER

HUNTINGTONS QUEENSLAND

December 2013



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FROM THE PRESIDENT

2013 has been a very challenging year for our committee and staff. Due to recent Queensland Government cost reducing activities our funding has been under review. During this past year our Association has been operating on a very lean budget to ensure we were able to continue providing the most necessary services to our families.

But...it is with very great pleasure that I can now announce that we have just been notified by Queensland Health that our current service agreement has been rolled over for six months (until 30th June 2014) with a meeting to be held early in the New Year to formalise a further 18 month agreement, 24 months of funding in total.

We will have several planning sessions in-house in the New Year as we need to change to meet the 'requirements' of Queensland Health especially in the formalisation of a partnership regime and also becoming skilled and trained to meet the challenges of the NDIS.

This will provide the Association with a wonderful opportunity to review the existing services we offer our families and to update and improve our services in line with our families' changing needs as well as establishing our Association to fit with the NDIS model of service provision.

Queensland Health's announcement has come at the perfect time to reassure our families, our staff and committee that Huntingtons Queensland can continue to provide families with the level of support they richly deserve.

I also wish to let you know that I will be resigning as President at the AGM in September 2014 but will remain on the committee. I plan on spending more time supporting my extended family.

Thanks so much to our committee and other volunteers for your continued support. I'd also like to thank our staff members for their dedication and professionalism throughout this very challenging year.

Lastly, I wish all of you a very merry Christmas and a joyous and prosperous New Year.

Gerry Doyle, President

Huntingtons Qld will be closed from 23/12/13 to 5/1/14



YOU MAY LIKE TO KEEP THESE IMPORTANT PHONE NUMBERS HANDY.....

13 Health	1343 2584	Energetex (power supply/outages)	131 962
Beyond Blue (depression, anxiety etc)	1300 224 636	GP Helpline (after hours)	1800 022 222
C'wealth Respite & Carelink Centres	1800 052 222	Lifeline Counselling & Support	131 144
Carers Qld (closed public holidays)	1800 242 636	Poisons Information	131 126
Disability Information Service	1800 177 120	SES (flood & storm assistance)	132 500
Emergency (ambulance, fire, police)	000	Weather warnings	www.bom.gov.au
Emergency Management Qld	www.disaster.qld.gov.au/		

FROM THE WELFARE DESK...

Hello Families and Friends,

This edition we thought we'd offer a different contribution from the welfare desk. Tressa and I are asked often, if not daily, about research, studies, information and advice for living healthily and proactively when someone is living at risk or gene positive with HD. In our spare time (did I just say SPARE?!?) we are scouring many information sources on the Internet, medical journals, newspapers, and newsletters to update our knowledge to be able to pass on to our families and carers the most up to date information we can find. This information covers not only all things HD, but information about predictive testing, IVF, housing, Centrelink, insurance, superannuation, health services, discrimination, carers, disability support services, aged care support services, nursing homes, counselling, specialists, talking to kids and so much more. All of this is on top of the lived stories, advice, experiences and thoughts from our HD families that only families can bring the "realness" to.

Over the past couple of months I've had people ask if we have a Facebook page. The short answer is - not yet, but we're working on it. We recognise the value in Facebook as a communication and information sharing tool, so it is on the agenda for next year to get it up and running in our spare time (there's that word again!).



In the meantime, we thought we'd share some of the sites that we ourselves follow to keep up to date on all things HD and more. If you're not on Facebook (you need a computer or a "smart phone" with Internet access) then it might be something to consider. Facebook is more than teenage kids taking photos with pouty lips and cute little photos of kittens. I'm sure there are kids and grandkids that will be more than happy to get you started.



HD Buzz <https://www.facebook.com/HDBuzzFeed>

About - Huntington's Disease research news. In plain language. Written by scientists. For the global HD community.

****Christine's thoughts:** *this website is by far, the best website for communicating information, results and breakthroughs in the HD sphere. We always go here for our information - and for clarification - and so by following them on Facebook we get updates each time they publish a new article. This site has to be Number One on your list!*



HDYO (Huntington's Disease Youth Organisation) <https://www.facebook.com/HDYouthOrg>

About - Supporting young people, all over the world, impacted by Huntington's Disease.

Mission - To provide and improve the support available to young people impacted by Huntington's Disease worldwide.

Description

- Material created specifically for young adults, teenagers, children and parents
- Multilingual site and content, thanks to the HDYO Translator Team
- Content covering many of the issues young people face with regards to Huntington's Disease
- Lots of videos, interviews and speeches with young people and professionals
- Interactive and educational material to help young people learn about Huntington's disease in an engaging format
- The opportunity to ask Huntington's Disease experts any questions you may have in our "Ask a question" section
- The HDYO forum - a place for young people to discuss HD and share experiences
- Newsletters, podcasts and much, much more

****Christine's thoughts:** *I would tell people about this site every day. Their Facebook page is a social outlet that updates you on the goings on, with a link to their website which is NUMER ONE for parents, kids and families. In fact, it is a site for EVERYONE! The videos, especially about the testing process and IVF are great - with A LOT of Australian content! We've even got some Queensland families and kids published and in videos.*





HD Youth Alliance Australia <https://www.facebook.com/theHDAlliance>

About - Changing the landscape for young people impacted by Huntington's Disease in Australia.

Description - Youth and young adults affected by HD take control and have a more positive HD experience through:

- Linking into communities of other young people, researchers and medical professionals
- Fundraising, advocating and lobbying for results on our issues
- Making positive lifestyle changes to lead healthier, more active lives

**** Christine's thoughts:** a great page with information about living positively with HD - whether you are at risk, gene positive or living with affected families.



Beyond Blue <https://www.facebook.com/beyondblue>

About - The national depression and anxiety initiative. We're here Mon-Fri 9-5. For immediate 24hr support please call 1300 22 4636.

Mission - To provide national leadership to reduce the impact of depression and anxiety in the Australian community.

**** Christine's thoughts:** tips and advice for depression and anxiety - great for everyone alike!



Lifeline <https://www.facebook.com/LifelineAustralia>

About - Need crisis support now? We're here to help. Call 13 11 14 (24/7) Chat to us privately online (8pm-12am AEST) Visit <http://www.lifeline.org.au/gethelp>"

Description - Lifeline's Facebook page provides a forum for members of the public to support the work of our organisation and gain access to information about our services, resources and campaigns. Lifeline is unable to provide crisis support on Facebook, and in some cases, we may remove posts where safety, risk and privacy are an issue.

**** Christine's thoughts:** this Facebook page is managed and monitored only during business hours. Has some great tips and advice.



National Disability Insurance Scheme <https://www.facebook.com/disabilitycare>

About - This is the official NDIS Facebook page.

Description - The National Disability Insurance Scheme supports Australians who have permanent and significant disability, to live their life and achieve their goals.

**** Christine's thoughts:** not yet in Queensland, but it's coming!



Department of Human Services (Centrelink) <https://www.facebook.com/HumanServicesAU>"

About - We're the Australian Government Department of Human Services, sharing Centrelink, Medicare, Child Support information that's relevant to you!

Mission - The Department of Human Services Facebook page has a particular focus on information for seniors, jobseekers, carers and people with disability. We also use this account to answer questions about our department.

**** Christine's thoughts:** keeps you updated with changes to pension rates, extra payments, holiday payments, reminders, and more.



Foodbank Queensland Ltd <https://www.facebook.com/pages/Foodbank-Queensland-Ltd/90610695824>

About - Foodbank Queensland is a not-for-profit, non-denominational community organisation that seeks food surplus and donations, then redistributes to welfare agencies that in turn help to feed the hungry.

Mission - It is estimated that as much as 20% of all food produced in this country cannot be sold for a variety of reasons. It may be incorrectly labelled, have faulty packaging, be part of a trial run or not produced to exact specifications. It's a sad



fact that most of this food ends up as expensive landfill - a terrible waste considering that the 300 agencies that access Foodbank Queensland are helping to feed more than 75,000 needy people in our state each week.

**** Christine's thoughts:** this is the main Facebook page - information about Foodbanks in and around where you live can be found here. For those west of Ipswich, the Loowood Foodcare Community is BRILLIANT!



City Councils

**** Christine's thoughts:** other useful sites to follow on Facebook are your local city council pages. They post useful information and reminders about services, rates, rubbish bin collections, and so on, as well as keeping you informed of services provided by the local councils to people with a disability, carers and the unemployed. For example - in Ipswich City Council, the City Hearts Cabs provide a transport service to and from local shopping centres on a weekly basis for only a couple of dollars to pensioners - door-to-door! Find out about your own council initiatives and giveaways by searching your city council site. If you have family living in other towns, maybe you can keep an eye on their city council sites too.

Other HD Associations

**** Christine's thoughts:** some of the other Australian HD Associations, such as Victoria and WA, have their own facebook pages. You might like to check them out - especially if you have family interstate. Likewise, Canada, America, the UK, Scotland and so many other countries have pages that they operate, each with interesting stories from families, awareness raising activities, fundraising and more. Might be a great way to get motivated and get involved. You can find them by typing "Huntington's Disease" into the Facebook search option.

I hope this has been useful to include this month. It is by no means an exhaustive list - if you are following other Facebook pages that you think are worth a mention, please let me know by email christine@huntingtonqld.com or give me a call. One final thing for you to check out is a YouTube clip. This is a presentation by one of the HD Buzz founders as he talks about current research and studies. It is wonderfully positive, informative, and everything you need to know about HD right now - condensed into an easy to watch 30 minute clip:

<http://www.youtube.com/watch?v=0fsoBBuirUg>

HD researcher and co-founder of HDBuzz, Dr Ed Wild, addresses the 3rd UK Conference on Huntington's Disease in Stoke on Trent. Entitled "Families as Members of the Research Team", Ed's talk encompasses the latest progress globally in Huntington's Disease drug research, why it's important for family members to get involved in as much research as possible, and how they can do so. The talk focuses on gene silencing for Huntington's Disease, phosphodiesterase inhibitors (PDE10) and kynurene monoxygenase inhibitors (KMO).

With another long and eventful year behind us, Tressa and I will both be taking some time off over the Christmas break. We would like to take this opportunity to thank our wonderful admin staff who provide so much support and assistance to us both - thanks Anne, Helen and Jan! Thanks also to our wonderful volunteers who assist with our day respite program, support group activities, transport, folding and packing Newsletters and last but not least for writing out our birthday and Christmas cards we send out that we know so many of our clients look forward to every year.

We wish all our families a merry Christmas and a happy and safe New Year, whilst we remember, with you all, those who are not here with us anymore. Keep buying yourselves time, families - the day will come.

Love and peace to you all

Christine Fox and Tressa Byrne - The Welfare Team



In September...



Christine and Tressa headed to Toowoomba for the day with some of our Coffee Catch Up group members to meet up with our Toowoomba counterparts at the Toowoomba Carnival of flowers. This is the second year the group has made the trek up the range (with a few wrong turns and scenic routes to boot!). It is always great to link in with other people who are gene positive or living at risk of HD - to share experiences and thoughts and provide support to one another. It's even BETTER when we get our photo taken with the (very cheeky!) Miguel from Channel Ten's "The Living Room." We watched him cook something - we'd love to tell you what it was but between his accent and antics it was too funny and distracting to be able to pay attention!

Our Coffee Catch Up group is only possible due to the very generous contribution made by the IOOF Foundation, who has supported our organisation for two years running. We are truly grateful and appreciative of the generosity and hope this relationship continues into the future.

And did you know?

That Tuesday the 3rd of December was International Day of People with Disabilities? Christine Fox, our Senior Welfare Officer, was joined by one of our families who volunteered their time and their stories to shoppers at the Brassall Village Shopping Centre for a few hours where we had a stall and awareness raising activities.



Thanks to Carmel, Shannan and Joe for their help and time! If you hear of any activities or events to help raise awareness of HD, please get in touch with our office.



CHRISTMAS DONATIONS TO HUNTINGTONS QUEENSLAND

If you or a friend would like to make a Christmas 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:

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

Address.....

..... Postcode.....

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

Email (please print clearly).....

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





Would \$500 assist you with education costs?

Receive up to \$500 in Matched Savings with Saver Plus

Saver Plus is a free ten month program that provides financial education, budgeting and saving tips to assist you:

- ✓ build your skills around managing money
- ✓ become a regular saver
- ✓ reach a savings goal

Once you finish the program ANZ will match your savings, up to \$500, which goes towards education costs for you or your child including:

- ✓ school and sports uniforms
- ✓ computers, tablets and laptops
- ✓ TAFE and apprenticeship costs
- ✓ sports fees, dance and music lessons
- ✓ text books and school stationery
- ✓ and much more

Can I join?

Saver Plus is offered by community organisations in over 60 locations across Australia. You may be eligible to join if you:

- ✓ have a Centrelink Health Care or Pensioner Concession Card
- ✓ are at least 18 years old
- ✓ have some regular income from work (yourself or your partner) including casual, part-time, full-time or seasonal work; AND
- ✓ have a child at school now or starting next year OR be attending or returning to vocational education yourself

To find out more, call or SMS your postcode to 1300 610 355 or email saverplus@bsl.org.au



Payment Options:

Cheque Money Order Visa MasterCard Electronic Funds Transfer (EFT) Cash

Bank: Westpac BSB: 734-002 Account No: 07-5025 *Please include your name in your EFT transaction.*

Credit Card No _____ / _____ / _____ / _____ Expiry Date ____ / ____ AMOUNT \$.....

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 Email: admin@huntingtonsgld.com



Announcing the 2014 Australian HD conference.....

“Embracing Opportunities with HD”

National Huntington's Disease Conference 2014

Perth, Western Australia 11th - 12th September 2014

The Conference will be hosted by Huntington's WA over two days - 11th & 12th September 2014.

It will bring together family members, researchers, allied health professionals, care workers and members and supporters of all Huntington's Disease Associations across Australia.



Details of key note speakers, the full programme and how to register for the Conference will be available early 2014.

Contact Huntington's WA: Phone: (08) 9346 7599 or Email: admin@huntingtonswa.org.au

UPDATE - CAM WILSON'S GUINNESS WORLD RECORD ATTEMPT – POSTPONED ONCE AGAIN DUE TO EARLIER INJURIES

Latest press release.....

Cam Wilson's Guinness World Record attempt, scheduled for November this year was postponed again due to injuries he sustained in the recent V8 Race 3 at the Gold Coast 600.

Wilson is a V8 driver recovering from neck, back and other injuries sustained in the high-speed collision on Sunday 27th October this year.

In a message on Facebook to his fans, Wilson said, “I am truly grateful for all those who have supported me. I will not let you down and will smash this record as planned in early February 2014 once my body is back to the condition it was”.

Date change

Now starting at midday on Tuesday 4th February 2014

Finishing midday Wednesday 5th February 2014

Venue

Go Karting Brisbane

870 Kingsford Smith Drive Eagle Farm

Cam's Fund Raising Goal

Cam is aiming to raise a minimum \$24,000 (his target is for over \$50k)

All proceeds to Huntington's Queensland

For more info

Phone 3868 2225

Website www.gokartingbrisbane.com.au



UQ HD Study – Volunteers Needed!

A message from the 6th World Congress on HD

"HD is the most curable of incurable diseases because we exactly know the cause. But to fight against this terrible disease we do need each other's' help. Scientists and HD families should work together and connect, to reach the goal of treating HD faster.

The UQ HD Study

In our lab we are studying in depth the relationship between HD and the immune system. Our goal is to understand the role the immune system plays in driving the progression of disease in HD. We hope to pave the way for a possible future therapeutic treatment for HD.

We would like to ask for your help to continue with our studies.

We need a small donation of blood (20mls – a tablespoon) from both HD patients and healthy volunteers. We would really appreciate you participating in our study – together we can do much more to fight against HD!

What is required?

- A single 20ml blood sample
- Signed consent
- Brief questionnaire & examination for HD patients

How can participate?

- Males & females over 18 years of age
- HD patients and healthy volunteers

For more information please contact: Dr Susanna Mantovani Mb 0468 753 805 Em: s.mantovani@uq.edu.au

We look forward to hearing from you.

Regards, Dr Trent Woodruff, School of Biomedical Sciences, The University of Queensland



Carers Queensland **SOME INTERESTING STATISTICS ABOUT CARERS**

Carers Queensland represents the diverse needs and interests of carers in Queensland. They empower carers by providing carers with information, education, training, advocacy, counselling and other support services that may assist in their caring role. They also aim to raise awareness about the valuable role that carers play.

Carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or are frail aged. *The Australian Bureau of Statistics 2012 Survey of Disability, Ageing and Carers* indicated that in Queensland:

- 484,400 Queenslanders are carers
- 275,000 carers are female (57% all ages, primary and secondary)
- 209,400 carers are male (43% all ages, primary and secondary)

Nationally, 2.7 million Australians were carers in 2012 with 770,000 identified as primary carers. According to Access Economics' report *The Economic Value of Informal Care in 2010*, unpaid carers provided a combined 1.32 billion hours of care per year and \$8.3 billion in resources would be required each year from the government's health and community sector to replace the work carried out by unpaid Queensland carers. Nationally, the cost would be \$40 billion.

The Carer Advisory Service provides info, support, planning and referral advice to help you in your caring role. For more info phone 1800 242 636 (free calls from local phones, mobile calls at mobile rates).




CHRISTMAS COOKING


Here's a very easy and yummy recipe to make with the kids during the school holidays. Keep these little balls in the freezer...they'll be great when your friends visit you on a hot Brisbane afternoon.

Julie's Rumballs

Ingredients:



- ✓ 250gms Philadelphia cream cheese (leave out of the fridge for an hour or two before you start)
- ✓ 125gms dark chocolate
- ✓ 12 milk arrowroot biscuits
- ✓ $\frac{1}{4}$ cup icing sugar
- ✓ 1 tablespoon desiccated coconut
- ✓ 2 tablespoons dark rum
- ✓ 1 teaspoon vanilla essence
- ✓ Extra desiccated coconut for rolling



Method:

1. Crush biscuits into crumbs – use a food processor or you can get a more exercise using a rolling pin
2. Sift icing sugar
3. Beat cream cheese until soft and smooth
4. Melt chocolate in a bowl over a saucepan of gently boiling water
5. Mix together cream cheese, melted chocolate, biscuit crumbs, sifted icing sugar, 1 tab coconut, rum and vanilla until well combined
6. Shape into small balls and roll in the extra coconut
7. Keep in the fridge and serve chilled
8. Or better still, store in the freezer and serve straight from the freezer. They don't freeze too solid, just so nice to eat on a hot Brissy summer day
9. Serve with chilled cherries

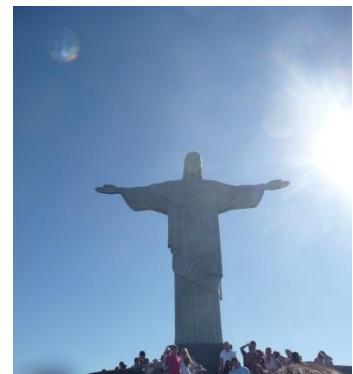


A message of hope from Rio de Janeiro

Report from the World Huntington's Congress 2013

Good day everybody,

First of all, I will present myself. My name is Susanna Mantovani. I'm a scientist at The University of Queensland, studying Huntington's Disease in Dr Trent Woodruff's research group. You may have met me at the Huntingtons Queensland meetings, or at the Royal Brisbane and Women's Hospital, at the HD clinic, where we have been asking for a small donation of blood from both HD patients and healthy volunteers, to help us study this pathology in more depth.



Thanks to Huntingtons Queensland's contribution, I had the privilege to attend to the World Huntington's Disease Congress, held in Rio de Janeiro in September this year. I would like to share with you a few impressions and ideas I learned there.

The first great thing about the Congress was its general organisation. It was structured in such a way that both the patients with their families and the scientists could often participate in the same seminar sessions. This allowed for a wider interaction between two worlds that are too often kept segregated: the world of people affected by HD and the scientific research community. This was the first important thing we all learned at the Congress: researchers, doctors and HD families should work together and connect, to reach the goal of treating HD faster. We need each other's help to grow stronger and to fight against this terrible disease.

It was also the first time a Latin American Country had hosted a World Huntington's Congress. This allowed the growing South American HD network to better integrate with the HD community from the rest of the world, to join their forces and grow stronger.

There have been a lot of presentations and discussion about the huge initiative called 'Enroll HD', which you might have heard about. It is a worldwide project, born in the USA and intended to accelerate the development of therapies for HD. It is designed as a research platform to collect uniform clinical data and biological samples to better study and understand HD. Thanks to this project more data and samples will be available to any investigator studying HD around the world, enhancing and speeding up any clinical trial on HD. Moreover, this project aims to involve as many HD families around the world as possible, since their contribution and experience is crucial and vital to the development of any new treatment. If you want to know more about this project, you can consult this website:

http://chdifoundation.org/index.php?option=com_content&view=article&id=121%3Aenroll-hd&catid=45%3Anews.

In Australia and New Zealand, 3 of the 10 anticipated hubs for Enroll HD are up and running and the others should follow soon. The Royal Brisbane and Women's Hospital together with The University of Queensland could be one of the next Enroll HD centers and we are all working towards this goal.

At the Congress I had the opportunity to meet Dr Ed Wild and Dr Jeff Carroll, two very passionate scientists in the field and founders of the HDBuzz news platform (<http://en.hdbuzz.net/>). This platform, as many of you might know, is the biggest website on HD providing scientific news on HD in plain language and connecting families and investigators around the world.

Every evening during the Congress, Ed and Jeff transmitted 'Buzzilia', an on-line report of Congress activities, streamed from Rio de Janeiro. I learnt a lot from them - they went from talking about science in high details, to being able to communicate any news and findings in plain and simple language. They could attract the attention of anyone in the audience, making us feel like a single force: patients, investigators, families, medical doctors, nurses, all together to find a way against HD.

I would like to tell you the main points of their presentations. I believe they sowed a seed of hope, which is the main take home message I had from the whole Congress: there is hope for HD if we work together.



The first point Ed made is that HD is the most curable of incurable brain diseases, because we know that the cause is a genetic mutation and so we know exactly where the problem is.

The second item of good news is that, as I said before, the global HD community is organising to generate powerful tools to fight HD.

The third reason to have hope is that with a simple genetic test we can find out if a person carries the HD gene, so in the future we might be able to start interventions before symptom onset. Nevertheless, many scientists think that having HD symptoms does not mean that it is too late for treatment. Obviously we still have to work and study a lot and to set up proper clinical trials, but there are good reasons to think that we have good weapons against HD.

The final beautiful image they described was the one of a glacier. To form a glacier, single flakes of snow fall down from the sky and it looks like a single flake can't do much, but compacted together a glacier can move mountains. Science is similar to that, we know that snowflakes are falling down, one by one, and we know that, all together we can make the difference.

I highly recommend you to have a look at all the episodes of Buzzilia, you can find them on YouTube at:

<http://www.youtube.com/watch?v=a6wHi63VzM>

http://www.youtube.com/watch?v=Wxt_YgOOyi4

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

They will take you through everything discussed during the Congress and keep you entertained at the same time.

It is heartening and strengthening to think that there are people working to find a cure for HD all around the world. That means that when half the world's scientists sleeps, the other half is working to fight HD. Together we leave no respite for this pathology, and, if it's true that "he who seeks finds", we will find a way against HD.

As you know there are different ways of studying a pathology. 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 HD have been generated since the discovery of the HD gene, but in the last years investigators have been able to precisely insert the human HD gene in mice. At the Congress it was shown how this new generation of mice can be helpful in preclinical studies and in elucidating the basic mechanisms of HD. This is part of the work we are conducting here at The University of Queensland, with the support of Huntingtons Queensland.

As I said before, we also work on human blood. We study cells and soluble factors that are found in blood of both HD patients and healthy people and we compare them. This is the next goal of our work: to study in depth how inflammation is involved in HD and how we can stop or at least slow down the inflammatory process that feeds the vicious process of neurodegeneration. At the Congress I met other researchers focusing on this or other aspects of HD and trying to design new drugs and find new effective biomarkers to control and fight HD. That means we are many working towards the same goal!

I hope I have shown in this report that there are more than a few signs of hope in this field and that we need each other's help to continue the battle and eventually win the war.

I conclude with a big thanks to the Huntingtons Queensland for its invaluable support. I leave you with these images of beautiful Rio de Janeiro, the city from where the HD hope is spreading around.



Dr Susanna Mantovani

School of Biomedical Sciences, The University of Queensland



Seizing the Day: Living with a Genetically Inherited Disease

The following article 'Living with Huntington's Disease' is one part of the three part story written by Rachel Garnett (published UK Sun Newspaper October 6th 2013) about genetically inherited diseases.

<http://www.express.co.uk/life-style/health/434569/Seizing-the-day-Living-with-a-genetically-inherited-disease>

Living with Huntington's Disease

Sue Cross, 35, is a driving instructor from Brighton UK. Her mother Liz, 75, has Huntington's Disease, a neurological condition that causes progressive mental and physical deterioration. The disease is inherited and Sue also carries the faulty gene. She says: "Growing up, it was my dad I'd turn to for reassurance. I love my mum but she was always emotionally remote and withdrawn. My uncle told me that she was outgoing and carefree when she was younger, but I never knew her like that.

Now I know about Huntington's Disease I think mum was showing symptoms for years before she was diagnosed. HD damages the brain cells that control emotions and behaviour as well as movement. She was often depressed – one of the first symptoms of HD – and would drink too much because of it. She could also be socially awkward and abrupt – I cringed sometimes at how she spoke to people. Over the years she saw various doctors but they never got to the bottom of it. We thought that's just the way she was." Then in 2009 her condition started to deteriorate rapidly. She became very twitchy, lost the ability to cook – which she used to be brilliant at – and stopped looking after herself.

Doctors thought she'd had a stroke but a neurologist tested her for Huntington's Disease and the result came back positive. I'd never heard of HD but it was a relief to get a diagnosis, so that at last we could get some help. Then I went on Wikipedia and saw that HD is hereditary. Worse still, it seemed that mum had actually been lucky because the disease often strikes when people are much younger. Was this going to happen to me? I knew I had to get myself tested and when my result came back positive too, I burst into tears. Images of being in a wheelchair or withdrawing from loved ones flashed through my mind.

When I told mum, she said she felt guilty because the faulty gene came from her. I don't think she really understood though, and within a few months she was asking me how I'd got it but I don't blame her – it's not her fault. Dad feels very sad but he doesn't show it in front of me. He told me before the results but he doesn't remember, that if I have HD, I should take lots of holidays. I went straight to Australia and blocked my worries out. But as soon as I got home, I went into delayed shock.

Then in January 2010 I joined my local branch of the Huntington's Disease Association. It helped to meet people who were facing the same situation. And I realised how important it is to raise funds for research, because a cure seems close.

It wasn't long after mum's diagnosis before the disease really took hold. In the space of a year she went from coming out with me for coffee to needing a wheelchair and not being able to wash herself. I bathed her, which felt like total role reversal, before it became too much and I got a carer for that. Dad took over the rest of her care. He's 77 now, but he's amazing.

The scariest thing for me is facing HD as a single person. Although I have lots of friends and my dad is wonderful, I would like to be part of a couple. I'd also love to be a mum, but would it be selfish to have a child who might carry the gene? There are ways, using IVF, where embryos that don't have the HD gene are placed inside you, but even then I might start to suffer symptoms while my child is still dependent on me.

The horrible thing about HD is that you may not be aware of your own symptoms. As I don't have a partner, I'm relying on friends to pick up on any changes and get medical help. I'm a very sociable person and I hate the idea that I could become



Sue has Huntington's Disease, a neurological condition that causes mental and physical deterioration



insular or depressed and not recognise it. For me the behavioural changes are the most distressing. I can go out in a wheelchair if I have to, but if I don't want to go out, that doesn't bear thinking about.

The hardest thing is not knowing when symptoms will start and constantly imagining that they have. My memory can be bad, and when I went for my yearly check-up at the hospital and told them I sometimes forget things, they said I was fine.

This autumn I'm going travelling again to South America and New Zealand. I haven't made plans for the future – I don't even want to think about ever needing care – but HD has made me grab life with both hands. By doing that, I hope to keep the disease at bay for as long as possible."



More evidence points to Huntington's Disease exercise benefit

Two studies show exercise benefits for some symptoms of Huntington's Disease. Just don't believe everything you read.

By Dr Tamara Maiuri on December 09, 2013 Edited by Dr Jeff Carroll. The authors have no conflicts of interest to declare.

A news article reports that a "breakthrough" program of physical, mental, and social stimulation could "halt Huntington's progression". Sounds pretty exciting — but does the science back up the hype?

Most people can agree that exercise is good for the body and mind. Why wouldn't it be a good idea to keep Huntington's Disease patients in shape? Most likely it would, but these 'obvious' ideas have to be formally tested before we can be sure. A number of health products proposed to be helpful to general health, such as specific vitamins, have later been found to be harmful.

An exciting article was recently published covering a study called the 'Huntington's enrichment research optimisation scheme (HEROS)'. The HEROS study looked at whether a program of physical, mental, and social stimulation could slow the progression of HD symptoms. A breathless article suggested remarkable results: that HEROS participants deteriorated at a 50% slower rate than patients who did not participate in the program. This sounds exciting, but let's take a closer look at the details.

What, exactly, was found?

Reading scientific news reports often leaves one wondering, "how do researchers really know that?" No one can be blamed for not wanting to go through tedious research reports to find out. But that's what HDBuzz is here for. We can tell you this — the original study certainly does not claim that "participants deteriorated at a 50% slower rate than the control group", as the headlines reported. So what does it show?

The researchers, led by Prof Mel Ziman at Edith Cowan University, asked HEROS study participants to carry out gym-based and home-based exercises as well as occupational therapy for 9-18 months. The researchers monitored aspects known to be affected in the early stages of HD, like weight loss, mental health, and cognitive function such as learning and memory.

What they found was a general trend toward improvement in some of these symptoms, particularly problems with movement. Program participants didn't lose as much weight as the 'no exercise' group, and they scored just a bit better on some of the learning and memory tests. Researchers have already published an initial analysis of the early, or 'pilot', phase of the study, and are now working on publishing the longer term follow-up study.



The authors of several new studies have studied the effect of exercise, along with other rehabilitative approaches, in HD patients.



These results do NOT mean that the exercise program “halted progression” as the title of the news article would have us believe. In order to do that, it would have had to completely stop every single symptom of HD. The authors of the HEROS study were careful to point out a number of areas that aren’t improved by the program, including depression, which is an important source of problems for people with HD.

“Why wouldn’t it be a good idea to keep Huntington’s Disease patients in shape? Most likely it would, but these ‘obvious’ ideas have to be formally tested before we can be sure.”

How does a study come to be misrepresented like this? Most likely, a combination of a press release lacking caution, and a reporter who didn’t ask enough questions.

Size matters

An important factor with studies like these is how confident the researchers are of their results. For example, if the participants’ responses to an exercise program differed wildly, with some responding very well and some not at all, then researchers would be less confident about the program’s success than they would if all the participants responded equally well.

But every patient is different — you could never expect each person to respond the same way! Luckily, there’s a way around this problem, which is to recruit more participants. The larger the group, the more confidence researchers have that the results they see are true and will translate to the real world.

The detailed report on the HEROS study is quick to point out that the results of the study must be interpreted cautiously, since it was made up of only 20 participants, hampering the confidence with which we can be sure this exercise program actually changes the symptoms of HD.

In addition, the full study has not yet been published, which means it has not stood up to the scrutiny of fellow scientists in the ‘peer review’ process. The key message here is that the results seem good, but we need more information to be definitive.



Rehabilitation was useful for some signs of HD, such as balance and movement problems, but wasn’t as much help in other areas, including depression.

Replication, replication, replication

Besides increasing the number of subjects, another way that scientists can improve the reliability of their findings is testing to see if they are ‘reproducible’. Experiments conducted in Europe should work the same way when they’re conducted in Australia, or Africa. This ongoing re-creation of one another’s results is an important way that science checks itself.

Luckily for those of us interested in HD treatments, another team of researchers lead by Jan Frich of the University of Oslo are also interested in improving the lives of HD patients with rehabilitation, including exercise.

These researchers recently described the results of a study conducted in Norway quite similar to the HEROS study run in Australia. In fact, the Norwegian scientists went a bit further, by actually admitting HD patients to 3 in-patient rehabilitation sessions, each lasting 3 weeks. So, over the course of a year, the patients involved received 9 weeks of intensive exercise and social activities.

“These studies support the idea that a sustained program of regular, exercise and rehabilitative therapy are of benefit to HD patients.”

Similar to the observations made in Australia at around the same time, the Norwegian scientists observe that rehabilitation and exercise lead to improvements in balance, walking ability and physical quality of life in HD patients. Interestingly, the Norwegian group did observe improvements in depressive and anxiety symptoms, which was not the case in the Australian study. What’s more, the Norwegian team’s results have been published in a peer-reviewed journal.



Mounting evidence in favour

The results of these studies support the idea that a sustained program of regular exercise and rehabilitative therapy are of benefit to HD patients. It reminds us that, while we await therapies to prevent or delay the onset of HD, there are a number of beneficial things we can do to improve the quality of life of HD patients today. What we can't conclude from these short studies is that the disease process in the brain is "halted" or reversed — but if people are walking, balancing and feeling better, that's perhaps not the main issue when it comes to decisions around exercise.

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