Gateway

News from Huntington's New South Wales
Volume 14 No 3 Spring 2011

From the President

Dear Friends

I'm writing to you from Melbourne where I have just attended the World Congress on Huntington's Disease. I last attended a WCHD back in 2005 and while travelling to Melbourne I kept wondering would anything have changed since then.

The first change I noticed was the format. Sunday was Family Day—families from all over Victoria as well as other states, New Zealand and international delegates gathered to hear about and discuss a wide range of topics including coping strategies, relationships and youth living with HD.

Another new feature was OzBuzz—at the end of each day two scientists gave an overview of the day's proceedings in laymen's terms. In addition three other researchers gave a summary of their presentations and they were under strict instructions not to use scientific jargon—if they slipped up they received a gong!

Attending the WCHD were those who have been involved with HD research and care over many years. However the greatest surprise for me was the number of young people at the Congress. Bright young scientists, researchers, neurologists and health professionals who have developed an interest in and a passion for HD.

Also present were many young people from families affected by HD. Fresh, young people ready and willing to carry on the mantle started by others some forty years ago.

I was really excited by this and it's my hope that there will be young, new, enthusiastic people willing to join our Board at our Annual General Meeting on 5th November 2011.

If you would like to discuss the possibility of joining the Board of Huntington's NSW, please do not hesitate to contact me at robyn.kapp@ahdansw.asn.au.

I look forward to seeing you at our AGM.

In Friendship

Robyn Kapp

Annual General Meeting

The Annual General Meeting will be held on Saturday 5th November 2011 at 2pm at the offices of the Association, 21 Chatham Road, West Ryde**.**

The Business of the Meeting is to
1. To accept the Minutes of the 2010 AGM
2. To accept the Annual Report of the Association
3. To accepted the audited Annual Financial Statements of the Association
4. To appoint the Auditor for 2011/2012
8. To elect the Office Bearers and Committee Members

Nomination forms for the Office Bearers and Board elections are available upon request.
Please contact the office if you need some sent to you.
Completed forms should be returned to Huntington's NSW no later than Friday 28th October 2011.
Nominations may also be made at the meeting.
Note: You must be a financial member to be able to nominate or vote. However non-members are welcome to attend.

After the formal part of the meeting, there will be a presentation of the World Congress on Huntington's Disease, followed by a delicious afternoon tea.

The Board and Staff would very much welcome your presence at our AGM

Please RSVP (for catering purposes only)
Phone (02) 9874 9777 or 1800 244 735 (NSW STD Freecall) or e-mail lily@ahdansw.asn.au

Farewell, Thank you and Good Luck …

It is with much sadness that we advise that Angela Lownie has retired from the Huntington Disease Service at Westmead Hospital.

Angela, as Clinical Nurse Consultant and Outreach Co-ordinator has made a magnificent contribution to improving the quality of life for people with HD and their families for more than 15 years.

She worked extremely hard at educating health professionals and nursing homes about HD and about caring for those affected in any way. She undertook a variety of research in caring for people, she was most enthusiastic, committed and dedicated to her role.

We wish Angela every happiness in her retirement and sincerely thank her for helping to light a candle so those affected by HD don't have to curse the darkness.

A new study INSPIRING hope for people with early onset dementia and their families

Early onset dementia is when a person has an onset of memory loss and/or other cognitive problems prior to the age of 65. These symptoms may occur due to a range of conditions such as Alzheimer's disease or frontotemporal dementia, or they may result from medical conditions such as multiple sclerosis or Huntington's disease, or the long term effects of alcohol misuse. The numbers of people with early onset dementia seem to be increasing however there is little known about this group.

The INSPIRED study, led by Professor Brian Draper and Dr Adrienne Withall from the Dementia Collaborative Research Centre at the University of New South Wales, recently won funding from the National Health and Medical Research Council (NHMRC). Dr Clement Loy, the Director of the HD Service at Westmead is also one of the investigators. The study will determine accurate information about the numbers of people affected, their different conditions, their experiences and those of their family members. Consumers will be interviewed across the South Eastern Sydney, Illawarra and Shoalhaven regions over the next two years. Importantly, the results of the study will inform service planners about the health and support service needs of younger persons with dementia and their carers, and will allow the development of training packages for health professionals working with these clients.

The INSPIRED study is a collaboration between researchers at the University of New South Wales, the University of Sydney, and at the Prince of Wales, St Vincent's, Sutherland and Port Kembla Hospitals. If you wish to seek more information about the INSPIRED study please contact the research co-ordinator Dr Prasad Nishtala on 9385 2617 or by email inspiredstudy@unsw.edu.au, or alternatively visit the study's website (http://www.inspiredstudy.org/).

Thank you for renewing your Membership!

Thank you to everyone who has renewed their membership of the Association. Grateful thanks also to those who have generously made a donation to the work of the Association. It means a lot!!

If you're unsure of whether you are up-to-date regarding your membership, please call Lily at the Association office and she can advise you.

It is important for lobbying and advocacy for the Association to have a membership that is representative of all Huntington's families and there is a "no fee" option for those who are on a pension or otherwise unable to pay the $22 fee. If you are a carer and take out a paid membership please encourage the person you care for to also join under the "no fee" option – there is strength in numbers!

Remember you can now pay your annual membership fee or make a donation by credit card.

Travelling North and West ...

Central Coast Support

The Central coast support group meetings have been well attended. We all have a great time at the meetings – people have told me that one of the highlights is the informal chat time after meetings.

The group, which regularly has new people coming along, recently heard a talk on 'Depression' from Ian Kilpatrick from Axiom Psychological and Coaching Services. This was quite enlightening, not just in a Huntington's context, but also generally. Depression is a serious problem for some people with Huntington's but also a much broader community issue, so we all benefited from Ian's comprehensive presentation.

We have also started having regular 'social nights', the first being dinner at Terrigal Hotel, and second ten pin bowling at Gosford, followed by dinner at the Central Coast Leagues Club.

In addition to facilitating the support group, I continue to make quite a number of visits to families and individuals.

Support group meetings are usually held in The Education Room at Matthew John Nursing Home, 351 Terrigal Drive Erina on the third Monday of the month. We have a great partnership with the team at Matthew John which is headed up by Director of Care Letitia Quirk. They recently donated some no longer needed equipment (hospital style beds and shower chairs) that are available for use by families affected by Huntington's.

If you are thinking of coming along to a support group meeting, please call Mark Bevan on 0410 629 850 to confirm the time and place of the next meeting.
Remember – everyone is welcome – love to see you there.

Out West – Bathurst and Beyond

Way out west – in June I travelled west to places I have never been before, and met some of the nicest people imaginable. Over 4 days, I travelled to 10 towns/cities (covering about 2,000 km), and had a wonderful time meeting with about 12 families, and visiting 2 nursing homes. It was just great to meet people who needed support, information, encouragement and just to talk with someone who can genuinely empathise with their situation. I was also able to meet up with Erin Baker, the genetic counsellor in Dubbo – a delightful young lady really committed to her job.

It was inspiring to meet such wonderful people, showing real courage and resilience in some very difficult circumstances. Well, I have to say that I cannot wait to get back there again, and meet up with those same people, and others who may need support. I am planning to be in Bathurst, Dubbo, Orange and the western region generally, from October 22nd to 25th. So if you would like to meet up, either in a group setting, or individually, I would love to hear from you. Please call me on 0410 629 850, or email me at mark@ahdansw.asn.au.

Far North Coast

I made my maiden voyage to the far north coast in April. It was a wonderful time, meeting many families across many towns and cities, covering about 2,000 kilometres in the week, and visiting people from Coffs up as far as Kingscliffe. I also met with Lesley Fraser from the Qld Huntington's Association to discuss how we can work together to most effectively support families located close to the Queensland border. The Queensland Association does a great job assisting some Huntington's families in NSW close to the Qld border, for which I thank them. I was also fortunate to meet with

Lorraine Hodgson, who is the genetic counsellor based at Kingscliffe, another genetic counsellor super committed to her job.

One challenge in this area as in other regional areas is the spread of families affected by Huntington's. It is very difficult to get families together for group meetings, as there is so much distance between many of them, and some are unable to travel the distances required to be able to meet with other people in the region. I am seeking to help people connect with other families in the area with a view to families forming a mutual support network. Many people in this area and others have indicated a willingness to participate – hopefully this will develop into a good ongoing support mechanism.

Given the number of people in the area impacted by Huntington's, and their needs, I am planning to return to the area from November 19th to 22nd.
If you live in the northern coastal area of NSW – from around Kempsey up to the border, and would like to make contact, or like to meet up with me on my next visit, you can email me at mark@ahdansw.asn.au or call me on 0410 629 850.

Mid North Coast

John Conaghan and I visited the mid north coast area in May, where a well attended 'support group' lunch was held at the Port City Bowling Club. Our thanks again to the club for making us so welcome. John and I also visited a number of families, and ran an in-service session for staff at a Nursing Home in Port. The training session was attended by about 15 staff and a family member, and feedback indicates that it was extremely helpful. In addition to that, various relevant information booklets were given to the staff for future reference.

John and I will be heading to the Mid North Coast area again on November 28 and 29, and would love to hear from anyone who would like to meet up with us, or attend the support group lunch. Please contact me by email at mark@ahdansw.asn.au or call me on 0410 629 850, and we can discuss how we can best serve you.

North West

I had the privilege of visiting the Tamworth /Gunnedah/Armidale area in March, meeting with a number of families, and visiting one care facility in the area. I was also able to meet yet another devoted genetic counsellor, this time in Tamworth - Melissa Buckman.

The meetings with clients were extremely profitable, and a good start to connecting with this area. By the time you read this, I will have visited this area again (from September 18th to 20th). Please contact me if you would like to catch up the next time I am in the area. Email me mark@ahdansw.asn.au or call me on 0410 629 850 – I would love to hear from you.

Do you have a story to share?

We want to hear from you. If you have a personal story or a contribution that you wish to make to the Newsletter please send it to us at the Association offices (see details on the back page) or by email to Robyn at robyn.kapp@ahdansw.asn.au.

Ten golden rules for reading a scientific news story

Avoid the hype: HDBuzz presents ten 'golden rules' for reading a news story or press release about Huntington's disease
By Dr Ed Wild on September 05, 2011, Edited by Dr Jeff Carroll

Real progress is being made on the road to Huntington's disease treatments, but sometimes it feels like scientists promise more than they can deliver. So, HDBuzz has come up with ten 'golden rules' to help you decide whether a news story or press release offers genuine promise for HD, or whether its claims should be taken with a pinch of salt.

Like a glacier, science moves slowly but can move mountains. Don't be fooled by anyone suggesting that a single snowflake can do the same

Snowflakes and glaciers
HDBuzz loves science. In our more philosophical moments, we like to imagine all the world's scientific research as a flurry of snowflakes, gently settling on a mountain top and gradually, over months, years, and decades, compacting into A huge, unstoppable glacier that can carve entire mountains.

No single snowflake could do that, but combined, over time, the power of science to change the world — and improve the lives of people with HD — is immense.

How science reaches the public
Science becomes 'official' when an article about a piece of research is published in a peer-reviewed scientific journal. But a lot of science reaches the public through press releases.

Increasing competition over scarce funding means that getting results published in a scientific journal may not be enough for scientists to keep their work going.

The agencies that fund science take their lead from the public, so one way for researchers to secure funding is to get the public excited about their research. So when a piece of work has so far only focused on a small area, one way to excite people is to get them to imagine the whole glacier, rather than just the snowflake.

So, universities and research companies have press offices, whose job is to encourage scientists to produce press releases, in which they often speculate about what applications their work may have, down the line.

Of course, part of what science is for is to come up with real-world uses for new discoveries. But it's a two edged sword, because many things that **might** happen, never do.

Another layer of speculation can get added, when press releases are turned by bloggers and journalists into news stories. Writing about big breakthroughs in common diseases gets more clicks and sells more papers than writing about small progress and obscure conditions.

What's the harm?
The result can be that press releases and news articles sometimes end up promising things that the scientific research could never deliver — or which are much further away than an article suggests.

This isn't the fault of the individual scientists, or of the press office, or the bloggers or journalists, or of the people reading the stories. Nobody sets out to mislead — but sometimes that can be the

outcome, and it's bad news because it can lead to disappointment and loss of hope.

Ten Golden Rules
The good news is that disappointment can be avoided if readers know what to look out for.

So, HDBuzz has come up with Ten Golden Rules for reading a press release or scientific news article. They're here to help you to draw hope from scientific news where it's warranted — and avoid being let down where it's not.

1. Be skeptical of anyone promising a "cure" for HD now, or in the near future.
2. If something sounds too good to be true, it probably is.
3. Has the research been published in a peer-reviewed scientific journal? If not, the press release may not be much more than speculation.
4. Ask yourself whether the press release is announcing the results of a project — or just the start of the project, a new partnership or funding approval. There's a big difference.
5. The only way to show that something works in HD patients is to test it in HD patients.
6. A positive result in an animal model of HD is a very good start — but can't be called a cure — and plenty of things that work in mice fail when tested humans.
7. Something that hasn't been tested in an HD animal model has a very long way to go to become a treatment.
8. Your mind is like a house — it's good to keep it open, but if you leave it wide open, you never know who'll walk in.
9. Not sure about something you've read? Ask HDBuzz to write about it!
10. Finally, remember that every day, science moves us towards effective treatments for HD. Even negative results and treatment failures help us to focus on more fruitful ideas.

An example — 'block and replace' gene therapy
Recently, a story headed "Molecular Delivery Truck Serves Gene Therapy Cocktail" appeared on news site Science Daily. Similar articles appeared on many other sites, all reporting on work led by Prof R Jude Samulski of the University of North Carolina, and published in the journal PNAS.

The news article revealed that Samulski's team had done something pretty impressive. The research centered on a disease called alpha-1-antitrypsin deficiency, 'alpha-1' for short.

People with alpha-1 develop liver problems, because they have two faulty copies of a gene that tells cells how to make the alpha 1 protein. Part of the problem is that the healthy protein is missing, and part of the problem is that the mutant protein made by cells is harmful.

Samulski's group used a form of 'double-barreled' gene therapy to fix this problem in mice with the same genetic problem. First, they made a DNA-like molecule that would block production of the abnormal protein — a form of gene silencing. Then, they added a replacement gene that would be used by cells as a recipe for making the healthy protein.

They packaged these two payloads into a virus called AAV, which attaches to cells and injects its contents into them. Mice treated with the virus restored healthy levels of the alpha-1a protein and didn't develop liver problems.

Great work — shame about the press release
Let's be clear — this is great science and an innovative approach to a devastating illness. So what's the problem?
Well, this research came onto our radar because the news reports about it all mentioned the

potential of the approach for treating other 'protein folding' diseases like "cystic fibrosis, Huntington disease, amyotrophic lateral sclerosis … and Alzheimer's disease".

The news stories said that, because that's what was said in a press release by the researchers themselves, and again in the PNAS article.

The trouble is, the research didn't directly involve any of those other diseases — and huge obstacles stand in the way of it working in Huntington's disease or the other conditions mentioned. But you wouldn't necessarily know that from reading the news stories.

In the case of HD, there are two main problems. The first is that the huntingtin protein, the protein produced by the HD gene that causes HD is huge — seven times larger than the alpha-1a protein. The AAV virus is just too small to deliver a replacement huntingtin gene. Other viruses might be able to, but they're not as good at delivering the cargo into cells. The other problem is that once the alpha-1 has been made, it's released into the bloodstream, which means that a little goes a long way. Huntingtin protein on the other hand, does all its work (and damage) inside cells — so any gene therapy needs to get into lots more cells in order to be beneficial.

The result of these problems is that the approach — ingenious though it is — simply can't be applied to HD now, and even if it were radically altered, it's unlikely it'll benefit HD patients for at least a decade — if at all.

You might think you have to know all about gene therapy to be able to spot these problems in applying it to HD.

In fact, there are enough clues there to enable non-scientists to treat this particular breakthrough with caution, even though it might have popped up in a Google news alert for "Huntington's disease".

Using the golden rules
Applying our golden rules to this particular press release causes several alarm bells to ring.

Rule 2. The press release suggests that this one approach could be useful for five different, major diseases — sounds amazing … could it be too good to be true? Proceed with caution.

Rule 5. Tested in HD patients? No, this research only went as far as mice.

Rules 6 and 7. What about an HD animal model? Nope, the mice were models for alpha-1 deficiency, not Huntington's disease.

So you don't have to be an expert in the science of gene therapy for our rules to provoke some healthy skepticism about this particular press release.

That's where rules 8 and 9 come in — keep an open mind but remain cautious about breakthroughs — and if you read something you're not sure about, feel free to ask HDBuzz to investigate — either by emailing editor@hdbuzz.net or using the suggestion form at HDBuzz.net.

Rule ten
Rule ten is our favorite — because it brings us back to waxing lyrical about the snowflakes and the glacier. Rule ten is there to remind us that — whatever a particular bit of news can or can't tell us about the search for effective treatments for Huntington's disease — **we're a bit closer today than we were yesterday, and tomorrow we'll be closer still.**

Living with HD:Decision-Making for Reproduction in Individuals At-Risk for HD

by Kimberly A Quaid, PhD, HDSA Centre of Excellence at Indiana University, USA

The Prospective Huntington At-Risk Observation Study (PHAROS) is a multi-site observational study that aims to establish whether experienced clinicians can reliably determine the earliest clinical symptoms of HD in a sample of 1001 individuals at 50% risk for Huntington's Disease (HD) who have chosen not to be tested. As part of the funding for the study, the NIH included money to conduct qualitative interviews with the subset of PHAROS participants. Interviewers were recruited from the research coordinators from the top PHAROS enrolment sites. Unstructured open-ended qualitative interviews were conducted on a subsample of 55 PHAROS participants at six PHAROS sites across the country: Atlanta GA, New York City, NY; Dublin, OH; Wichita, KS; Minneapolis, MN; and Indianapolis, IN.Most of the literature on reproduction in those at-risk for HD has focused on the impact of genetic testing on reproductive decision-making. In our interviews, we sought to understand the reproductive decisions in those at-risk who had chosen not to be tested. After reading and re-reading our interview transcripts, we indentified three groups of participants:

1. Those who had children despite knowledge of their risk,
2. Those who did not know their risk prior to having children; and
3. Those who knew their risk and chose not to have children.

For those in Group 1 who know of their risk and decided to have children, we identified four main themes:

1. Hoping for a Cure,
2. Feeling Guilty,
3. Magical Thinking;
4. Just Another Something.

The theme "Hoping for a Cure" reflects the fact that several individuals in this group stated explicitly that their decision to have children was based on the hope for a cure in the near future. The idea was that by the time their children reached the age of onset of symptoms, there would be a cure available and they would not have to worry about developing HD.

The second theme "Feeling Guilty" reflects the feelings of guilt expressed by some participants about the decision to have children despite their genetic risk.

The third theme "Magical Thinking" embodies the stated belief, on the part of participants, that they simply would not get HD. The fourth theme "Just Another Something" was a direct quotation from one of our participants and reflects the desire on the part of our participants to live their lives as normally as possible while refusing to let the risk of HD influence their decision, including, the decision whether or not to have children.. From this perspective, HD was just one possible negative event in a long list of potential negative life events and should not be given any special attention when making life choices.

For Group 2, those who had children before they knew of their risk, we identified two major themes:

1. Too Little Too Late, and
2. Getting It Wrong.

The theme of "Too Little Too Late" reflects the fact that in this group, many lacked information about HD or the inheritance of HD prior to choosing to start a family.

The second theme "Getting It Wrong" characterizes the participants in this group who had information about HD, but whose information was either inaccurate or simply wrong. Thus, in this group, they made the choice to start a family without fully understanding the genetic aspects of HD and only later came to appreciate the fact that they may have already passed on the genetic mutation that causes HD.

For the third group of participants, those who knew of their risk for HD and chose not to have children, we identified three main themes:

1. Vigilant Witness,
2. Stopping HD; and
3. Being Alone.

For the main theme "Vigilant Witness" participants shared poignant stories about witnessing the decline and death of family members due to HD. Many had been actual caregivers of sick relatives, often a parent, and most had witnessed the destructive forces of HD in several generations.

In the second theme in this group, "Stopping HD," many had been told in no uncertain terms, and sometimes by their own family members, not to have children, and to stop the line of HD in their family. This advice was taken to heart.

In the third theme, "Being Alone" participants described how they lived their lives avoiding intimate relationships, or denied themselves having children in order to avoid harm to others should they become ill. As a consequence of these choices, many voiced worry about the fact that if they were to become ill, there was no one to take care of them.

When predictive testing using linkage first became available in 1986, many health professionals, myself included, believed that one major use of the technology would be to allow individuals at-risk to determine whether or not they carried the HD gene and use further testing and reproductive technologies to prevent passing on the HD gene. We believed this because that was what we were told by individuals at-risk. However, the number of individuals at-risk choosing to be tested remains low; most requests for testing come after the at-risk individual has completed his or her family, and the number choosing prenatal testing is miniscule.

The decision whether or not to have a child is intensely personal under the best of circumstances. When there is a 50% chance to pass on an incurable genetic disorder, the decision becomes even more complicated. There are your hopes and wishes for the future, the experience of HD in your family, your fears of future illness, and the desires of your partner, all which need to be factored into an irrevocable choice. We did this study to shed light on some of the factors that go into making these decisions and hope we did so in a manner that is respectful of all choices that were made and adds to our understanding of the experience of being at-risk for HD.

Reference: Quaid KA, Swenson MM, Sims SL, Harrison JM, Moskowitz C, Stepanov N, Suter GW, and Westphal BJ for the Huntington Study Group PHAROS investigators and coordinators (2010) What were you thinkin?: Individuals at risk for Huntington Disease talk about having children. Journal of Genetic Counseling 19:606
Acknowledgement: The Marker – Spring 2011, Huntington's Disease Society of America.

The HD Outreach Service Has Moved

The HD Outreach Service has now moved from Lottie Stewart Hospital at Dundas to Westmead Hospital. Please note their new contact details below:

Westmead Hospital
HD Service,
Westmead Hospital,
Hawkesbury Road,
Westmead 2145

Phone: 02 98459960

Huntington's Disease Service

invites you to
come along to our

FAMILY AND FRIENDS SUPPORT GROUP

for a get together with other carers who, like yourself, are caring for a partner, a family member or a friend with HD.
Come along and join us as we share our chatter, laughter, tears and experiences.

2011 Sessions

28 September, Wednesday, 10.30am
19 October, Wednesday, 10.30am
16 November, Wednesday, 10.30am
Dec - Christmas Get-Together - TBC

Sessions will be held
at
Huntington's NSW Offices
Elsie Court Cottage
21 Chatham Road
West Ryde NSW 2114

For RSVP and further information, please contact:

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Web Site: www.ahdansw.asn.au

AHDA (NSW) Inc
The Australian Huntington's Disease Association (NSW) Inc is a not-for-profit organisation established in 1975.

Our Mission
The energies and resources of the Australian Huntington's Disease Association (NSW) Inc are directed towards satisfying the needs of people with or at risk for Huntington's Disease and their families in NSW and the ACT by providing and/or facilitating delivery of a range of quality services.

Our Philosophy
People with Huntington's Disease and their families are individuals with equal value to all other members of Australian society, with the right to treatment and care by knowledgeable professionals and care givers, the right to appropriate support services and the right to have the best quality of life possible.

Our Services
These include education and information; advocacy; counselling and referral; holiday programs; family support; rural outreach and client services.

Our Board 10/11
President: Robyn Kapp OAM
Vice President: Anne Low
Treasurer: Richard Bobbitt
Secretary: John Conaghan
Don Ayres
Karen Bevan
Keith Dingeldei
Jim Finn

Association and Other Useful Contacts

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Ramona Watts
Family Support Co-ordinator

Lily Shu Yue Ma
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