Gateway

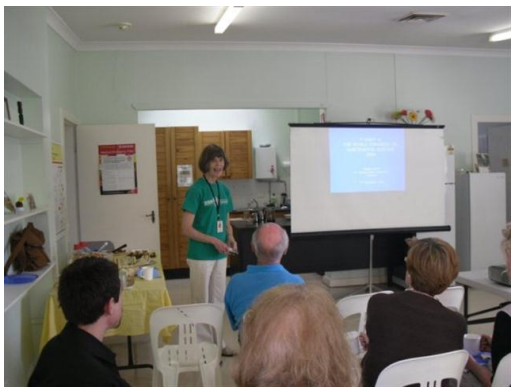
News from the Australian Huntington's Disease Association (NSW)
Volume 12 No 3 Summer 09

A Successful AGM

Our AGM was held on 7 November 2009 at the offices of the Association and was attended by 23 members and guests.

People came from the Central Coast and Newcastle to attend the meeting. Our guest speaker this year was Angela Lownie, the Huntington Disease Service's Outreach Coordinator/Clinical Nurse Consultant, whose talk you can read about in this Issue of Gateway.

The Annual Report of the Association was presented to the members.



Angela Lownie at the Association's AGM

From the Executive Officer

I am happy to report that the Association is progressing well during this period of re-building. Our AGM, which you can read about in this Issue, was a great success. During the last few months, we have re-established many connections and made some new ones, all of which will benefit our community in the future. Our staff have worked hard to lay the foundations to rebuild and reinvigorate our programs. Their hard work is being repaid as we have increased numbers in both the attendees at the social/lunch club, and enquiries and contacts from HD families throughout NSW and ACT. At the Association office we all have a sense of excitement for what we can achieve together in the year ahead.

The World Congress held in Vancouver, Canada in September, which you can also read about in this Issue, had a strong contingent of representatives from NSW. Hearing the reports back from the various delegates has really touched and inspired us at the Association.

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From the Executive Officer

One of the messages from the conference was that the ability to share ideas and information with members of the HD community is critical to the success of providing support to families and to finding a cure. This has highlighted for us the importance of this newsletter, our website, the various programs we run and the contact events we have planned for the future.

Finally, as the year rapidly comes to an end, I want to thank everyone who has supported the Association throughout the last year. Without the support and contributions of our board, members, staff, volunteers, HD and other professionals, donors and all those affected in someway by HD, we simply could not function.

Everyday I feel privileged to be here and to be associated with such a great group of people. I look forward to the New Year and to continuing to work together to make a difference.

I leave you with the favourite quote of Katy, a young carer aged 13, who spoke at the World Congress and gave an insight into her life as the carer for her dad who was diagnosed with HD in 2006. She quoted: "Yesterday is History, Tomorrow is a Mystery and Today is a Gift."

As always, please feel free to contact me either by phone at the Association or by email to ingrid@ahdansw.asn.au

Ingrid van Tongeren
Executive Officer

A Successful AGM (continued from Page 1)

In addition, Dr Elizabeth McCusker also provided a brief update about the latest happenings in research, including the Phase 3 HORIZON Dimebon study in which Australia, including NSW is participating.

As usual, during the AGM the members elected our committee for 2010. The following office bearers were elected: Anne Low (President), Robyn Kapp OAM (Vice President), Richard Bobbitt (Treasurer) and Viki Moraitis (Secretary). Elected as members of the committee were Karen Bevan, Mark Bevan, John Conaghan, Keith Dingeldei, Jim Finn and Elaine Sammut. We welcome the new members Karen Bevan and Mark Bevan. Karen, although new to the Board this year, is well known to the members of the Association through her previous role of Administration Assistant/ Activities Co-ordinator at the Association office. She is also well known for her tireless efforts and contributions to the success of Camp Breakaway. Mark is also well known to the Association having served faithfully for years on the Board as both an office bearer, including President, and as a committee member. We congratulate all our Board members on their election to the Board and wish them the best in the year ahead.

"Together, we can triumph over HD"

Our AGM Guest speaker Angela Lownie gave us a highly informative, engaging, entertaining and very warm account of the conference and her experiences at the World Congress on Huntington's Disease held at the Westin Bayshores Hotel in Vancouver from 12 to 15 September 2009. As part of her talk she wore the emerald green 't' shirt with the salmon logo given to conference participants and showed us a slide show. In addition she had on display 4 of the 6 scientific posters that the Westmead contingent to the conference prepared as part of the 283 poster display hosted at the Conference.

Angela highlighted 3 of the sessions she attended which were of particular relevance to us.

The first of these was the presentation by Jeff Carroll who spoke on the role of families in HD research. Jeff's message was to encourage HD affected families to get involved.

The second session was Dr Julio Montaner, an HIV/AIDS researcher, who spoke of what the Huntington's community can learn from other diseases. He highlighted how far effective long term treatment regimes had come in the last 20 years and noted that those advances had been based on heartache, struggle and EFFORT and suggested that we can take heart from their experiences in our quest for a cure.

The third session Angela spoke about was the session presented by Sarah Noonberg and Karl Kieburtz on Dimebon as a treatment for HD. Angela explained that Dimebon seems to work by improving the function of the cell components called mitochondria (which are involved in energy utilisation) and as such if Dimebon works by enhancing mitochondrial function it may benefit patients with HD. The phase 3 HORIZON study of Dimebon which Australia (including NSW) is part of, hopes to assess the impact of Dimebon on cognitive, behavioural, motor and overall function.

Angela noted that her take home messages from these three sessions were that those with HD and their families are making a difference and that there is hope for effective treatments.

She also spoke of how the social events held in the evening and the teas and breaks were also a vital part of the networking and connections made at the conference. Angela spoke of how they provided an opportunity to speak about problems and issues with those in the "same boat" and how the feeling of those at the conference was that this sharing provided the glue that can hold us all together through difficult times as we work towards the theme of the conference which was "Together we can triumph over HD".

Huntington Happenings

Camp Breakaway – March 2010

Our next camp for people with Huntington's Disease will be for those living in the community and will be held from Monday 15 March to Friday 19 March 2010. It is hoped to have another camp for the residents of Lottie Stewart Hospital later in the year.

You can attend this camp with or without your carer if you have one. However, if you want to attend without a carer you must be able to walk, sit, stand, dress, undress, shower, eat, drink and use the toilet without requiring assistance. If you cannot do these things without assistance you may still be able to come as long as your carer accompanies you to the camp. If this is the case, please have your carer call either Ramona or Ingrid at the Association so we can discuss the matter and assess your eligibility for the camp.

For all enquiries about the Holiday Camp and to obtain an Application form please contact us at the Association offices.

Applications close on Friday 29 January 2010.

March Camp Volunteers Needed

If you have helped us with previous camps and would like to assist us with this camp please call us at the Association and let us know your availability. If you have never volunteered before but would like to, we'd love to hear from you as well. If you can't be there for the whole camp but are available for part of the time or just want to come up and help during the day then give us a call at the office and let us know your availability.

Have you forgotten something?

A big thank you to everyone who has renewed their membership for this year. Our thanks also go out for the donations that many of you have made to the Association. Your generosity and continued commitment to the Association is very much appreciated, especially in these difficult financial times.

Also we must apologise for the misleading letter that was sent out with the last Gateway and membership renewal form. We hope that any misunderstandings have been cleared up.

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!

If you're unsure whether you are a paid up member, haven't yet renewed but need another form or would like to become a member please call Lily at the Association offices and she can check the database for you or simply send you a form.

Fundraising Event - Day in the Vines Concert

The Concert will be held on Sunday 10th January 2010 from 10am-6pm at Sherwood Winery 1187 Gowings Rd Sherwood (via Kempsey). Full details on this exciting upcoming event can be seen on the poster for the event in this Issue.

A Day in the Vines Raffle

Just a reminder that anyone who is interested in buying or selling tickets for the big Raffle which will be drawn at the event should contact either Naomi on 0411050630 or Lily at the Association offices.
Tickets are $2 each or 3 for $5. The fabulous prizes are: -

1st prize

Two nights accomodation for 2 & 2 games of 18 holes of golf at Bonville Golf Resort.

2nd prize

Two nights accommodation for 2 at Smoky Cape Lighthouse, Lighthouse Rd, Arakoon.

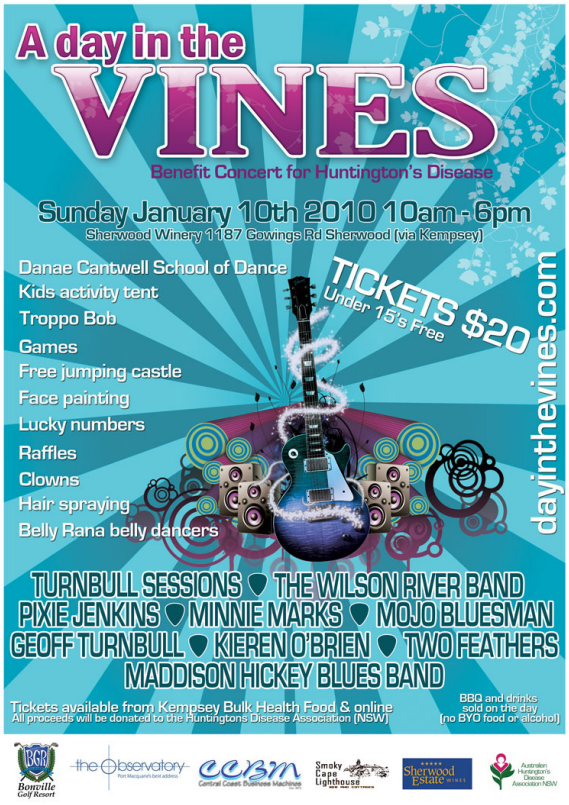
3rd prize

Two nights accommodation for 2 at The Observatory, Port Macquarie.

Request for Donations of Items for Sale on the Day

If anyone has any art & craft items or anything else that they would like to donate to be sold on the day please contact Naomi on 0411050630 or by email to nay_cake@hotmail.com

You can also read more about the event at http://www.adayinthevines.com



Tell us what you really think ...

Tell us what you do and don't like about this newsletter so we can keep on improving it.

You can call us at the Association offices or email Ingrid at ingrid@ahdansw.asn.au.

Family Support Program Update

It has been a busy time at the Association this last few months. We have been attempting to make contact with more carers to find out how they are coping with caring for their loved ones with HD and if there is any way in which we can assist them. Carers have been keen to share with us their uplifting stories of bravery and courage, and we would like to hear from more of you, even if you would like to just have a chat and to discuss the day-to-day basics of living with HD.

In November a few of us attended Lottie Stewart Hospital for the annual presentation of Awards. It was inspiring to see these dedicated staff members achieving awards for their outstanding service and kindness to the residents at Lottie Stewart Hospital, and for others, their years of effort and dedication in helping the hospital run smoothly. Following the presentation we went to the Residents' Recreation Room to view the exhibition of art works created by the residents and were humbled by the wonderful and imaginative works of the residents. Many of the artists were from Huntington's Lodge and had spent many weeks sketching, painting and creating collages in preparation for the exhibition.

Our social/lunch club has continued to be a big success. We have been alternating club time at Elsie Court Cottage with excursions every other fortnight and have been enjoying each other's company. Several of our members who had been absent for a while have come back to join us as they missed the socializing and laughter associated with our lunches and outings! Please read more about our social/lunch club in our report in this issue of Gateway. If you have HD or care for or know of someone with HD who would like to join us every other Tuesday, please do not hesitate to contact Ramona or Lily on 02 9874 9777. Alternatively, you can email us at ramona@ahdansw.asn.au or lily@ahdansw.asn.au.

"Surviving Huntington's" blog

"A Survivors Guide to Huntington's Disease" is a blog written by Angela F whose mother was diagnosed with Huntington's Disease. Angela attempts to cope with the difficulties she was experiencing by expressing herself through the blog. She talks about what living with her mother's illness means to her, and the important decisions that she has to make. In this post she writes poignantly about her fond memories of her mother and how these helped her to cope. Angela is concerned that she might be a carrier and undergoes genetic counseling, learning that she also carries the mutated gene. She deals with this courageously, and along with her partner looks into the possibility of IVF treatment so that she can have children. Angela's candid and courageous writing about both her own and her mother's illness make this a valuable resource for people with Huntington's Disease and their families as well as those involved in the care of people with Huntington's Disease. Angela's blog can be found at http://survivinghuntingtons.blogspot.com/

Social and Lunch Club News

Our social/lunch club has been "on fire" this last quarter. We have been alternating between lunching at Elsie Cottage and going on an excursion each fortnight. Our clients can't decide which is the better of the two options!

A lunch outing

Lunch at Elsie Cottage is often a gourmet affair - last month Lily and I baked a homemade chocolate cake and served it with vanilla custard for morning tea. For lunch we had cooked a scrumptious meat lasagna smothered in cheese sauce (almost everyone had seconds!), followed by fruit salad and ice-cream. That was a tremendous hit, but everyone was too full to play bowls after that so we ended up playing a wild game of Uno instead. I lost every game but I suspect the rules had been surreptitiously altered beforehand!

Bobbin Head

In September we enjoyed a beautiful day at Bobbin Head at Kuringai Chase National Park. We walked around the marina and stopped for a picnic overlooking the water while ducks and people on canoes looked on as we ate. The day was absolutely glorious and everyone enjoyed the fresh air and warm sun on our backs as we strolled towards Apple Tree Bay. It was a lovely day out.

Going to the movies

Just for something different, we went to the movies last week, and to get into the spirit of Christmas we saw "A Christmas Carol" with the voices of Jim Carey and Gary Oldman. It was a pretty amazing animated movie, a bit scary at times when The Ghost of Christmas Past, Present and Future confronted mean old Ebenezer Scrooge, but it had a delightful ending which put a smile on everyone's face.

We are planning an awesome Christmas party on Dec 15th and would love for people with HD and their carers to come and join us. Please call either Lily or Ramona on 9874 9777 or email me at ramona@ahdansw.asn.au if you are interested in joining us. We would love to celebrate Christmas with you!

Social club in full swing

Ramona Watts
Family Support Officer

HD World Congress Vancouver 2009

By Naomi van Dijk and Michelle O'Brien

It was a huge privilege for us to attend the world congress in Vancouver and to have this opportunity to learn from so many professionals, scientists and most importantly, HD family members. The devastating impacts of this disease was evident throughout the conference, as was the strength and commitment the HD community has to improving the lives of all those affected. It was expressed on several occasions throughout the talks that "Huntington's Disease is a family disease, the whole family is the patient and while one family member may get a diagnosis, the disease impacts on everyone." We felt that this message acknowledges the complexities of the disease throughout whole families, and acknowledges the diverse and challenging needs within the HD community.

The conference began with the "Ariel and Ralph Walker Day", which gave families an opportunity to come together to discuss a variety of topics. We attended several sessions focusing on youth, fundraising, staying strong throughout HD and using our internet resources to reach families and the community. Again there was a strong theme of "family". These smaller group discussions expressed the strong need for families to share stories, share their sadness, pain and loss, but also share a common goal to move forward to support each other by sharing ideas and resources for staying strong.

This day was particularly important for us as it enabled us to establish connections with young people in families where someone is affected by HD. The connections that we made will surely continue to grow beyond the conference. There seems to be a "Youth Movement" occurring and with young people being our future, it seems very timely that we support them through what can be a very difficult times, living in a family with HD affected members. Brynne Stainsbury from Canada along with Katie, also from Canada, and Kirsten from Scotland, hosted a discussion session around their youth web projects. This provided a forum for us to share our idea of an Australian youth webpage and to share current Australian projects and youth camps, which are occurring in some states (SA). The importance of these projects was strongly validated and we now have an international support network to continue to share our ideas and ways of working together in the future.

Another big topic of discussion was fundraisers and drawing in volunteers and how we do this without burning out our HD community. Many ideas were discussed and included drawing on the broader community like schools and churches for support. An important point that was raised was to give people small jobs and avoid overwhelming them by not using the same people over and over. We also need to ensure that we thank our volunteers, without the pressure to keep on helping. A volunteer appreciation event was also discussed which is one way of sustaining our volunteers and acknowledging their hard work. Naomi took the opportunity within these fundraising discussions to share our "A Day In The Vines Benefit Concert for HD" which was received with great enthusiasm!...we may even have a few international visitors to the day!

HD World Congress Vancouver 2009

the topic of "Quality of Life" for someone with HD was raised many times. There were discussions about the importance of early interventions to help provide and maintain quality of life for as long as possible, through accessing supports and medications early. There was a 'new' idea discussed around what they call stage 0, which discussed the importance of healthy living, including diet, exercise and lifestyle before the onset of symptoms. We heard that even though HD is not treatable, there are some early psychiatric symptoms that can be treated, especially depression, so people can live healthy lives for as long as possible.

Mid stage discussion involved looking at what the person liked before they developed HD as they are going to be the things they continue to enjoy throughout their life with HD. It's not so much about finding new activities or things for them to do, but more about knowing the person prior to symptoms, so carers can be in touch with the persons needs. Life books were discussed as a great way for someone who is entering care, to be able to share with their new carers who they are and what they like to do. Life books give carers a deeper understanding of the person prior to HD and it gives them the dignity and respect they deserve as an individual, not just an illness.

We heard a wonderful story where a woman with Huntington's had a real passion for high heel shoes. Nurses kept trying to convince her not to keep wearing her beloved shoes as it was increasing her chances of falling. As her symptoms progressed she was forced into a wheel chair. For most people this would have been very upsetting, however the lady was delighted, as this meant she could wear whatever shoes she wanted. The next time the nurses saw her she was sporting the tallest pair of bright red high heels the woman could find! It was great to hear this as it helped us understand the fact that people with Huntington's still enjoy the things that they did before they became symptomatic, and how significant it can be for them to maintain their pleasures in life!

HD World Congress Vancouver 2009

Oliver Quarrell from the UK spoke about Juvenile Huntington's Disease, and its impacts on individuals and families. JHD, meaning onset prior to 20 years of age, makes up 5% of cases of HD. Oliver shared case scenarios and again highlighted quality of life issues for these young people, and the importance of ensuring they have access to family and community, and continue to be involved in the activities they enjoy. Jeff Carroll from Canada gave a heart-warming talk entitled "The Individual in Research" Jeff's mother recently passed away from HD in 2007. He went through genetic testing himself in 2003, and received a gene positive result. Jeff, who is a scientist, has dedicated himself to finding treatments and a cure for HD. He has used his passion and personal experiences with HD in this work in the lab with Michaela Hayden and the rest of the team at the Centre for Molecular Medicine and Therapeutics at the University of British Columbia in Canada. Jeff shared his moving story with IVF pre-implantation genetic diagnosis. He gave a huge acknowledgement to all couples who are going through this often very emotional and overwhelming process, especially to his wife who gave birth to their twins in 2006. Jeff's commitment and passion for HD research was truly inspiring. Jeff's ability to use his experience to help others, and to inspire people to participate in trials and research, was received with great enthusiasm. Jeff received the longest standing ovation of the conference. Jeff recently did an article for "The Globe and Mail" which you can read at http://www.theglobeandmail.com/life/article787356.ece

There were many other highlight talks at the conference, particularly the talks from HD family members. BJ Viau shared his personal journey with his mother having HD and the success of his hooperthon fundraiser! Barb Marshall, a women from Canada, had a table set up where she was selling raffle tickets and sharing her story of living with HD. Barb gave a very touching speech at the end of the conference, when her raffle was drawn, about how much she had achieved in sewing her quilt, and the significance of her good care from her neurologist. Warren Evans gave a talk "Life lessons from Laura and Laura's hope". Warren gave us a very moving talk about his daughter journey with JHD and then entertained us with his very enthusiastic talk about fundraising! His line of the day was "rip their hearts out...then ask for money!' He spoke about not being afraid to ask for money...and how it's ok to make people say no! Laura Jean Kokoska shared her family's story with HD and gave a talk on "Improving the quality of lives of People with HD through Kundalini Yoga and Meditation". She gave us some practical exercises and got us all participating in yoga exercises and chanting. I don't think there was dry eye in the room after her presentation! All these family members, and many more, shared something of themselves with others, and it is this sharing which creates great opportunities for building strength, connections and networking.

Powerpoints of the talks will be available for viewing at www.hdaustralia.org

2009 September 12 - 15 World Congress on Huntington's Disease Vancouver, Canada

Axonal transport impaired in HD

Marsha L. Miller, Ph.D.

Researchers at the University of Illinois at Chicago College of Medicine have identified the mechanism by which axonal transport is impaired in neurons in Huntington's disease. Using mouse, squid, and cell models of HD, Dr. Scott Brady and Dr. Gerardo Morfini and colleagues found that the HD protein activates an enzyme called JNK (for cJun Nterminal kinease) which causes the impairment.

Axons are nerve fibers which project from the neuron and carry electric impulses. The longest axons in the human body are those of the sciatic nerve which run from the base of the spine to the big toes of each foot. Axons in the brain are much smaller of course but are still many times longer than the body of the neuron. Axonal transport is critical for the survival of neurons. Proteins are synthesized in the cell body and then are transported in microtubulins or 'tracks' which run along axons to the synapses, the junctions through which neurons signal to each other. Vesicles containing neurotransmitters are also carried to the synapses for release. When the transport system becomes impaired, synapases and axons become dysfunctional, signaling is reduced, and the cell begins to die.

The specific form of JNK which does the damage is JNK3 which is found in the brain and testes. JNK3 phosphorylates kinesin-1, the motor protein of the axonal transport system which moves the cargo toward the ends of the axons. Phosphorylation reduces the ability of kinesin-1 to bind to the microtubules, thus impairing transport. If the mutant protein impairs such a critical function as axonal transport, then why do neurons remain healthy for years? As we age, this function becomes less efficient.
"If you take a hit when you're very young, you still are making more and transporting more proteins in each neuron than you need," Dr. Brady said, "But as you get older and older, the neuron produces and transports less. Each hit diminishes the system further. Eventually, the neuron falls below the threhold needed to maintain cell health.'

Presymptomatic HD mice were found to have impairment of axonal transport, suggesting that this is an early pathology in the disease. The researchers have concluded that inhibiting JNK activation is a promising therapeutic target. Dr. Brady and his colleagues have also found impairment of axonal transport in Alzheimers and other neurodegenerative diseases. "There is a common theme and a common Achilles heel of the neuron that underlies all these diseases," Dr. Brady said. "We've invented a word, dysferopathy, (from the Greek 'fero', to carry or transport) for these adult-onset neurodegenerative diseases. All have disruption of the axonal transport system in common."

Reference:

University of Illinois at Chicago Medical College press release., http://www.hdlighthouse.org/showUpdate.php?p_articleNumber=650, Posted to the HDL: 23 September 2009

The search for genetic modifiers

Marsha L. Miller, Ph.D., October 29, 2009

The age of onset varies widely in Huntington's Disease, from infancy to old age. Statistical analysis of large samples of patients shows that the single most important factor influencing age of onset is the CAG count, explaining about two-thirds of the variance. The higher the count, the earlier the average age of onset. Although this relationship is very clear on the aggregate level, there are significant variations among individuals and it is possible for two people with the same count to have onsets a decade or more apart. Analyses of data collected from Lake Maracaibo, Venezuela where there is a high percentage of individuals with the Huntington's Disease gene shows that both environmental and genetic factors play a role in producing these variations. The environmental factors are not clear but it is reasonable to suppose that good health practices may make a difference.

Some progress has been made in finding genetic modifiers and there is good reason to look for them. The HD protein causes numerous pathological processes in the brain and it is difficult to determine which targets should be prioritized for drug development. If a variation in a gene associated with a process that is impaired in HD results in an anticipation or a delay in the age of onset, then this is a good indication that this is an area in which treatments should be developed because they are likely to be effective. Further, since the modifier is affecting onset, it involves an early pathology rather than one later in the disease process.

The latest genetic modifier study was conducted by researchers in the Department of Neuroscience at the University of Pisa in Italy. They found that a variation in the DNA repair gene, hOGG1, is associated with higher CAG repeats and earlier onset. The polymorphism reduces OGG1 activity and increases 8-oxoG formation, oxidized damage to the DNA. This finding makes sense in that other researchers led by Dr. Cynthia McMurray found that somatic expansion of the CAG count occurs as a result of the process of removing oxidized base lesions, and is dependent on a single base excision repair enzyme, 7,8-dihydro-8-oxoguanine-DNA glycosylase (OGG1).

Two Coalition for the Cure researchers, Dr. James Gusella and Dr. Marcy MacDonald have reviewed the genetic modifier studies in a new journal article and noted some limitations. First, the studies have small numbers of participants which makes it hard to find the modifiers and get statistical significance. Some of the studies which found a probable genetic modifier failed to be replicated in a subsequent study.

Second, there have been methodological problems. Multiple hypothesis testing needs to be corrected for statistically. When a researcher is doing exploratory work and testing for a number of possible variables, the probability goes up that an association will be found which has actually only been produced by chance and not causation.

The search for genetic modifiers (cont.)

Third, some of the studies have not linked the genetic variation to a specific mechanism. For example, two separate studies have found that a polymorphism in the PPARGC1A gene is associated with delayed onset but it's not clear what that variation actually does.

Fourth, by only looking at genes thought to have some connection to aggravating or mitigating a known HD pathology, researchers may be overlooking other possible genetic modifiers. Drs. Gusella and MacDonald have concluded that the potential of this type of research can be expanded by doing genome wide analyses on large human samples and by taking an unbiased approach as opposed to the candidate approach. In the candidate approach, a researcher looks at genetic variations in a protein thought to be involved in HD pathology.

For example, loss of brain derived neurotrophic factor (BDNF) appears to be a major pathology in HD so researchers have looked at variations in the BDNF gene to see if they are associated with earlier or later than expected onset. No associations have been found, suggesting that the loss of BDNF is not a factor leading to onset as it has been classically defined, as the onset of motor symptoms, and continues to be so defined for the purpose of these studies.

In the unbiased approach, no hypotheses or assumptions are made. By looking at the entire genome in a very large sample, researchers should be able to find previously unsuspected genetic modifiers if they are present and resolve the questions raised by the studies of smaller patient population. Thanks to volunteers around the world who have donated samples for DNA analysis, it should soon be possible for researchers to conduct such studies. The results are likely to be very helpful in directing the development of new treatments.

References:

F. Coppede, F Migheli, R. Ceravolo, E. Bregant, A. Rocchi, L. Petrozzi, E. Unti, R. Lonigro, G. Siciliano, and L. Migliore. **"The hOGG1 Ser326Cys polymorphism and Huntington's disease."** Toxicology 2009 Oct 23. [Epub ahead of print]

James F. Gusella and Marcy E. MacDonald. **"Huntington's disease: the case for genetic modifiers."** Genome Medicine 2009 Aug 21;1(8):80. [Epub ahead of print]

Kovtun, Y. Liu, M. Bioras, A. Klungland, S.H. Wilson, C.T. McMurray, **"OGG1 initiates age-dependent CAG trinucleotide expansion in somatic cells."** Nature 2007 May 24;447(7143):447-52.

http://www.hdsa.org/research/news/geneticmodifiers.html

Are you a youth or a younger person?

Hello to everybody reading the Gateway,

Let me start by introducing myself even though I possibly know most of you anyway. My name is Suzie Docherty and I am a Social Worker with the HD Service. I have been working with families and individuals living with HD for ten years now and I have always wondered what else can be done to address the needs of younger people who are touched by HD in some way.

Having attended the International HD congress in September in Vancouver, Canada, I came back with the feeling that we should try to offer more to the younger HD community. America and Canada have a very strong younger persons support network, in saying this I must add that both these countries have higher number of people with HD.

I have recently spoken to Ingrid and the Association has also been thinking about this and is keen to start something that can address younger people's needs as well.

It would be really great to hear from younger people throughout NSW who would be interested in meeting up with other people, in similar situations living with HD. Many people may feel isolated and alone and this could be a chance to meet up with others, share stories, experiences and laughs, whilst doing some fun activities and having some food together.

What we are asking for is feedback from younger people and whether or not you would be interested in meeting other similar people, in an informal, relaxed and fun environment.

We would love to hear from you if you're interested in meeting others in similar situations. If you are interested please call me. My phone number is 9845 6703 and work Monday to Friday. If I don't answer, please leave a message on my answering machine and I will return your call as soon as possible. I am often out in the community doing various things and therefore unable to answer all the time.

We would like to take this opportunity to wish everyone a safe, fun, happy Christmas and New Years.

Xmas Cheers,

Suzie Docherty

The Companion Card has now been launched in NSW. It is for people with a significant and permanent disability who always require an attendant carer to support their participation in community activities and venues. The cardholder is entitled to a second ticket for their companion at no charge when presented at affiliate organisations.

The Companion Card boasts a rigorous application and audit process which ensures that the card reaches its intended audience. To be eligible for the Companion Card, the applicant must meet all of the following eligibility criteria:

- a resident of NSW
- have a significant and permanent disability
- are unable to participate in most community-based activities without significant assistance with mobility, communication, self care, planning and the use of aids and other technologies does not meet those needs

their level of support is life-long
The Companion Card is not provided to people who only require social support, assurance or encouragement.

For more information on the NSW program please visit www.nds.org.au/nsw/companioncard.htm or the National website www.companioncard.org.au or
Free Call 1800 893 044.

Huntington's Disease Service

invites you to
come along to our

FAMILY & 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.

2010 Sessions

20 January, Wednesday, 10.30am
17 February, Wednesday, 6.00pm
17 March, Wednesday, 10.30am
14 April, Wednesday, 6.00pm
19 May, Wednesday, 10.30am
16 June, Wednesday, 6.00pm
21 July, Wednesday, 10.30am
18 August, Wednesday, 6.00pm
15 September, Wednesday, 10.30am
20 October, Thursday, 6.00pm
17 November, Wednesday, 10.30am
Dec - Christmas Get-Together - TBC

Sessions will be held
at
Cumberland Cottage
Lottie Stewart Hospital
40 Stewart Street
Dundas NSW 2117

For RSVP and further information, please contact:
Social Work Department at Westmead Hospital c/-
Suzie Docherty – 98456703
Jet Aserios – 98457528

Australian Huntington's Disease Association (NSW) Inc

PO Box 178, West Ryde, NSW 1685
21 Chatham Road, West Ryde, NSW 2114
Telephone: (02) 9874 9777
Facsimile: (02) 9874 9177
STD Free Call: 1800 244 735 (Country NSW only)
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 09/10
President: Anne Low
Vice President: Robyn Kapp OAM
Treasurer: Richard Bobbitt
Secretary: Viki Moraitis
Elaine Sammut
Keith Dingeldei
Jim Finn
John Conaghan
Karen Bevan
Mark Bevan

Association and Other Useful Contacts

Ingrid van Tongeren
Executive Officer

Toni Zhang
Acting Administration Officer

Lily Ma
Administration and Activities Assistant

Vacant
Family Support Coordinator

Ramona Watts
Family Support Officer

Huntington Disease Service
Dr Clement Loy
Director
Westmead Hospital
(02) 9845 6793 (leave message)
Lottie Stewart Hospital
(02) 9804 5803
(Tuesday afternoon)

Research Queries
Dr Elizabeth McCusker
(02) 9845 6793

HD Clinic Appointments
Outpatients Department
Westmead Hospital
(02) 9845 6544

Outreach Service
Suzie Docherty
Social Worker,
Westmead Hospital
(02) 9845 6699

Outreach Service
Jet Aserios
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Westmead Hospital
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Angela Lownie
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Lottie Stewart Hospital
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Lottie Stewart Hospital
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Huntington's Lodge
Joan Stewart
Nursing Unit Manager
Lottie Stewart Hospital
(02) 9804 5854
Nursing Staff
(02) 9804 5803

Predictive Testing
Fiona Richards
Social Worker,
The Children's Hospital,
Westmead
(02) 9845 3273

Hunter HD Service
John Conaghan
Social Worker,
Hunter Genetics,
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