

# Gateway

News from Huntington's New South Wales  
Volume 13 No 4

Summer 2010

## A SUCCESSFUL AGM AND A NEW NAME



Our AGM was held on 6 November 2010 at the offices of the Association and was attended by 30 members and guests. People came from the Central Coast and Newcastle to attend the meeting.

At the start of the AGM we had our guest speaker who this year was Dr Clement Loy, Director/Neurologist, Huntington's Disease Service, Westmead Hospital speaking on "What's New In Huntington's Disease?". Dr Loy reported to the meeting on 3 main areas. Firstly, he provided a summary of the findings of both recently completed and ongoing clinical trials namely HART & MermaiHD (ACR16/Huntexil/Pridopidine), HORIZON (Dimebon/Latrepidine), 2CARE (Co-enzyme Q10) and CREST-E (Creatine). Secondly, he spoke on 2 new areas of interest with respect to research, specifically RNA interference (RNAi) and Autophagy. You can read about developments in these 2 areas in this Issue. Finally he provided information on HD-NSW, the prevalence study of HD in NSW to be conducted in 2011, which is being funded by the Association and the Brain Foundation. More information on this study will be provided in Gateway in 2011.

After our guest speaker, the Annual Report of the Association was presented to the members. As usual, during the AGM the members also elected our committee for 2011. The following office bearers were elected: Robyn Kapp OAM (President), Anne Low (Vice President), Richard Bobbitt (Treasurer) and Viki Moraitis (Secretary). Elected as members of the committee were Karen Bevan, John Conaghan, Keith Dingeldei, Jim Finn and Don Ayres. You will no doubt notice the absence of long time board member Elaine Sammut. Elaine has been involved in the work of the Association for many years and whilst she will maintain an interest in the organisation she chose not to re-nominate this year. We thank her for the many years of service she has given the Association and for the professionalism and dedication she has always shown. We also welcome new Board member Don Ayres. We congratulate all our Board members on their election to the Board and wish them the best in the year ahead.

The members also voted on the special resolution before the meeting and unanimously decided that the Association adopt the trading name of "Huntington's New South Wales" after which the AGM concluded and everyone enjoyed a beautiful afternoon tea of homemade food provided by staff and board members.

## From the Executive Officer

As I look back on 2010, I am happy to report that Huntington's New South Wales (as we are now called) continues to progress from strength to strength. During the last year, we have re-established many connections and made some new ones, all of which serve to benefit the HD community now and in the future. Our staff have all worked hard to deliver our programs and we continue to see increased numbers in both the attendees at the day respite program (social/lunch club), and enquiries and contacts from HD families and professionals throughout NSW and ACT.

The National Conference held at the University of Queensland's Brain Institute in Brisbane in September, had a strong contingent of representatives from NSW, including Ramona, Mark and myself from the Association. The Conference brought together scientists, researchers, health professionals, care workers, other experts and members of HD Associations from all the states, as well as people with HD, their carers and family members and others affected in some way by HD. It was highly informative, touching on topics ranging from the worldwide research into HD, latest drug trials, best practice in care and the support needs of families and community services caring for those affected by HD. You can read Mark's report on the conference in this Issue. Hearing about the exciting research developments in HD as well as hearing people's personal stories has really touched and inspired us at the Association. The ability to attend events such as this and be updated on what is happening and to share ideas and information with everyone involved with HD 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. DVDs for the keynote speakers can be ordered directly from Huntington's Queensland. They can be contacted by email on [admin@huntingtonsgld.com](mailto:admin@huntingtonsgld.com) or by phone on (07) 3391 8833

The business meeting of Huntington's Australia which is the National Association was also held whilst we were all in Brisbane and I can report that excellent progress is being made towards planning for the IHA Family Day as part of the World Congress in Melbourne in September 2011. You will also be pleased to know that whilst it is some time in the future, the National Conference in September 2012 will be held in Sydney which will provide a wonderful opportunity for our local HD community to attend and be a part of things.

September was a big month!

The Fundraising event at Mingarra on the Central Coast was an overwhelming success with approximately \$52,000 raised from the event. A big thank you must be extended to everyone who contributed to make this event such a success and also to the attendees on the night whose generosity in supporting HD is much appreciated. You can read more about the event and see some wonderful photos from the night in this Issue.

Our AGM, which you can also read about in this Issue, was a great success. Finally, as the year rapidly comes to an end, I want to take this opportunity to wish everyone a very Merry Christmas and a Happy New Year and to thank everyone who has supported

the Association throughout the last year. Without the support and contributions of our board, members, staff, volunteers, HD & other professionals, donors and all those affected in some way by HD, we simply could not function. Every day I feel happy to be here and to be associated with such a wonderful group of people. I look forward to 2011 and to continuing to work together to make a difference.

As always, please feel free to contact me either by phone at the Association or by email to [ingrid@ahdansw.asn.au](mailto:ingrid@ahdansw.asn.au)

*Ingrid van Tongeren*  
Executive Officer

### We have a new name!

Some of you might have noticed that we have a new name and are now known as "Huntington's New South Wales". This name change was adopted by members at the recent AGM and follows recent name changes to the other state associations and to the national association.

All our contact and other details remain the same.



## Huntington Happenings

# IT'S TIME TO THINK ABOUT CAMP BREAKAWAY!

We are approaching the end of the year, and already we are thinking of activities for next year ... A highlight for our members is the annual camp.

As in the previous years, we will be hosting our camp at Camp Breakaway, located in San Remo on the Central Coast from Monday 14 to Friday 18 March 2011. The camp is open to Association members with HD and their carers, and we welcome you to come and join us for 5 days of pampering, great food, excellent company and lots of laughs.

The camp will also provide much needed respite to carers (spouses, parents, siblings, friends) who care for people with HD and provide them the opportunity to relax, share problems, ideas and concerns.

Camp Breakaway is set in 25 acres of peaceful bushland reaching down to Lake Budgewoi, and is specifically designed as a place where people with disabilities can have a "break away" from their usual routine.

Accommodation is in cabins (twin share), with en suite bathrooms and disabled access.

Recreational facilities include:

- Pleasant picnic areas with gas barbecues
- Tranquil garden with rock pool and waterfall - a quiet area to sit and relax
- Nature trail
- Lakeside walking trail
- Large level grassed area
- Bird aviary

Please call us at the Association or email Ramona ([ramona@ahdansw.asn.au](mailto:ramona@ahdansw.asn.au)) or Lily ([lily@ahdansw.asn.au](mailto:lily@ahdansw.asn.au)) for a Camp Application Form.



## Do you like this newsletter?

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](mailto:ingrid@ahdansw.asn.au)

## Mingara event: \$52, 000 raised to support Central Coast HD families



Saturday September 18 saw a huge fund raising event at Club Mingara on the Central Coast as over 300 people attended a wonderful dinner dance.

The room was packed, there was excitement in the air as the event unfolded. Many people attending had never heard of Huntington's prior to the night, while at the other end we had people who have lived as part of a Huntington's family for many years, and we also had some professionals who work with HD.

We were treated to a wonderful night of talks, presentations, food, music and dancing.

Highlights included:

- Talks by Ian Kilpatrick and Mark Bevan on the basics of HD, our experience with HD, and the hope we have for the future,
- A very moving family DVD from the Faulkner family,
- Katie and Holly's wonderful vocal performance as they presented 3 songs to a very appreciative audience,
- Lots of dancing to a great band, 'The Flames',
- A giant raffle of donated prizes,
- An auction of many donated items – sporting memorabilia, a coffee machine, an original painting, a fishing charter trip and much more.

The key organisers of the event were Holly Faulkner, Deb Faulkner and Ian Kilpatrick – well done and thank you to them. A job brilliantly done! Of course there were many other people who contributed in big ways through donations, putting in time at the event with set up and pack up, and so on. Thank you to all.

The actual profit on the night was just over **\$52,000** and this will all be put directly back into work supporting HD families on the central coast.



## Day Respite Program (Social/Lunch Club)

We have been fortunate with the weather recently, and despite the incessant rain, on outing days we have had lovely sunny weather. This quarter has seen us enjoying several trips, including an outing to the beautiful Chinese Gardens at Darling Harbour. We had a lovely walk in the gardens, trying to name the different flowers in bloom, admired the huge goldfish swimming around in the ponds and sat under a willow tree for a rest while we caught our breath after our big walk. The highlight of that trip was a delicious sidewalk lunch in Chinatown followed by a visit to the ice cream parlour...

Lunch at Elsie Cottage has continued to be a gastronomic affair as we prepare the favourite foods of our members, work together on craft activities, play board games and cards, and enjoy each other's company. Don't forget our Christmas Party coming up on December 14<sup>th</sup> at Elsie Cottage. Lily and I will be hard at work preparing a gourmet meal and festive treats, so please join us for a day of feasting, fun and frivolity.

If you know of anyone with HD who might be interested in joining our group for social activities, a good chat with friends, and just time out with people who know what you're going through, please call us at the Association on 9874 9777 or email [Ramona@ahdansw.asn.au](mailto:Ramona@ahdansw.asn.au)

We would like to take this opportunity to wish everyone a very Merry Christmas and all our warmest wishes for a happy new year.



Out and about in the Chinese Gardens at Darling Harbour and a delicious lunch in Chinatown.

## 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 Ingrid at [ingrid@ahdansw.asn.au](mailto:ingrid@ahdansw.asn.au). The next Issue will be published in late February 2011. The deadline for articles is 9 February 2011.

## HD Research Update

### Autophagy and Antioxidants

By Marsha L. Miller, Ph.D.,  
September 28, 2010

A team of researchers at the University of Cambridge led by Dr. David Rubinsztein has explored the relationship between autophagy and the production of reactive oxidative species (ROS). They found that it is possible to induce autophagy without increasing toxic ROS and that some antioxidants reduce autophagy.

Autophagy, which literally translates as 'self eating,' is a very old cellular house cleaning process (it's found in organisms from yeast to mammals). Damaged parts of the cell, pathogens, and large proteins are surrounded by autophagosomes. The autophagosomes deliver their cargo to the lysosomes by fusing with them. The lysosomes then consume the material. Researchers are interested in upregulating autophagy as a potential treatment for Huntington's Disease.

Autophagy is an alternate method of protein degradation. The normal huntingtin protein is degraded in the cytosol of the cell by the Ubiquitin Proteasome System (UPS) in which proteins that are not needed or that have misfolded are tagged for degradation by a small protein called ubiquitin. The unwanted protein is then moved into the proteasome, a barrel like protein complex, which breaks it down into amino acids that can then be recycled. However, in Huntington's Disease, the UPS is unable to handle the HD protein properly.

There are a number of issues still to be resolved. One issue was raised by researchers who found that that cargo recognition was impaired in Huntington's Disease and cellular garbage wasn't getting to the lysosomes. Another issue, which is addressed by Rubinsztein and colleagues, is whether autophagy can be enhanced without increasing reactive oxidative species.

Energy for cellular processes is produced in the mitochondria. During the process, ROS is produced. ROS are molecules of oxygen with only one electron, instead of two electrons that are bonded together which is the normal form of oxygen. This means they can go scavenge for other molecules to bond with. Normally this isn't a problem because nearby antioxidants will bond with the ROS molecules and render them harmless. When levels of ROS rise however, they cause oxidative stress, destroy cellular compounds, damage proteins, lipids, and DNA, and lead to cell death.



One pathway that induces autophagy is also known to increase ROS. Starvation induces autophagy but it also increases ROS. Rubinstzein and colleagues wanted to know whether all pathways to inducing autophagy would do the same. They looked at two types of non-HD cells (HeLa and COS-7 renal cells), adding rapamycin, an antibiotic, and trehalose, a sugar, both of which have been shown to induce autophagy. Each increased autophagy but neither increased ROS.

Next they looked at the affect of various antioxidants on autophagy in the COS-7 renal cells. Autophagy was measured by levels of LC3-II, a marker for autophagosome formation and autophagosome-lysosome fusion. They looked at N-acetyl-cysteine (NAC), cystamine (in the pipeline as a potential HD treatment), and glutathione. All three impaired the induction of autophagy by trehalose in a dose dependent manner. They also looked at the effect of NAC and cystamine on rapamycin induced autophagy and on basal (normal, not induced levels of) autophagy and got similar results.

NAC, cystamine, and glutathione are all thiol antioxidants, organic compounds that contain a sulfur-hydrogen bond. The researchers next examined whether a non-thiol antioxidant Iso inhibited autophagy. They found that Vitamin E also impaired trehalose induced autophagy. They also upregulated the gene for SOD11 which scavenges superoxide. Upregulating SOD11 reduced basal autophagy.

The researchers examined the effects of antioxidants and autophagy in drosophila models of HD. A low dose of NAC alone did not exacerbate the disease but a high dose did. However, a low dose coupled with rapamycin reduced rapamycin's ability to rescue cells. This was also true for cystamine. Over-expressing SOD11 exacerbated the disease.

The researchers also found that NAC and vitamin E significantly increased the number of aggregates of mutant huntingtin in a zebrafish model of HD. Rapamcyine and clonidine, both autophagy inducers, decreased the aggregates but this affect was partially blocked by co-treatment with NAC.

NAC was also found to inhibit starvation induced-autophagy in the livers of mice.

Autophagy inducers are in the pipeline as are antioxidants and cystamine. This study shows how important it is to understand the mechanisms by which potential treatments work and how they interact with other potential treatments at various doses and at various points in the disease process. Because Huntington's Disease is a multi-hit disease, combination treatment will be necessary, at least until a treatment which interferes with the expression of the HD gene is available.

#### Reference:

Benjamin R. Underwood, Sara Imarisio, Angeleen Fleming, Claudia Rose, Gauri Krishna, Phoebe Heard, Marie Quick, Viktor I. Korolchuk, Maurizio Renna, Sovan Sarkar, Moise ´s Garcı ´a-Arencibia, Cahir J. O'Kane, Michael P. Murphy and David C. Rubinsztein. **"Antioxidants can inhibit basal autophagy and enhance neurodegeneration in models of polyglutamine disease."** Human Molecular Genetics 2010 Sep 1;19 (17):3413-29. -

## CHDI to Partially Fund RNAi Development Efforts with Anylam and Medtronics

Anylam Pharmaceuticals, Inc., Medtronic Inc. and CHDI Foundation, Inc., announced today (3 November 2010) that they have formed a collaboration to advance ALN-HTT, a novel drug-device combination for the treatment of Huntington's disease. ALN-HTT consists of an RNAi (RNA interference) therapeutic targeting huntingtin, the gene responsible for Huntington's disease, that is being developed for delivery to the central nervous system (CNS) using an implantable infusion system developed by Medtronic.

"Anylam and Medtronic have shown leadership and encouraging progress in developing a novel drug-device combination for the treatment of Huntington's disease," said Robi Blumenstein, President of CHDI Management. "Their collaborative approach demonstrates a combined commitment to tackle this devastating disease and this program is closely aligned with CHDI's mission. We welcome the opportunity to accelerate this program and look forward to continued advancement toward clinical testing in patients."

Anylam and Medtronic have worked collaboratively to advance ALN-HTT for the treatment of Huntington's disease. Under this new collaboration, CHDI has agreed to initially fund up to 50% of the investigational new drug (IND) application-enabling activities.

Over the course of the existing collaboration, pre-clinical data have been generated supporting the continued development of ALN-HTT for the treatment of Huntington's disease, including:

- demonstration that an siRNA targeting the huntingtin gene achieves sufficient distribution for coverage of brain regions affected in Huntington's disease;
- data showing that direct delivery to the CNS results in robust silencing of the huntingtin gene mRNA which was achieved at substantial distances from the infusion site, an important step towards translating this delivery approach from pre-clinical models to the larger human brain; and,
- results showing that ALN-HTT is well tolerated following continuous direct CNS administration over a period of approximately one month.

"The ALN-HTT program represents an exciting opportunity to combine innovative medicines with our drug delivery technology in an area of extreme unmet medical need," said Gregory Stewart, Ph.D., Director of CNS Drug Therapy R&D in the Neuromodulation Business at Medtronic. "With no effective disease-modifying therapies available currently for patients afflicted with Huntington's disease, the collaboration between Anylam and Medtronic, and now support from CHDI, will work to develop a novel treatment strategy for this devastating neurodegenerative disease."

### About RNA Interference (RNAi)

RNA interference (RNAi) refers to the disruption of translation of messenger RNA by introducing a short, double-stranded section of RNA which matches the target RNA. The gene continues to exist but the instructions do not go out and the protein is not made.

RNAi is considered a revolution in biology, representing a breakthrough in understanding how genes are turned on and off in cells, and a completely new approach to drug discovery and development. Its discovery has been heralded as "a major scientific breakthrough that happens once every decade or so," It discovery was awarded the 2006 Nobel Prize for Physiology or Medicine.

*From previous page*

#### About Alnylam Pharmaceuticals

Alnylam ([www.alnylam.com](http://www.alnylam.com)) is a biopharmaceutical company developing novel therapeutics based on RNAi for the treatment of a wide range of disease areas, including respiratory syncytial virus (RSV), liver cancers, TTR-mediated amyloidosis (ATTR), hypercholesterolemia, and Huntington's disease. For more information, please visit.

#### About Medtronic

Medtronic, Inc. ([www.medtronic.com](http://www.medtronic.com)), is the global leader in medical technology.

#### About CHDI Foundation, Inc.

CHDI Foundation, Inc. ([www.chdifoundation.org](http://www.chdifoundation.org)) is a privately funded, not-for-profit, virtual biotech company that is exclusively dedicated to rapidly discovering and developing therapies that slow the progression of Huntington's disease. CHDI seeks to bring the right partners together to identify and address critical scientific issues and move drug candidates to clinical evaluation as rapidly as possible. CHDI's activities extend from exploratory biology to the identification and validation of therapeutic targets, and from drug discovery and development to clinical studies and trials.



### HDBuzz is coming ...

HDBuzz is a new internet portal that will bring the latest news about Huntington's disease research to the global HD community, written in plain language, by HD scientists. It will provide easy-to-understand digests of scientific papers and conference reports that will be free to read and share. You can watch the HDBuzz launch announcement from the European Huntington's Disease Network plenary meeting in Prague, Czech Republic on YouTube by following the link on the HD Buzz website.

The address is <http://hdbuzz.net/> There you can also enter your email address if you want to be contacted as soon as HDBuzz launches which will be in early 2011.

## Family Support Program

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. We have been supporting carers and running support groups in the ACT, Illawarra, Central Coast and of course locally in Greater Sydney.

Our day respite (social/lunch club) program has continued to be a big success. We have been alternating lunch club at Elsie Court Cottage with excursions every other fortnight and have been enjoying each other's company. You can read more about this program in this issue of Gateway.

Lily has been enjoying herself at a craft workshop every Wednesday mornings – she has learnt how to make some wonderful Christmas decorations and cards and has been bringing back her skills to Social Club and making us try all she has learned! It is a great experience for our Social Club members as we work simultaneously on fine motor skills and camaraderie – believe me when I say there are often a lot of laughs as we work our way along some of Lily's latest inventions!!

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 me at [ramona@ahdansw.asn.au](mailto:ramona@ahdansw.asn.au) or [lily@ahdansw.asn.au](mailto:lily@ahdansw.asn.au) Alternatively, you can call us on 02 9874 9777.

### **We are back in Canberra**

With several staff changes and the death of our beloved Maria, staff at the Association have not been able to have a presence in the Canberra/ACT region for quite some time. Last month I made a long awaited trip to Goulburn and Canberra to speak at a variety of nursing homes and assisted living houses with HD clients in their care. It is so important to be able to impart information and advice to the dedicated and caring staff at these facilities who look after our loved ones, and I truly believe that everyone got a lot out of it in terms of understanding and appreciating the needs of a person with HD. The highlight of the trip was finally meeting some of the wonderful carers and their spouses affected with HD.



We had a lovely get to know you session and a delicious dinner at the local Football Club in Ainsley. I want to thank everyone who gave so freely of their time and who opened up candidly to tell us what you needed. I hope that we at the Association will be able to meet your needs in supporting you and will certainly endeavour to do so. Dates for upcoming support group meetings have not yet been finalised but the group is attempting to meet regularly in Canberra, with staff from Sydney coming down several times a year with information on the latest research and other pertinent news.

If you missed our meeting in October but would still like to be involved, contact Ramona at the Association on (02) 0874 9777, email [Ramona@ahdansw.asn.au](mailto:Ramona@ahdansw.asn.au) or Daryl Heavies in Canberra on 0412 809950. We would all love to hear from you.

*Ramona Watts*

## National Conference report

I attended the National Conference in Brisbane from September 8 to 10. What a great time. There were so many highlights that it is hard not to report on every session attended and everyone I met. It was incredibly helpful to meet various people from the other state associations from round Australia. I heard about the various programs that were running in different states, and the different structures and services provided. But it was particularly important to meet individual people so committed to serving Huntington's families around the country, to hear their stories, share in their experiences, and to learn from them. In addition to association workers, I also met many family members who openly shared their experiences.

Of course the various sessions of the conference were amazingly informative and enlightening. The reports on research were just great, and confirmed that there is wonderful work going on even in Australia. Presentations included information on the HD forum, established by Michelle and Naomi on the mid north coast of NSW, and it along with others was very well received by the large audience. A highlight for me was hearing Jimmy Pollard share from his vast experience in HD care, which included some great role playing and some very practical tips for carers and for understanding the situation of HD people.

We heard of heroic work by the state associations, with some people round the country having been involved serving HD families for 30 or more years. Very inspiring stuff. Thank you. To see the emotional involvement of professionals was also inspiring – many clearly see their HD work as a lot more than a job, and their commitment to serving the HD community in various ways really shines through.

I had the privilege of presenting with Ramona on our Holiday Camp program, and it was exciting to share with the attendees something from our experience of nearly 30 years of running Holiday Camps in NSW. I came away from the conference enthused and encouraged that I am part of a much bigger team, all seeking to serve HD families and filled with hope of a better future for Huntington's people.

*Mark Bevan*



## Central Coast Support Group

The Central Coast support Group has been meeting regularly each month since July. Between 12 and 20 people have attended each meeting, and we have had a great time sharing and learning together. Topics discussed have ranged from how to deal with various aspects of being part of a HD family, personal issues raised by group members, preparation for our fund raising event, and being educated by some care experts from Matthew John Aged Care Facility at Erina, where we now hold our meetings.

It is probably an opportune time to say a little more about Matthew John (MJ). It supports and provides accommodation for people of various ages and medical conditions, and cares now for some residents with HD. They work closely with family members to ensure that individual care needs are continually being met. While an aged care facility is not the ideal place for a younger person to live, MJ is seeking to meet their challenging care needs 24 hours a day. MJ has skilled and educated staff who manage changing behaviours and attend to personal care needs that contribute to the life of the HD person, with a real focus on the HD person being treated with dignity and respect. Families are totally involved and consulted on a regular basis assisting staff to make decisions ensuring care is continually provided in a manner that is in the best interest of the resident.

Many services are provided to including a Physiotherapist (30 hours per week), therapy aids, and lifestyle personnel who provide activities to meet the abilities and personal interests of our residents. Clinical care needs are review by registered nursing staff, many of whom have had significant experience in mental health.

I must say it has been wonderful to see the involvement of MJ staff, particularly Letitia Quirk, Director of Care, with the support group, and see their eagerness to support Huntington's families in whatever way they can.

Our upcoming meetings are scheduled for

- Monday January 17 at 7pm
- Monday February 21 at 7pm
- Monday 21 March at 7pm

at 'The Education Room' Matthew John Aged Care Facility, 351 Terrigal Drive, Erina.

Everyone is welcome at the meetings - but if you are new to the group, it would be wise to **call and confirm the meeting time and place** before attending – call Mark on 0410 629 850.

Watch this space for further news on the Central Coast Support group.

## Do you live in the Mid North Coast Area?

The Association has funds raised at various events over the last couple of years that are earmarked to help families in the Mid North Coast area.

Direct financial assistance is available to help with:

- Remedial therapies for people with HD
- Equipment needed to live with HD
- The cost of families and people with HD attending training, national conferences, specialists etc
- Support groups for families affected by HD

If you are interested in finding out more or wish to make an application for assistance please call Ramona or Ingrid at the Association offices or email them on [ramona@ahdansw.asn.au](mailto:ramona@ahdansw.asn.au) or [ingrid@ahdansw.asn.au](mailto:ingrid@ahdansw.asn.au).

## Family Support in the Mid North Coast



John Conaghan from Hunter Genetics and I, have made several trips north in the past couple of months. We have been to Port Macquarie and surrounds twice, and to Buladelah / Forster once.

These trips have been mainly about providing support to families through personal visits. We visited some people who were at home and others who are receiving care in various facilities.

A recent highlight was the Association's lunch for HD families held on October 29 at Port City Bowling Club in Port Macquarie. We had 17 people attend – some old friends, and some new faces. People were so immersed in conversation that we did not leave the club until about 4pm. Hopefully we will be able to host another one in early 2011. Thanks so much to the Port City Bowling Club for making us so welcome. And of course thanks to all the people who came along to make it a wonderful time together.

*Mark Bevan*



## 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

19 January, Wednesday, 10.30am  
16 February, Wednesday, 10.30am  
16 March, Wednesday, 10.30am  
20 April, Wednesday, 10.30am  
18 May, Wednesday, 10.30am  
15 June, Wednesday, 10.30am  
13 July, Wednesday, 10.30am  
24 August, Wednesday, 10.30am  
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:

**Jet Aserios: (02) 9845 7528**  
Social Work Department  
Westmead Hospital

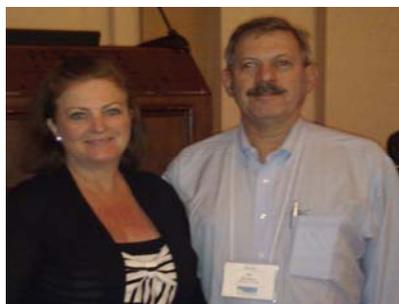
## Huntington Study Group (HSG) Meeting - October 2010

In October, the Association sponsored Jane Griffith and David Gunn from Westmead to attend this important research meeting in the USA. The meeting allows review of current projects and enables the Westmead site to be considered for inclusion in HSG studies.



**Westmead Hospital's PREDICT coordinator, David Gunn, and PREDICT Principal Investigator Dr Jane Paulsen .**

Currently Westmead continues to participate in COHORT, PREDICT 2, HORIZON and HORIZON plus, 2CARE, CREST-E and is about to start a CAB beta study. Detailed descriptions of these studies are on the HSG web site which is at [www.Huntington-Study-Group.org](http://www.Huntington-Study-Group.org) David and Jane provided this report of their trip.



**Jane Griffith Neuroscience Trial Coordinator and Ira Shoulson, MD, Chair, Huntington Study Group Executive Committee .**

This year's Huntington Study Group conference took place in La Jolla, San Diego. This being David's first HSG meeting it was a very good introduction to all of the research studies that the HSG is currently undertaking. At the present stage, the PREDICT 2.0 study is progressing well, with over 800 people participating world-wide.

The conference also gave our Westmead Hospital research group of neurologists Dr McCusker and Dr Loy, and Jane Griffith our nurse coordinator, the chance to meet with the people we work with everyday via email, but never see. In particular we talked about the newest changes to the PREDICT study that are going to be taking place soon.

These changes are intended to make PREDICT visits smoother for participants and more informative for researchers. This study, now into the second 5 years of National Institutes of Health America funding, aims to identify the very earliest changes taking place in HD by studying people who do not have a diagnosis but carry the mutation and those who have tested without the mutation.

We saw first hand the CHDI (Cure Huntington Disease Initiative) Foundation's dedicated commitment to funding HD Research.

The conference ended with the 4<sup>th</sup> Huntington Disease Clinical Research Symposium. This was an opportunity to see some of the research being done at other HD research centres from Europe and the USA.

One of the key points discussed at the meeting was how to better reach people within the HD community and offer them the chance to participate in clinical trials. Participants are always needed in clinical trials for continued research into potential HD treatments and to improve the lives of those living with HD. If you are interested in clinical trials participation, please email [hsgtrials@gmail.com](mailto:hsgtrials@gmail.com) or phone the staff on the following numbers: -

Doctors: Dr Clement Loy, Dr Elizabeth McCusker	<b>02) 9845 6793</b>
Nurse Co- coordinator: Ms Jane Griffith	<b>02) 9845 9139</b>
Research Neuropsychologist: Mr. David Gunn	<b>02) 9845 5519</b>

Along with the staff here at Westmead Hospital's HD Research Unit, we would like to thank AHDA (NSW) for funding our attendance and allowing us the opportunity to attend this vital meeting.

*David Gunn and Jane Griffith, Westmead Hospital*

## Issues with a Nursing Home?

From time to time issues can arise in relation to a family member or loved one in a nursing home or aged care facility. Whilst every effort should be first made to sort out the problem face to face with the nursing home or facility in question if the issue is not resolved you can raise your complaint and have it looked at by the Aged Care Complaints Investigation Scheme.

How can I provide information, raise a concern or make a complaint?

You can provide information or make a complaint either on free-call 1800 550 552 or in writing to:

Aged Care Complaints Investigation Scheme  
C/- Department of Health and Ageing  
GPO Box 9848  
In your Capital City.

You can also submit the online form available at the website at <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-complai>



### How does the CIS work?

When you contact the CIS they will:

- listen to and clarify your concerns;
- explain how the CIS works; and
- inform you of your right to have the assistance of an advocacy service if you wish.

The CIS will, where appropriate:

- take detailed notes and record information in the CIS database;
- decide if the information provided relates to an approved provider's responsibilities;
- refer the matter to another agency if that is more appropriate;
- investigate the information we receive to determine whether or not a service provider is providing appropriate care and services;
- tell providers who have not met their responsibilities what they have to do to address an issue and specify the timeframe in which this must be done;
- provide feedback on the outcome of the contact.

There are however, some matters the CIS cannot deal with. For example, they cannot say who should make financial, legal or health decisions on behalf of a care recipient. They cannot comment on industrial matters such as wages or employment conditions or provide legal advice on any problems.

### Who manages the CIS?

The CIS is managed by the Office of Aged Care Quality and Compliance within the Department of Health and Ageing. If you have any concerns about the way the CIS has handled your complaint or concerns, you can raise them with the CIS Manager in your State or Territory. Alternatively, you can contact the Aged Care Commissioner.

### Aged Care Commissioner

The Office of the Aged Care Commissioner has been established to independently review the way in which the CIS handles complaints. The Aged Care Commissioner can look at decisions made by the CIS in relation to the investigation of complaints and also has the power to examine, as a result of a complaint or on their own initiative, the CIS's administrative processes for investigating complaints.

The Office of the Aged Care Commissioner can be contacted during business hours on free call 1800 500 294.

Further information can be found on the Office of the Aged Care Commissioner's website at: <http://www.agedcarecommissioner.net.au>



## Huntington's New South Wales

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](http://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: Viki Moraitis  
Don Ayres  
Keith Dingeldei  
Jim Finn  
John Conaghan  
Karen Bevan

## Association and Other Useful Contacts

### Association Staff

**Ingrid van Tongeren**  
Executive Officer

**Toni Ling Zhang**  
Administration Officer

**Lily Shu Yue Ma**  
Administration and Activities Assistant

**Ramona Watts**  
Family Support Co-ordinator

**Mark Bevan**  
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**  
**Suzie Docherty**  
Social Worker,  
Westmead Hospital  
(02) 9845 6699  
Currently on Maternity Leave

### **Jet Aserios**

Social Worker,  
Westmead Hospital  
(02) 9845 6699

**Angela Lownie**  
Clinical Nurse Consultant,  
Lottie Stewart Hospital  
(02) 9804 5863

**Jeanette Moxon**  
Outreach Nurse,  
Lottie Stewart Hospital  
(02) 9804 5863

### Huntington's Lodge

**Sue Grant**  
Acting 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,  
(02) 4985 3100