



Gateway

News from the Australian Huntington's Disease Association (NSW)
Volume 13 No 2

Winter 2010

Making Connections

A Visit From Our Local MP



On 22 March 2010 Mr Victor Dominello MP, State Member for Ryde attended the offices of the Association to present us with a cheque for \$7,166.50 which the Association had been granted under the NSW Department of Premier and Cabinet's Community Building Partnership Program. The funds will be used to repair the roof of the Community Room which we use as a venue for our social and lunch clubs, support groups and various meetings. Receiving these funds means that the Association can repair the leaking roof which will mean that we will all have unfettered use of the space in the future. The Association is very grateful for the support it has received for this project from our local member, Mr Victor Dominello MP and the State government. Repair work is scheduled to commence in late June/early July and is expected to be completed by the end of July 2010.

Making the Connection: The HD National Conference - 9 and 10 September 2010

Huntingtons Queensland, in collaboration with the Queensland Brain Institute – The University of Queensland, is hosting a National Huntington's Disease Conference in Brisbane in September this year. The theme "Making the Connection" reflects the meeting and sharing of knowledge and experiences with all those involved in the Huntington's field – family members, community services, researchers, allied health professionals, care workers and members and supporters of all HD Associations across Australia. Flyers, Programs and Registration Forms can be obtained from the Huntingtons Queensland website at www.qahda.com If you prefer you can call them on (07) 3391 8833 or email them at admin@huntingtonsqld.com and they will send you the forms.



From the Executive Officer

We are now almost half way into the year and as the winter cold bites, we are all warmly reflecting back on all of the exciting, fun outdoor activities and events that the Association has already run in the earlier months of 2010. The Camp in March was a fantastic success which everyone was thrilled to have attended. The lunch/social club has also had a variety of outings including the ever popular visit to the Sydney Fish Market. Many more activities are planned for the future. You can read reports about these events in this Issue.

There are also larger events on the horizon. September will see a busy month for those associated with HD. The National Conference will be held in Brisbane on the 9th and 10th of the month. I urge you all to consider attending the National Conference. They are only held every second year and provide such a wonderful opportunity for everyone to have direct contact with other people with HD, families, carers and of course with national and international experts in the Huntington's field. There is also a fundraising event on the 18th of the month at Mingarra on the Central Coast which looks to be a real cracker of an affair.

You can also read about both of these events in this Issue of our newsletter.

I would also like to let you know about the staff changes here at the Association. Toni Zhang who has been with us for some months firstly as a volunteer and then acting in the role of Administration Officer has now been appointed to that position. We are very lucky and pleased to have her with us. Toni has written an article introducing herself which you can read in this issue of Gateway. She can be contacted by telephone at the office or by email on toni@ahdansw.asn.au

Mark Bevan has also joined the Association as Family Support Officer. Many of you will already know Mark, who is a past President and Board member of the Association and who has been very active in many of the Association's camps and other activities over the years. Mark will be based in the Central Coast and his position will have the primary focus in the team of meeting the needs of the Central Coast and Mid North Coast area. He will be working in close conjunction with John Conaghan. Mark will be telling you more about himself in the next Gateway.

Mark will be on board in his role in June and you will be able to contact him by email on mark@ahdansw.asn.au
Welcome Mark!!

Ramona Watts, who many of you have known as our Family Support Officer is now working in the position of Family Support Coordinator and will continue to run our Social Club with Lily Ma, as well as reaching out to our carer's and clients in the Sydney and Canberra region. If there is anything that Ramona can assist you with, please do not hesitate to contact her by phone at the office or via email to ramona@ahdansw.asn.au

As always, if you have any ideas for anything else that you might be interested in taking part in through the Association or you have ideas about how we could provide you with better services, please feel free to contact me either by phone at the Association or by email to ingrid@ahdasnw.asn.au

Ingrid van Tongeren
Executive Officer

Huntington Happenings

Renew Your Membership!

Your membership of the Association are due for renewal on 1 July 2010, unless you have pre-paid for the 2010/11 membership year, and a membership form is enclosed with the newsletter.

If you're unsure of whether you have pre-paid 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!

Website for Young People - Our HD Space is Here!

The new website for younger people is live! There you can find information about HD in 3 categories specifically written for younger people aged 8 to 12, 13 to 17 and the over 18s. The website also has some great information about getting involved and an 'Ask a Question' section where younger people can post a question and get a reply from one of the panel of experts linked into the site. The site also has links to My Space and facebook so younger people can meet other younger people who are in the same situation as them online.



Congratulations to Michelle O'Brien, Naomi Van Dijk and Tony Mims for all their hard work and commitment to this project. Well done guys! They welcome all feedback on the site so check out the site at:

<http://ourhdspace.org>

New Central Coast Support Action Group

The people organising the Fundraising Event at Mingara which you can read about in this Issue are also setting about creating a support action group for people with HD and their families on the Central Coast. For more information contact Ian Kilpatrick on 4324 5400 or at ian@axiopsych.com.au, Holly on 0401 203 198, or Mark from the Association on 0410 629 850 or at mark@ahdasnw.asn.au

Huntington Happenings

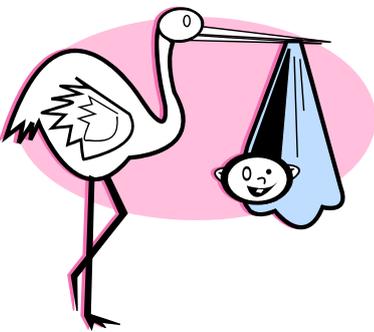
New Administration Officer: Toni Ling Zhang

My name is Toni Ling Zhang, and I am very excited to become a member of the staff of the Australian Huntington's Disease Association Inc. (NSW). I have a background of accounting in private business. However, I was always looking for an opportunity to use my skills in not-for-profit organisation, where staff are more focused on helping people.

I first started with the Association in September 2009 as a volunteer to assist with accounting and administration. In March, I became the Association's administration officer. I enjoy working within our wonderful team and meeting our clients. Especially, the time we spent together at Camp Breakaway which was interesting, meaningful and memorable to me. It allowed me to get to know everybody more by walking along the lake, having meals and tea, and doing activities together. I will keep trying my best in my role for the Association to meet your needs.

Please feel free to contact me either by phone at the Association or by email to toni@ahdansw.asn.au.

Suzie Docherty on Maternity Leave



Suzie Docherty, the Social Worker from Westmead Hospital who is well known to many of you is now away from work on maternity leave. She is not due back at work until February 2011.

She has advised us that in her absence you will be able to access your backup key worker from Lottie Stewart Hospital, Clinical Genetics or Westmead Hospital.

It will either be Jet Aserios, Angela Lownie, Jeanette Moxon or Fiona Richards.

You could access this person by calling Outreach on 9804 5863 and speaking to either Angela or Jeanette. Alternatively you could call Jet on 9845 7528. Suzie's colleagues will point you in the right direction and let you know who is your backup worker, so you know who to call when a need arises.

Suzie said "I hope everyone manages reasonably well while I am gone and I will look forward to seeing you all on my return back from babyland".

Social Club

Social Club Dates for 2010

Make sure you don't miss out on all the fun.
Put these dates in your diary now!

All meetings are on Tuesdays at 21 Chatham Rd West Ryde between 10.30 AM and 2.30 PM unless otherwise advised.

A separate application is required for the holiday camps.

Month	Dates
June	29
July	TBC School Holidays 20
August	03 17 31
September	14 28
October	TBC School Holidays 19
November	02 16 30
December	14 Xmas Party

Exciting Excursions Galore!



Social club has continued this year with several exciting excursions and lunch at Elsie Court Cottage. Some of our recent excursions included a great day out at Sydney fish market where we enjoyed lovely fresh fish and chips, and last week saw our group at a rib tickling time at the movies followed by a picnic lunch .

Lunch Club at Elsie Court Cottage has continued to be a gourmet affair with Lily and Ramona attempting to outdo each other and win over everyone's taste buds with our creative cuisine competitions! 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.

Camp Breakaway A Runaway Success

The HD Association's annual camp last month was once again a runaway success. This year brought 21 campers together at Camp Breakaway in San Remo on the Central Coast. Most of the campers set off on a chartered bus from the Association's headquarters in West Ryde. There was lots of excited chatting in the back of the bus, even some chatting up of the not-bad-looking bus driver! The campers' cheeky mood had begun even before we had arrived at our destination.

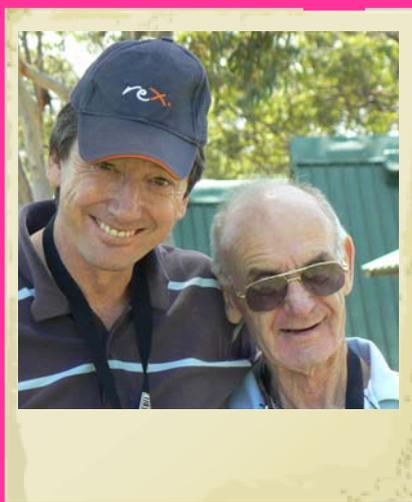
On arrival we were greeted by some of the staff, volunteers and other campers who had made their way to Camp Breakaway on their own. Everyone excitedly checked out their bedrooms and who they were sharing with, hugs and handshakes were dispensed unashamedly as campers recognised friends from previous years' camps; everyone was chatting at once, catching up on lost time. It was a lovely atmosphere of congeniality, renewal of old friendships, and a warm welcoming of new campers.

The next 5 days brought glorious warm weather and sunshine to Camp Breakaway. Each morning began with a wake-up call at 7 o'clock, followed by a scrumptious hot cooked breakfast as well as cereals, fruit and yogurt. Often too full to move, we would then head off for a leisurely walk down to the scenic Lake Budgewoi where the more adventurous of us would attempt a bit of a jog while the others walked along slowly, appreciating the beauty of the pristine lake, stopping to pat dogs and to chat with mothers pushing their babies in prams.

Morning tea would be awaiting us when we returned, followed by a quiet indoor craft activity organised by the talented Karen Bevan, often involving copious amounts of glue (and the resulting sticky fingers), sequins, lacquer, sea shells and a wonderful array of stickers. Our campers took great pride in creating their artworks to take home with them and we saw many colourful and unique creations in our craft room, many of which now will be hanging on a wall at home and on fridge doors.

After a bit of personal time, we would gather for a scrumptious hot lunch (There has been debate as to whether or not the cheesy tuna mornay or beef stroganoff was a favourite) followed by an outdoor activity of bowls, boules, mini-golf or hoop and rings. Regardless of the activity, all events ended up with campers and staff in hysterics, as rules were unashamedly bent, alliances were swapped, old friendly rivalries surfaced....

Dinner was often the highlight of the evening. Robyn Kapp, Vice President of the Board and chef extraordinaire would whip up wonders like succulent roast turkey with vegetables smothered in gravy followed by sticky date pudding with golden butterscotch sauce and lashings of freshly whipped cream. The delicious meals, tastes, textures and "what's next for dessert" was the most popular table talk many an evening as our campers relaxed at the end of the day surrounded by good food and good friends. It was sad farewells to everyone when it was time to leave. We have all benefitted from having such precious time with one another, campers, staff, and volunteers alike, and the close bonds and friendships that were formed over those five days will always be treasured.



Cargo Recognition is Impaired in HD

Marsha L Miller PhD

One of the major pathologies in Huntington's Disease is the accumulation of the toxic huntingtin protein in both the cytosol and the nucleus of the affected neurons where it causes damage leading to cellular dysfunction and cell death.

There are two methods by which cells degrade and recycle proteins. One is through the Ubiquitin Proteasome System (UPS) in which proteins which are not needed or which 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. The normal huntingtin protein is degraded in the cytosol through the UPS.

"In our investigation of how the accumulating huntingtin protein affects the functioning of cells, we found that it interferes with the cells' ability to digest and recycle their contents."

However, in Huntington's Disease, the UPS is unable to handle the HD protein properly. There's an alternate system of protein degradation called (macro)autophagy which literally translates as 'self eating.' In this 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.

The mutant huntingtin protein is removed from the cytosol through autophagy. This process is unavailable in the nucleus of the cell which depends on the UPS.. One suggested strategy for treatment is to enhance autophagy to at least deal with the problems caused in the cytosol. And indeed, studies have shown an increase in autophagy occurs in response to the mutant protein.

Researchers at Albert Einstein Medical College in New York City have carefully examined the autophagy process in various cell models derived from two HD mouse models and HD patients. As did other researchers, they found an increase in autophagosomes in tissue from HD patients. They also found that the autophagosomes form normally and fuse normally with the lysosomes. In a seeming paradox, however, they found a reduction in proteolysis (the breakdown of proteins) in both the striatal and non-neuronal HD cells that they examined.

Cargo Recognition is Impaired in HD (cont.)

"Studies have shown that Huntington's disease occurs in part because the mutated huntingtin protein accumulates within cells and is toxic to them," said Ana Maria Cuervo, M.D., Ph.D., professor of developmental and molecular biology, of anatomy and structural biology, and of medicine at Einstein and senior author of the Nature Neuroscience study. "In our investigation of how the accumulating huntingtin protein affects the functioning of cells, we found that it interferes with the cells' ability to digest and recycle their contents."

Dr. Cuervo and her team discovered that the defective huntingtin proteins stick to the inner layer of autophagosomes, preventing them from gathering garbage. As a result, the autophagosomes arrive empty at the lysosomes. They found an enhanced binding of the HD protein with P62 at the autophagic membranes. Since P62 appears to be necessary for the autophagosomes to recognize cellular garbage, this could explain the problem.

The researchers also found an increase in abnormal lipids and depolarized mitochondria which may be caused, in part at least, by the autophagosomes failure to recognize them as material (or cargo) for degradation and recycling. Their ongoing presence could contribute to the damage that leads to cell death. This research shows that enhancing autophagy will not work as a treatment. "It doesn't matter how active your lysosomes are if they're not going to receive any cellular components to digest," she said. "Instead, we should focus on treatments to help autophagosomes recognize intracellular garbage, perhaps by minimizing their contact with the defective huntingtin protein. By enhancing the clearance of cellular debris, we may be able to keep Huntington's patients free of symptoms for a longer time."

This study is a good example of why basic research continues to be needed. At first it looked like discovering or developing drug to enhance autophagy could result in a major treatment. Then it was discovered that autophagy is available in the cytosol and not the nucleus where mutant HD does a lot of damage - still a potentially good treatment but perhaps not as powerful. Now it has been learned that the autophagosomes don't recognize and degrade the HD protein. While an autophagy-related treatment might still be a possibility, it would need to address the cargo recognition problem instead.

References:

Quotes and graphic from the Albert Einstein College of Medicine Press Release

Posted to <http://www.hdlighthouse.org> 24 May 2010

Neurosearch Amends the ACR-16 Results

Marsha L Miller PhD

Neurosearch has released a press release which involves a correction to previously announced results of the Huntexil (ACR16) clinical trial in Europe.

In February, Neurosearch announced that there was a statistically significant difference between the treatment and control groups in the primary endpoint, the Modified Motor Score of the United Huntington's Disease Rating Scale. Probability was reported as .02 meaning that the likelihood of these results being a chance variation rather than a meaningful treatment difference is less than 1 in 50.

On April 28, they announced that they had adjusted for CAG counts in their original analysis (but had not disclosed this). They found faster progression as the CAG count increased. Including the CAG count as a variable in the analysis resulted in the probability of .02. Once that adjustment was removed from the analysis, however, $p = .0425$. A probability of .05 or less would normally be acceptable; however, since this study involved two treatment groups, p needed to be .025 or less for the results to be considered statistically significant.

The problem is that the results of a clinical trial must be assessed based on the way that it was originally set up. An adjustment for CAG counts was not originally specified as part of the assessment. Neurosearch should have been clear that they had made such an adjustment in reporting the results for the primary endpoint of the study. In addition, they still do not have all of the CAG counts of participants so the adjustment was a preliminary one.

This means that the results look promising but are not conclusive and it is likely that an additional Phase III study is likely to be necessary before Neurosearch can apply for approval. The difference between the treatment group and the experimental group on the Total Motor Score is statistically significant and that is encouraging. However, it was the Modified Motor Score that was the primary endpoint so again, the trial cannot be classified as successful.

Given the promising data obtained in this trial, I believe it is worthwhile for HD patients to participate in HART and any future trial of this drug.

Posted to <http://www.hdlighthouse.org> 24 May 2010.



HD Research at Westmead Hospital: An Update

Huntington Study Group Projects



PREDICT 2: recruiting people who have had predictive testing without the HD mutation and with the mutation but who have no evidence of HD onset at a recent Neurological consultation. This study aims to identify the most reliable signs of first onset with a plan for earlier treatment trials.

Contact Mr. David Gunn, Neuropsychologist/co-ordinator

COHORT: recruiting anyone from an HD family, study looking for other influences on the gene and the variations in HD and preparing for clinical trials of medications.

HD MAPS: affected siblings (brothers and sisters)

2 CARE: high dose Co Enzyme Q 10 versus placebo enrolling people who have very early HD, usually still working for a trial of very high dose CoE Q 10 versus placebo.

CRESTE: high dose Creatine versus placebo enrolling affected people with moderate HD changes

HORIZON: Trial of Dimebon versus placebo in moderately affected people (nearing completion)

Please indicate if you are interested by email or phone message and details of studies will be sent. More information is available on the Huntington Study Group (HSG) Website at:

www.Huntington-Study-Group.org

Research staff can be contacted in the Neurology Dept on Mondays and Wednesdays or email us at hsgtrials@gmail.com.

Dr Clement Loy,

Dr Elizabeth McCusker 02 9845 6793

Nurse Co-ordinators

Ms Jane Griffith

Ms Linda Stewart 02 9845 9139

Research Neuropsychologist

Mr. David Gunn 02 9845 5519

Family Support

Family Support Programs Update

The last few months has seen us very busy at the Huntington's Association. Camp Breakaway took a few months in planning and has been the talk of the month. All the clients who attended the camp reported having had a wonderful time, with days full of activity, games and laughter, and a lot of time spent talking and bonding with one another. Carers too had a much needed respite, several of whom went on holidays while they knew that their charges were in capable hands. All in all, a huge success, and thoroughly enjoyable for clients and staff alike.

Our fortnightly meetings with Social Club have continued to flourish, alternating between excursions and lunch at Elsie Court Cottage. With everyone's input at social club, we are continuing to explore different excursions opportunities that are interesting and accessible for our clients, and whilst at Elsie Court Cottage, Lily and I cook nutritious, appetising meals for our lovely clients who come each fortnight.

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

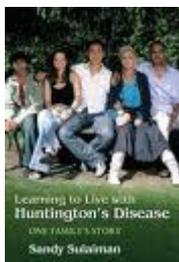
21 July, Wednesday, 10.30am
18 August, Wednesday, 6.00pm
15 September, Wednesday, 10.30am
20 October, Thursday, 6.00pm
17 November, Wednesday, 10.30am
Dec - Christmas Get-Together - TBC

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/-
Jet Aserios – 98457528

Learning to Live with Huntington's Disease

by Sandy Suleiman



This book is one courageous family's poignant story of coping with the diagnosis, the symptoms and the effects on family life of Huntington's Disease.

Sandy and members of her close family speak frankly about coping with the symptoms of a progressive, ultimately terminal, illness as those symptoms emerge; including involuntary movements, depression, clumsiness, weight loss, slurred speech and sometimes violent outbursts. The family describe the challenge of remaining united and how they approached issues such as whether or not to be tested for HD, how much information to disclose to relatives, whether to have children or not and the feeling of guilt experienced by siblings who do not inherit the illness. Both honest and positive, the author stresses the vital importance of re-inventing yourself and your present, prioritising relationships and retaining a sense of humour.

Inspiring and supportive, **Learning to Live with Huntington's Disease** is essential reading for medical practitioners and researchers, psychologists, occupational therapists and rehabilitation specialists as well as individual's with HD and their families and friends.

A copy of this book is now available for loan from the Association's library.

Please contact us if you wish to borrow it.

Do you live in Canberra Region and surrounds?

Do you live in the Canberra Region and surrounds, and have Huntington's Disease or care for someone who does? Daryl Heavies is a dedicated carer who would like to meet people who deal with HD in their daily lives, and with the help of the Huntington's Disease Association, would like to start up a support group in Canberra. If you are touched by HD, and would like to get to know people in similar situations, discuss ways of coping, share your feelings and just connect with others who understand you, call Daryl Heavies on (02) 6116 8873 or Ramona at the Association on (02) 9874 9777 or at

ramona@ahdansw.asn.au .

We want you!

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 The next Issue will be published in early September.

The deadline for articles is 13 August 2010.

Being A Carer—Kathryn's Story

At the end of last year, we asked carers to write in and tell us what it meant to them to be a carer of someone with Huntington's Disease. Thank you for all your wonderful contributions and sharing of your heartfelt trials, tribulations and conflicting emotions. We have included a letter by Kathryn Thomas who has summarised her many years of what it is like for her to be her husband's carer.

"Once I was a wife, a lover, a partner – now I'm labelled "carer". Once our future was filled with plans of more overseas trips and meeting new friends, but now that has all changed. My future came to a halt when my husband was diagnosed with this disease in 1999, our world came tumbling down. No longer can I go where I'd like to go, so I feel somewhat trapped and isolated, only leaving him for short trips to do shopping and see doctors etc – my time is always limited.

Do I feel anger, disappointment, yes I feel that I've been cheated out of the "rest of my life" as my life revolves around my husband and my future is unimaginable. My marriage vows mean more to me now than ever before, "in sickness and in health". I'm here for the long haul-"til death do us part". There are brief moments when I have the "Old Ron" back, he struggles to retain his capacity for mending items around the house, which under the circumstances brings tears to my eyes.

Being a carer makes me feel like a nurse on call 24 hours a day, as night time can sometimes bring "things that go bump in the night". Accidents on the way to the loo, or falling out of bed, or slipping over – a good nights' unbroken sleep is for me a rare thing.

What counts is how you manage to live with the fact that some things will always be a bit wrong. I am therefore doing my best in a difficult situation. I have no fear – it is more than good enough. So being a carer and being referred to as "the carer" is rather vague. We all care for people in different conditions and varied diseases. The word care in my dictionary says "to look after, do what has to be done"! That is exactly what we do, we are needed as they require special needs and we are the caring loving people that fill this role. A stranger could not cope as well as us, we matter in this world, we don't often get thanks and praise, we just get on with it because **that's what needs to be done!**

It is a privilege and an honour to take care of my husband, though trying at times, but I'm sure that the memory of his love will see me through. This disease will not win, I am determined to live alongside this disease but not get buried underneath. We walk this road together." - *Kathryn Thomas*

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.

Get Ready to Dine and Dance! – 18 September 2010



In conjunction with the Australian Huntington's Disease Association (NSW) Inc, a group of people on the Central Coast have organised a **Charity Dinner Dance and Charity Auction** to be held at Mingara Recreation Club on Saturday the 18th of September 2010. All proceeds will be used to assist those affected by Huntington's disease living in the Central Coast region & the hope is that we can raise enough money to ensure that there will be services available to assist those affected by HD now and into the future.

The auditorium is booked, the band has been hired and the drinks are on ice...but we cannot do this alone. So this is where you come in! The success of the Dinner Dance and Auction is dependent on YOU. Here is your opportunity to have a great night out and help a worthy cause at the same time.

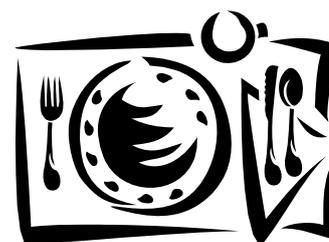
Tickets cost \$100.00 per person which includes canapés on arrival, two course meal & 6 hour beer/wine/soft drink package. There will also be raffle tickets sold on the night, with your chance to win some fantastic prizes.

Where: Mingara Recreation Club, Mingara Rd, Tumbi Umbi NSW 2261

When: Saturday 18 September 2010

Time: 6pm

Dress: Cocktail / Formal



Please contact Holly Faulkner via phone or email if you are interested in attending on the night. There are only 300 tickets available & they are already selling fast!! Contact details: Ph: 0401 203 198 or E-mail: plhq@bigpond.net.au.

Do you live in the Mid North Coast Area and want to attend the HD Conference?

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. One of the areas for which financial assistance is available is to help families and people with HD attending attend national conferences (see the ad for the conference in this issue of Gateway). Conferences are a great way for people with HD and family members to access information, support networks, meet others and learn about research.

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 or ingrid@ahdansw.asn.au.



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

Association and Other Useful Contacts

Ingrid van Tongeren

Executive Officer

Toni Zhang

Administration Officer

Lily 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 Service

Suzie Docherty

Social Worker,
Westmead Hospital
(02) 9845 6699
Currently on Maternity Leave

Outreach Service

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

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,
(02) 4985 3100