



Gateway

News from the Australian Huntington's Disease Association (NSW)
Volume 11 No 3

Summer 08/09

Exciting Things To Come ...



Dr Elizabeth McCusker speaks at the Association's AGM in November

We elected a new board and had Dr. Elizabeth McCusker as our speaker. Thanks to all who came to be with us especially those from outside the Sydney area. You can read more about our AGM inside this issue.

We also recruited and hired a new Administration Officer, Sasa Berber, in October 2008. The good news for 2009 is that we were given assurance by the Health Department that we will be getting the Carers grant for 18 months beginning January 2009.

Thus, we are at present in the process of advertising, recruiting and hiring a new Family Support Coordinator first, then a Family Support Officer soon after that. Hence, our staff will grow by at least two more people shortly which will put us at 5 part-time employees altogether.

I trust you had a Merry Christmas and a Happy and safe New Year 2009. As we begin this New Year I have a sense of excitement and anticipation as to what lies ahead. Allow me to report to you in this issue some celebrated highlights from 2008 and anticipated exciting things to come in 2009.

Our AGM which was held on 29 November at the West Ryde Council Hall was successful.

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From the Executive Officer (cont)

We are looking forward to some new outreaches in our Family Support Department this year especially those that relate to country NSW and areas outside of Sydney. Despite the fact that that department had been vacant for the last few months of 2008, I am thrilled to report to you that our Sydney Carer Support group which we started in cooperation with social workers Suzie and Jet is doing well. We had ten attend the last group, six of them were men! We are indeed excited about that. We look forward to maintaining and growing those outreaches in 2009. You can read more about that in the Family Support section inside this issue as well.

We have also been fortunate to find good volunteers to help around the office.

The first is an administration assistant who helped us at the AGM and continues to help us with administrative tasks 2 days a week 6 hours a day. The other is a gardener who has done a tremendous job with tasks that needed urgent attention at our Elsie Court cottage here in West Ryde. We are very pleased with the work those two volunteers are doing. Allow me to take this opportunity to thank all those who volunteer to help us in other areas as well.

We are also currently networking and talking with the Huntington's Disease Service to re-start both the social club and camp once a year for their clients. This is in addition to our ongoing lunch club and camp for our own clients. Our own camp is scheduled for April 20-24, 2009, Monday through Friday. More about that inside this issue as well. 2009 indeed holds many challenges and opportunities.

This will necessitate innovative ways to secure more funding for our Association to enable us to maintain and expand our service base both qualitatively and quantitatively. Thus, I am hoping I will have enough time to launch more into the fund raising area with various initiatives such as the quarterly "Care and Share" event, fund raising letter appeals, and corporate donor partnerships.

Finally, I just want to thank all those who are involved one way or the other in the story of our success. Our board, staff, volunteers, other professionals we network with, and especially our donors without whom we would not be able to carry on. Thank you from the heart and I look forward to new exploits and new heights in improving our services to families as we work together towards that goal in 2009.

Sincerely,
Walid

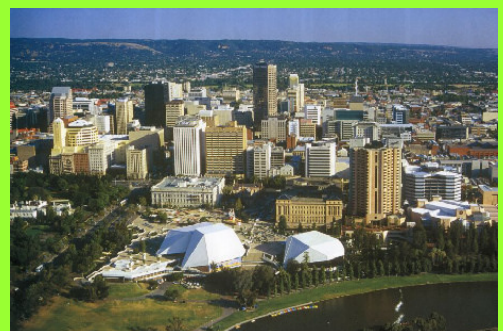
National Conference

Walid Nassar and Viki Moraitis represented our Association at the National Conference in Adelaide, back in September 2008.

They also participated as voting delegates in the National AGM.

It was a great time of networking with the CEOs of other states and other professionals. The speakers were engaging and the conference was first class. DVDs for the two keynote speakers,

James Pollard and Dr. David Craufurd, can be ordered from the SA Association at (08) 8271 2922. Although we are not there yet, a lot of research is ongoing towards finding a cure.



Huntington's Happenings

Staff Update

Since our grant was a bit delayed, Judy Fullston resigned on 7 October 2008 to take up a full-time position with Centrelink. Our best wishes go with her.

We also recruited and hired Sasa Berber as our new Administration Officer. Sasa has been with us since 20 October 2008 and is doing well.

Since we have received assurance that our Carers grant will come through, we are now in the process of recruiting and hiring a Family Support Coordinator (previously known as Carer Support Coordinator) and a Family Support Officer soon after that. We will keep you informed.

AGM Highlights

Our Annual General Meeting was held on 29 November 2008 at West Ryde Council Hall and was attended by over 30 members and guests. People came from the Central Coast, Newcastle and even as far as the Coffs Harbour area. Our speaker was Dr. Elizabeth McCusker who shared on "20 Years of Change and Progress." After going through the fascinating history and milestones of the past twenty years she made the statement that (paraphrasing) at the end of the day it is really all about caring for the families. We could not agree more! The Association awarded Dr. McCusker Lifetime Membership in honour of her long service to the HD community and the Association.

Certificates of Appreciation were also awarded to the following individuals in recognition of their service and contribution to our Association: Karen Bevan, Robert Curran, Chris Dixon and Graham Petty our long-time auditor.



President Anne Low addresses the AGM.



Michelle O'Brien shares her story at the Association's AGM in November.

Michelle O'Brien also shared for a few minutes about her HD Forum on the internet. You can find out more by visiting that website at www.hdaustralia.org.

An article in the December issue of Marie Claire details Michelle's experience with HD in her family.

We look forward to networking more with Michelle and the HD community she is part of in the Coffs Harbour area in 2009.

Huntington's Happenings (cont)

Committee Update

As customary, during the AGM the members elected our committee for 2009. The following office-bearers were elected: Anne Low (President), Robyn Kapp (Vice President), Richard Bobbitt (Treasurer), Viki Moraitis (Secretary). Also committee members: Mark Bevan, Keith Dingeldei, Elaine Sammut, Jim Finn and John Conaghan. We welcome the new members John Conaghan and Robyn Kapp. Robyn Kapp, although new to the committee this year, is not new at all as she was the longest serving Executive Officer who was very instrumental in bringing the Association to where it is today. We are excited she is now on the board to help us out during this transitional stage. Both Robert Curran and Ian White resigned from the committee and we thank them for their faithful service and wish them the best.

Also unfortunately, due to reasons beyond his control such as transportation difficulties, Mark Bevan resigned from the committee recently. Mark had served faithfully for years as both an office bearer, including President, and as a committee member. We take this opportunity to express our warmest appreciation to Mark and acknowledge his valuable and faithful service all those years and to wish him the absolute best.

April Camp

Our first Camp this year for people with Huntington's Disease is scheduled for Monday 20th April till Friday 24th April at Camp Breakaway at San Remo on the Central Coast.

There will hopefully be another camp this year for residents of Lottie Stewart Hospital, so this camp will be for those living in the community.

To be eligible to attend this holiday camp you must be able to walk, sit, stand, dress, undress, shower, eat, drink and use the toilet without requiring assistance. However if a carer is accompanying you we will assess your eligibility on that basis and through discussion with your carer.

For all enquiries about the Holiday Camp contact us at the Association's office. Applications from those who have not previously attended a camp are especially welcome.

Applications close on Friday 6 March 2009.

April Camp Volunteers Needed

We are calling on all volunteers who had helped us with previous camps to register their interest and availability to assist with the upcoming camp. If you had never volunteered before but would like to, we'd welcome hearing from you as well. We may only need a couple of extra volunteers to be there overnight throughout the week and the priority will be for those who have past experience with our camp. Those who would like to help during the day only are always welcome especially if they are close to the Camp (San Remo, Central Coast) or can manage their own transportation. Call us at the office to register your availability.

Huntington's Happenings (cont)

Donor Appreciation

We extend our appreciation to each and every one of our faithful donors. You are a vital part of the work we do and we need your continued generosity to maintain and expand our services.

Special thanks go to the following individuals:

Ken Raffe; A.R. & J Gates; Mrs. Dahl; Peter Forrester.



Special thanks also go to the following business entities:

Optiver Corporation; Hargrove Foundation; Gadens Lawyers.

Many thanks also go to the estate of Maisie Ellen Johnson for the very generous bequest the Association received in October 2008.

Corporate Donations

There is something we can all do in order to help our Association further. All of us have family and friends who work with different corporations and businesses. Most of these either already have a charitable donation program in place, or are very open to donating to non-profit entities that are recommended to them. Thus, you can recommend our Association to a friend or acquaintance who owns a successful business, as well as ask other family and friends who are employed by corporations to recommend us for possible corporate donations through their established programs to help community non-profits. For example, the donation we just received from Optiver Corporation was due to the recommendation of Derek, son of Dr. Elizabeth McCusker, who works for their IT department. I strongly recommend those of you who catch the heart for this to write down on a piece of paper the names of people you know who may be candidates to help us in this manner. Then contact them and find out if the possibility with their corporation exists, then just ask them to contact us! Thank you.

Fund Raising Letter

We will also be starting a fund raising letter that will go to our members and mailing list friends on a quarterly basis, at least for now. It will highlight certain needs we have or projects/activities that we are involved in and ask for a generous donation. I will write those letters myself and will just share from the heart with you our friends. There is no obligation whatsoever to give and you can ask to be removed from that list at any time if you do not wish to receive those. That said, from my own experience with fund raising with non-profits for the past 20 years now, I do know that there are some, however, who would like to be reminded of present needs and planned projects and who gladly and generously respond as they are able to. Also, please remember that no gift is too small and we all give according to our abilities. *Generosity is measured by equal sacrifice not equal amounts!* With that in mind, you can expect that first fundraising letter sometime this quarter. I am hoping I will have good news to report to you from our cumulative fundraising efforts shortly.

Huntington's Happenings (cont)

Be There for Care & Share!

We have already outlined our new "Care & Share" fundraising event that we will be having at Elsie Court Cottage quarterly. Due to the AGM crunch, the first Care & Share which was scheduled for 15 November 2008 was replaced with an email fundraising endeavour.

The next "Care & Share" event will be:

When: Saturday 28 March 2009

Time: 4.00pm (till 5:30pm)

Where: Elsie Court Cottage @ 21 Chatham Road, West Ryde RSVP: No later than Wed 25 March

Parking: Shopping Centre nearby

Call (02) 9874 9777 or email hdassoc@ahdansw.asn.au and let us know **how many** will be coming.

[Please put "Huntington's" in the subject as we do get a large volume of e-mail and do not want to miss yours!]

Christmas Party

Our Christmas party for the Social Club this year was another opportunity to have some fun, enjoy gifts and be blessed by Christmas Carols. Patrick and Meg Chavez and their beautiful children entertained a riveted crowd of clients, staff, and volunteers as they sang and performed for us. Thank you Patrick, Meg and family for that wonderful cheerful time. Also, Leila Nassar (Walid's wife) sang a couple of beautiful solo Christmas favourites. Karen Bevan was also present and helped us with the event (Meg, by the way, is Karen and Mark Bevan's daughter). Thanks also to Lily our Administrative/Activities Assistant for organizing the party and doing the decorating, gift shopping and cooking.



Enjoying lunch.



Karen Bevan, daughter Meg and husband Patrick Chavez

Huntington's Happenings

Christmas Hampers

In conjunction with Wesley Mission and Huntington's Outreach at Lottie Stewart Hospital, the Association provided twenty three families and individuals with Christmas hampers (18) and gift vouchers (5) this Christmas. Thanks to Angela Lownie and her team at the Outreach Centre who helped with the facilitation, packing and distribution of those Christmas goodies. Thanks also to all those who volunteered and helped us get it done on time: Karen Keast, Jeanette Moxon, Jet Aserios and Sari Susanto our administrative volunteer.

Introducing John Conaghan

John Conaghan was recently elected to our Board and is our newest Board member. John lives in Newcastle and has worked as a social worker for 23 years with the local area health service and has worked for the past 18 years at Hunter Genetics in Waratah with families affected by Huntington Disease. John's work spreads over a large geographical area including the Hunter and mid north coast regions and he has a special interest in the needs of this group. John is married to Suzanne and has one child, Tomas. John's interests outside of work include swimming, test cricket, renovating the family home and spending time with family.

Spotlight on Research

Introducing Dr. Clement Loy

Clement Loy trained as a neurologist at St. Vincent's and Westmead Hospitals, Sydney. He first worked with the Huntington Disease Service at Westmead in 2003, as a clinical fellow under Dr. Elizabeth McCusker.

It was then that he was introduced to, and became interested in the care of people with Huntington Disease. He then sub-specialized as a cognitive neurologist at the National Hospital for Neurology & Neurosurgery, Queen Square. Upon his return from London, Clement undertook further laboratory research in molecular genetics, working with people with familial dementia.

Last year he rejoined the Huntington Disease Service as director, after Dr. McCusker moved into a research role.

Clement considers it an absolute privilege to be able to join Huntington Disease families as a fellow traveler on a journey which is both difficult and full of surprises. The selflessness and resilience of families caring for people with Huntington Disease continue to inspire him. He is very fortunate to work with an expert and dedicated team at the Huntington Disease Service, and looks forward to a long association with the Huntington Disease community. Last but not least, Clement and his wife Sally are expecting their first child in March, and he can't wait to become a father!

Spotlight on Research

Antioxidants Could Help HD Sufferers Study Suggests

ScienceDaily (Oct. 10, 2008) - Therapeutic strategies to strengthen antioxidant defences could help to prevent the progression of Huntington's Disease. This is the suggestion from the results of the first ever trial on human samples carried out by researchers at the University of Lleida.

A study carried out by Catalan researchers shows that oxidative stress and damage to certain macromolecules are involved in the progression of Huntington's Disease (HD), which is characterised by psychiatric and cognitive disturbance, involuntary movements (chorea) and dementia.

The research was carried out using human brain samples obtained post mortem from people affected by HD, which were compared with samples from control patients (C) who had died from unrelated illnesses or other causes. The two cerebral areas most affected by this illness - the striate cortex and cortex - were studied.

The samples, which were provided by the tissue bank at the University of Barcelona's Institute of Neuropathology, were divided into HD-C group pairs based on gender, age, and the length of time after death before the tissue had been removed.

"Bidimensional electrophoresis techniques were used to compare the differences between the proteins present in the brains of the sick people and those of the controls," said Elisa Cabiscol, professor of biochemistry at the University of Lleida, and one of the report's authors. "The results showed that more than half of these were enzymes related to antioxidant defence systems."

This study, which used human samples for the first time and was funded by Spain's Consolider-Ingenio 2010 Programme, found that the brain tissue from people suffering from HD had elevated levels of proteins that eliminate reactive oxygen species (ROS), or free radicals, as they are more commonly known.

(Continued next page...)



Some antioxidant-rich foods.

Spotlight on Research (cont)

There is a situation we call oxidative stress in the brains of these patients, and as a result the neurones (and other cells in the brain, such as the glial cells) attempt to defend themselves by increasing their antioxidant defences," said Nabisco.

"In normal conditions, the balance between ROS generation and antioxidant systems allows cells to function correctly. However, in a situation of oxidative stress, ROS generation exceeds the cells' defence capacity, causing changes in the cells that ultimately cause them to die.

Our proteomic study has made clear how important a role oxidative stress plays in this illness, calling for the use of therapeutic strategies that boost antioxidant defences or prevent the formation of ROS, in order to try to halt or slow down the progression of this devastating disease," added the researcher.

Acknowledgment:

Study Reference 10.1016/j.freeradbiomed.2008.05.014 Copyright © 2008 Elsevier Inc.
Proteomic and oxidative stress analysis in human brain samples of Huntington disease.

Source:

<http://www.sciencedaily.com/releases/2008/10/081010092322.htm>

World Congress on HD 2009

For those of you who may be interested, the World Congress on Huntington Disease will be on in Vancouver CANADA 12-15 September 2009. It is organized by the local organizing committee headed by Dr Michael Hayden and Dr Blair Leavitt of University of British Columbia, representatives of Huntington Disease Society of Canada, World Federation of Neurology Huntington Disease Research Group and International Huntington's Association. The website address is:
<http://www.worldcongress-hd.net/html/2009/intro> .



Families and Carers

Sydney Carers Group

We began our Sydney Carers group the last quarter of 2008. Soon after the first meeting which was attended by only 3 carers, our Carer Support Officer resigned to take up full-time work somewhere else. The Executive Officer networked with social workers Suzie Docherty and Jet Aserios to continue and grow that group. The second meeting saw 7 carers attend, and the last meeting we had 10 in attendance and six of them were men! Those meetings are jointly facilitated by Walid (our E.O.) and social workers Suzie and Jet. It is NOT a “professional” type support group but rather a relaxed, friendly heart-to-heart group with ample time for carers to share stories and struggles. The feedback from those who attended has been great. If you are a Carer in the Sydney area, we invite you to call our office and come and check out this new and exciting group.



The Sydney Carers Group in action.



The last Sydney Carers Group meeting included six men!

Location: 21 Chatham Road, West Ryde
Group Meetings: See Schedule (Light lunch provided)
Contact: 02 9874 9777

Working Carers Sydney Group

For those working carers who can only attend in the evening, we have planned alternative meetings to suit your schedule.

Those will be held on the last Wednesday of alternative months in the evening. Please call our office at least one week in advance to register your interest in attending the group.

Location: 21 Chatham Road West Ryde
Group Meetings: See Schedule (next page)
Contact: 02 9874 9777

Families and Carers

Carer Support Group Schedule

Carer Support Group Schedule

January to June 2009

Don't carry the burden alone...

Those support groups are the perfect place to form new friendships, share what is on your heart, as well as hear what others have to say, and lighten up a bit the caring journey as you walk alongside others on the same road. In addition, once we get our Family Support Coordinator on board we will be planning recreational days such as outings and other activities for this group to enhance our sharing time together and have some fun as well!

Don't miss out...call our office and come and join us.

Date	Day	Time
29 January	Thursday	1030 – 1230 (Day)
25 February	Wednesday	1800 – 2000 (Eve)
26 March	Thursday	1030 – 1230 (Day)
29 April	Wednesday	1800 – 2000 (Eve)
28 May	Thursday	1030 – 1230 (Day)
24 June	Wednesday	1800 – 2000 (Eve)

HD Australia Forum

Michelle O'Brien shared at our AGM about her HD Australia Forum. Michelle's story was also published in the Marie Claire magazine, December 2008 issue. The purpose of this web-based forum is to be an additional support tool for individuals and families living with HD where networking and sharing can take place. Anyone with internet access can join in and read the messages at any time, although if you want to reply you will need to register as a member.

We do recommend that you take full advantage of this tool. It can be a very significant tool especially for those who live in remote areas or away from metropolitan HD service areas and feel somewhat isolated. Also, young people of HD families who are internet savvy can also benefit from such a forum. Check it out at www.hdaustralia.org.





Australian Huntington's Disease Association (NSW) Inc

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21 Chatham Road, West Ryde, NSW 2114

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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 08/09

President: Anne Low

Vice President: Robyn Kapp

Treasurer: Richard Bobbitt

Secretary: Viki Moraitis

Elaine Sammut

Keith Dingeldei

Jim Finn

John Conaghan

Association and Other Useful Contacts

Walid Nassar

Executive Officer

Sasa Berber

Administration Officer

Lily Ma

Administration and Activities Assistant

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

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