



Gateway

**News from the Australian Huntington's Disease Association (NSW)
Volume 13 No 3
Spring 2010**

Australian Huntington's Disease Association (NSW) Inc

2010 ANNUAL GENERAL MEETING

**SATURDAY 6 NOVEMBER 2010
1.00PM — 3.00PM**

**At the Offices of the Association
Refreshments will be served
Non members welcome**

**Guest Speaker: Dr Clement Loy, Director and Neurologist,
Huntington Disease Service, Westmead Hospital**

Speaking on "What's New in Huntington's Disease?"

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

Agenda

1. Apologies
2. Minutes of Previous AGM
3. Business Arising from Minutes
4. Annual Report
5. Annual Financial Report
6. Annual Statement
7. Appointment of Auditor
8. Election of Office Bearers and Committee Members
9. Special Resolutions
 - 9.1 The following special resolution is proposed for consideration: -
That the Association adopt the trading name of "Huntington's New South Wales"
10. General Business

Nomination forms for the Office Bearers and Board elections are available upon request.
Please contact the office if you need some sent to you.
Completed forms should be returned to AHDA (NSW) no later than Friday 29 October 2009.
Nominations may also be made at the meeting.

Note: You must be a financial member to be able to nominate or vote.

From the Executive Officer

At the Association, we are always looking for ways to advocate for the needs of the Huntington's community, particularly in these changing times in the health sector.

One recent initiative which we have been involved in is the formation of a NSW peak body of health consumer organisations who can work together to try to influence health policy and service provision for our respective members in NSW.

Until recently NSW had been the only major state without this kind of consumer voice. To redress this problem, representatives from 20 health related organisations which work with consumers, including the Association and other members of the Neurological Diseases' Alliance of which we are a member, recently met in Sydney over two meetings and agreed to the establishment of Health Consumers NSW (HCNSW).

HCNSW will now join other Australian states' peak consumer organisations to influence health policy and service provision and to contribute to the Health Reform process. The aim of the body is to play a vital role in shaping a responsive health system - public and private - in our state.

NSW Health Minister Carmel Tebbutt funded the first meetings, indicating her in principle support of this real opportunity for NSW

health consumers to be heard. The motto of the organisation is "Nothing about us without us, please!" We will keep you updated on our involvement with this peak body as time goes on.

In terms of the Association's programs, as always the day respite program (lunch/social club) has had a variety of outings including a visit to the Power House Museum and a winter picnic. You can read reports about these events on page 5 of this Issue. Many more activities are planned for the future and new participants are very welcome at any time. You will find the calendar for future dates on page 5 of this Issue.

Mark Bevan who joined the Association as Family Support Officer in June has hit the ground running and is involved in many exciting events taking place in his areas of primary focus which are the Central Coast, Hunter/New England and Mid North Coast areas. On page 13 of this issue you can read about what is happening north of Sydney and on page 10 you can also find out more about Mark.

September is proving a very busy time for everyone. By the time you read this the National Conference in Brisbane and the fundraising event on the Central Coast will have both just concluded and you can look forward to reading the reports on these exciting events in the November Issue of Gateway.

I really hope to see some of you at our AGM which will be held at the offices of the Association on 6 November. At this meeting the membership will be asked to consider a Special Resolution to change the trading name of the Association. If you agree to this change it will mean that whilst our legal name will remain the same, we will start using the name "Huntington's New South Wales" as our public name. This change has been proposed to bring us into line with the other state Associations and also with the National Association. You will find further details about the AGM on the cover page of this Issue.

As always, all of our staff are here for you so please feel free to contact them should the need arise. 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

Membership Renewals



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

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

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



Support for all Australians affected
by Huntington's Disease

Have you checked out the HD Australia forum recently? It is a community run resource for all Australians affected by Huntington's Disease. It includes opportunities to connect with others online and links to the latest HD research and news stories. Accompanying this Gateway you will find a flyer giving you more information regarding this important resource for everyone affected by Huntington's. You'll find the website at: <http://www.hdaustralia.org>

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

New Physiotherapy Guidance Document for those with HD

Physiotherapy is becoming more frequently recommended for people with HD but to date, there have been no specific implementation guidelines.

The Physiotherapy Working Group of the European Huntington's Disease Network (EHDN) has developed a comprehensive Guidance Document for Physiotherapists. It aims to assist therapists in implementing a plan of care that is consistent with current best practice in physiotherapy provision to people at all stages of HD.

The document will be reviewed and updated as new research becomes available. The current version is available free of charge for download at:

<http://freedownloadbooks.net/ehdn-doc.html>



Our HD Space

Our HD Space is the new website for younger people. 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. Accompanying this Gateway you will find a flyer giving you more information regarding this important resource for younger people affected by Huntington's. The website is at <http://ourhdspace.org>



Your Stories are Important!

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 late November. The deadline for articles is 12 November 2010.

Day Respite Program (Social/Lunch Club)



Program Dates for 2010

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

All social club excursions and lunch club meetings are run on Tuesdays between 10.30am and 2.30pm unless otherwise advised.

Lunch club meetings are held at the offices of the Association at 21 Chatham Road, West Ryde. Excursions all depart from the same address at 10:30am.

Month	Dates
September	28
October	12 TBC School Holidays 26
November	09 23
December	7 14 Xmas Party

Life's A Picnic!



We have had several exciting trips this third quarter with the Day Respite Program (Social/Lunch Club). We are continuing to alternate between fortnightly outdoor excursions and lunch in at Elsie Cottage.

The last few months have seen us on a nostalgic journey through memory lane at the Powerhouse Museum where we visited their "Back to the 80's" exhibition, exploring Australian life and popular culture in the 1980's, revisiting the era's toys, fads and disco music.



We have also been to the movies and have had several picnics at the local park when the weather permitted. On the odd warm and sunny day, we have taken the opportunity to make a trip to the park for a game or two of outdoor bowls and bocce, whilst enjoying Lily's and my "gourmet fare" on park benches and picnic rugs on the grass.

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

HD Research Update

" New Insight into Wasting Disease"

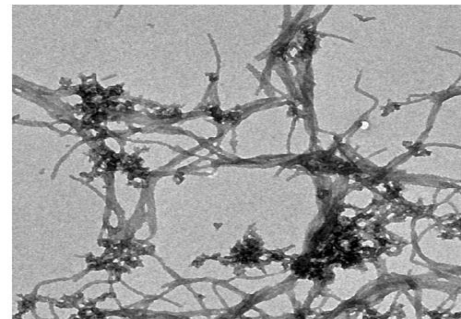
by Jennie Curtin

Australian researchers have for the first time been able to see inside the mutant proteins that are responsible for the incurable illness Huntington's disease.

The Scientists from the University of Melbourne hope their work may one day lead to effective treatments for Huntington's and other degenerative diseases.

Dr Danny Hatters, from the University's Department of Biochemistry and Molecular Biology, said the team used state of the art equipment that enabled them to see in greater detail than ever the clumps of proteins that ultimately destroy brain cells.

"It's really very exciting, " Dr Hatters said. "Trying to understand how these clusters form has baffled scientists for a long time. This is the first time anyone has been able to see these clumps. It also allowed them to identify areas that could be targeted in drug treatments, he said.



Mutant huntingtin protein assembles into long tangled fibrils *in vitro*

Huntington's is an inherited disease where the brain cells degenerate and eventually die. It affects coordination and leads to a decline in mental facilities and emotional reactions. Symptoms which usually appear between the ages of 35-45 include uncontrolled and jerky movements, walking difficulties, problems with speech and swallowing, difficulty concentrating, short-term memory loss, depression and mood swings.

Treatment focuses on alleviating the symptoms with a range of antipsychotics, anti-depressants and tranquillisers. A closer understanding of how the protein clusters form and change should lead to better knowledge of how drugs work, and a better drug treatment regime, Dr Hatters said.

"Importantly our research techniques could have applications in assisting to find drug targets for other neurodegenerative diseases where toxic clusters of proteins play a role in the progression of the disease, such as Parkinson's disease, " he said.

The above article appeared in *The Sydney Morning Herald*, Friday 30th July 2010

The research findings referred to in this article are from the following publication: -

Olshina MA, Angley LM, Ramdhan YM, Tang J, Bailey MF, Hill AF and Hatters DM (2010) "Tracking mutant huntingtin aggregation kinetics in cells reveals three major populations including an invariant oligomer pool" *Journal of Biological Chemistry* 285, 21807-21816.

Weight Loss and Sleep Problems in HD

Why do Huntington's patients suffer from sleeplessness, and why do they lose so much weight?

This was the question which Ahmad Aziz sought to answer in the research which he undertook toward his PhD. Dr Aziz obtained his PhD from Leiden University in the Netherlands on Wednesday 31 March 2010. He was the first Leiden PhD researcher to obtain his doctorate funded by a Mosaic subsidy. Mosaic is a grant program for students from ethnic minorities so that they can complete a PhD research program.



Dr Ahmad Aziz

An aggregating protein causes many of the symptoms of Huntington's disease, an incurable and frequently fatal brain disorder. Mosaic recipient, Dr Ahmad Aziz discovered that the abnormal protein also aggregates in the hypothalamus, the part of the brain that regulates the autonomic nervous system and the endocrine system. Aziz investigated the severity and causes of a number of less well-known symptoms of Huntington's disease: weight loss, sleep disturbances and a poorly functioning autonomic nervous system. He established that many patients suffer from weight loss and sleeping problems.

Abnormalities in the hypothalamus appear to account for some of these symptoms. The hypothalamus was an obvious suspect for Aziz, as it regulates the autonomic nervous system and the endocrine system. Aziz established that certain nerve cells are lost in a part of the hypothalamus. In this part as well as in other parts of the hypothalamus abnormal protein aggregates were found. These hypothalamic nerve cells play an important role in the maintenance of body weight and a normal sleeping pattern.

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Sleep and depression

Many of the patients investigated by Aziz get to sleep too late and wake up later in the morning than healthy people. Moreover, it appeared that the further the sleep rhythm is displaced, the more depressive the patients are. These patients also suffer from more cognitive abnormalities.

The disruption of the sleeping rhythm could partly be due to a shift in the rhythm of the 'sleeping hormone' melatonin. That rhythm is regulated by the biological clock in the hypothalamus. Many Alzheimer's patients also have an abnormal sleep/wake rhythm. This can partially be corrected by light therapy and the administration of melatonin. Huntington patients might also benefit from such an approach.



Continued on Page 9

Reduced Creatine Kinase

by Marsha L. Miller, Ph.D.

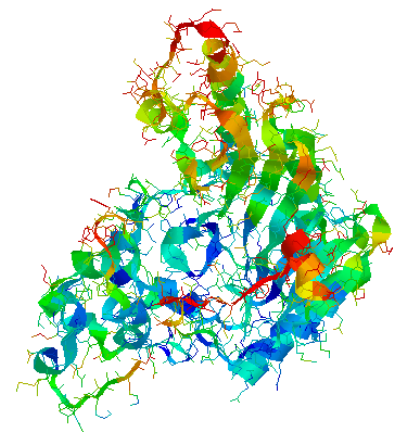
A major goal of current clinical research in Huntington's disease has been to identify preclinical and manifest disease biomarkers, as these may improve both diagnosis and the power for therapeutic trials. Although the underlying biochemical alterations and the mechanisms of neuronal degeneration remain unknown, energy metabolism defects in HD have been chronicled for many years.

Robert Ferrante, Steven Hersch, and colleagues have identified a potential biomarker for Huntington's Disease progression that can be measured in blood samples. An isoenzyme of creatine kinase, CK-BB, was shown to be reduced in the blood and brains of two mouse models over time. What is exciting is that CK-BB was also found to be reduced in the blood of pre-manifest gene carriers, and reduced even more in symptomatic patients.

Creatine kinase is an enzyme that plays a crucial role in the production and maintenance of energy in cells. When the cell needs energy, creatine kinase causes the transfer of a high-energy phosphoryl group from phosphocreatine to adenosine diphosphate (ADP) to form adenosine triphosphate (ATP) which is the source of energy for cell metabolism.

Creatine kinase maintains levels of ATP even when energy is consumed by the various functions of the cell. It has long been thought that there is a problem with energy production in HD and ATP levels are known to be very low in the brains of HD mice. Creatine kinase is critically important for cells to maintain energy homeostasis and deficiencies of creatine kinase are harmful.

There are three creatine kinase isoenzymes and the one which is specific to the neurons which degenerate in HD is CK-BB. Mice which have been engineered to lack the gene which produces CK-BB develop similar symptoms to those who have been engineered to develop HD. These include reduced body weight, brain atrophy and impaired spatial learning.



Creatine Kinase

The researchers studied CK-BB in blood and brain samples from the R6/2 mice and the 140 CAG knock in mice. Human blood samples were obtained from the REVEAL-HD project and included premanifest gene carriers, HD patients, and spouses who served as controls. Postmortem HD brain tissue which had been donated for research was also examined.

They found that CK-BB was progressively reduced over time in the blood and the brains of both mouse models. CK-BB was reduced in the brains of premanifest gene carriers and further reduced in those who were symptomatic. CK-BB was also significantly reduced in the caudate nucleus of HD brains, with the amount of loss correlated with the stage of the disease.

Continued next page

From previous page

If further research validates CK-BB as a biomarker throughout disease progression, it would be a valuable indicator of when future treatments should start. It could also enable clinical trials of potential new treatments in premanifest gene carriers and serve to shorten clinical trials for HD patients by providing an objective and sensitive endpoint.

In addition, this work provides additional support for the hypothesis that energy metabolism is impaired in Huntington's Disease and for the rationale behind the current Phase III clinical trial of creatine. Dr. Steven Hersch, director of the Phase III creatine trial, is encouraged by the results. "This discovery of a progressive deficiency of creatine kinase in blood and brain is very exciting because we urgently need biomarkers to help make clinical trials more efficient, because it helps explain why creatine has been so effective in HD mice, and because it makes the case for testing creatine in HD patients all the more compelling."

Posted to <http://www.hdlighthouse.org> on 4 August 2010

Weight Loss and Sleep Problems in HD (cont.)

Weight loss

Although the mutated Huntington's disease gene mainly causes damage in the brain, it is expressed in virtually all tissues, even though it does not cause damage everywhere. However, Aziz demonstrated that weight loss in the initial stages of Huntington's disease is not the consequence of other symptoms, such as hyperactivity, but is directly related to the mutation. This indicates that the cause must partly lie in the peripheral tissues, such as muscle and fat tissue. The defective gene probably causes damage there as well.

Influence of the normal gene Huntington's disease is caused by a mutation in the huntingtin gene. In the mutated gene the DNA sequence C-A-G is repeated too often. Aziz's research reveals that weight loss and the number of CAG repeats are directly correlated: the greater the number of repeats, the greater the loss of weight.

The number of CAG repeats in the normal huntingtin gene can also influence the symptoms of the disease. This is because each person carries two copies of the huntingtin gene. In a normal gene there are 35 or less CAG repeats. Huntington patients have one normal gene and one defective gene with 36 or more repeats. Aziz discovered that the number of CAG repeats in both the normal gene and the defective gene is important for the rate at which the disease progresses. However, the effect of the normal gene is small and is mainly important for understanding how the disease develops and for a correct interpretation of future drug studies. It follows that such studies must take into account the differences in the number of CAG repeats in both genes.

Acknowledgement: Dr Ahmad Aziz (Leiden University)

Family Support Program

Meet Family Support Officer Mark Bevan



My name is Mark Bevan and I have recently started in the new role (2 days per week) of Family Support Officer with the NSW HD Association, serving the HD community in the northern half of the state, with a particular focus on the Central Coast, Hunter and Mid North Coast.

I am married to Karen, and we have 2 'children' and 10 grandchildren (yes that's right – 10).

My father in law had HD, and he passed away in 2000. Karen and I have been involved with the HD Association in various ways since about 1980, and I was one of the workers on our early holiday camps held in the 1980's. We have obviously also been involved as members of a HD family, so I come to this role with some understanding of HD issues and trust I can put this to good use.

My working history is quite varied and previous roles include a lot of time in the Information Technology industry, working as a Police Officer, several years as a Pastor, and also as the manager of a 24 hour call centre.

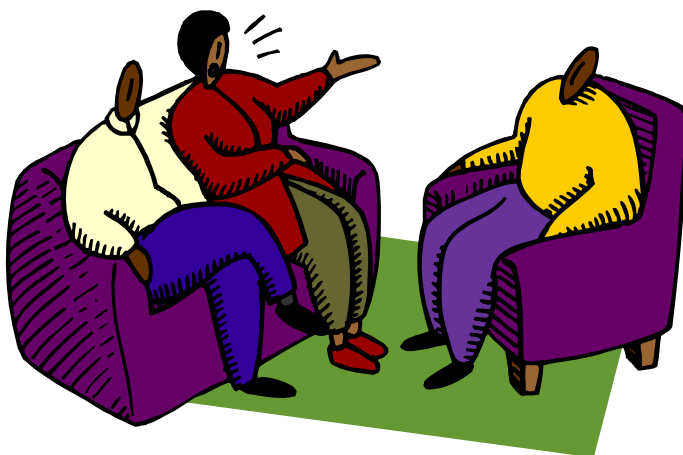
We live in the Lake Macquarie area (between the Central Coast and Newcastle), and I will be based there with a view to being able to more effectively serve the HD community in the areas for which I am responsible. The role has its focus on providing as much up front support as possible to families and health professionals. To that end I will work closely with John Conaghan from Hunter Genetics, as he has such vast experience with Huntington's families, and great knowledge of Huntington's issues generally.

I have to say that I am extremely excited about the possibilities and potential for supporting and serving the HD community, and I look forward to meeting many readers of Gateway in the future. One initiative in which I am involved and about which I am extremely enthusiastic is a new Central coast Support group, which held its first meeting (they are monthly) on Monday 26th July. You can read more information about the group on the next page of this Issue and you can also read a report about the first few meetings of the group on page 13 of this Issue of Gateway.

I would love to hear from you – so please contact me if you want – either by email at mark@ahdansw.asn.au or call me on 0410 629 850.



Central Coast Huntington's Disease Support Group



The Central Coast Huntington's Disease Support Group provides a chance for people with Huntington's Disease, their carers, friends and family to get together regularly to enjoy good company, education and support, over some light refreshments. The group meets monthly.

The next meeting will be on
Monday 27th September,
starting at 7:00pm running through to 9.00pm

It will be held at
Axiom Psychological & Coaching Services,
46 George St
East Gosford NSW 2250.

All Welcome

For any further information, please contact:

Holly Faulkner: 0401 203 198

Ian Kilpatrick: (02) 4324 5400

Mark Bevan: 0410 629 850

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.*

Remaining 2010 Sessions

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



For RSVP and further information,
please contact:

Jet Aserios: (02) 9845 7528

Social Work Department
Westmead Hospital

Family Support Program - Update

We have had yet another couple of very busy months here at the Association. We are so happy to welcome our new Family Support Officer Mark Bevan who started with us at the start of June. Many of you will know Mark from early days as he has been very proactive with our annual camps as well as having been on the Board of our Association for many years.

Mark has a long history with the Association and will be working primarily with our carers and clients in the Central Coast region. Welcome aboard Mark!



We are still attempting to reach out to carers in the Canberra and surrounds region in the hopes of establishing a support group for carers. If you are a carer of someone with Huntington's Disease, or have a friend or family member with the disease and would like to find out more, please contact us at the Association on 9874 9777, or email me at Ramona@ahdansw.asn.au

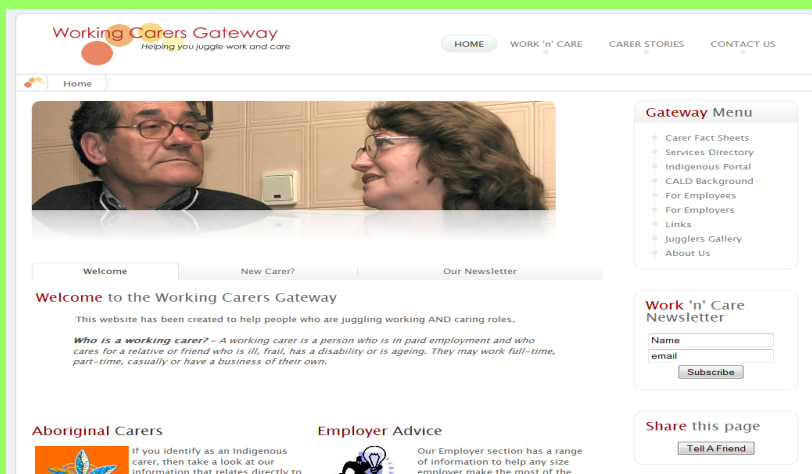
Social Club has continued to thrive in these few months. The weather has not been ideal in the winter months, which resulted in a few of our planned outdoor excursions being moved indoors. Nonetheless our social club members have continued to enjoy great camaraderie, home-cooked food and a lot of laughs, as well as much needed more reflective moments of talking and sharing of personal experiences.

Online Support for Working Carers

If you are in any sort of paid employment and care for a relative or friend who is ill, frail, has a disability or is ageing then you are a working carer.

The Working Carers Gateway at <http://www.workingcarers.org.au/> includes factsheets for carers, information for employers and employees and assistance for Indigenous and CALD carers.

It's just one of the recommended links which you can find listed on the Association's website at <http://www.ahdansw.asn.au/> and is well worth a look.



Central Coast Support Group

The Central Coast Support group has started meeting. We held our first 2 meetings in the offices of Axiom Psychological and Coaching Services at 46 George Street, East Gosford on July 26th and August 10th.

A very exciting time at both meetings! Twelve people attending the first meeting was beyond my wildest expectations. And to prove that was not a one meeting wonder, we had 13 at the second meeting. Due to this overwhelming response, we are already considering a larger venue for future meetings, but they will continue at the above address for now.

A big thank you to Deb and Holly Faulkner, and Ian Kilpatrick, for taking the initiative and getting this support group up and running. Great work. We have agreed to meet monthly, and the next meeting will now be Monday September 27th, same location, and starting at 7pm. You can see the ad for the Support Group on page 11 of this Issue of Gateway.

Some people attending the meetings already knew one another, but others made completely new connections. There has been a great honesty and understanding as people have shared their personal stories, their hopes, dreams and concerns.

The incidence of HD on the Central Coast was a keenly discussed topic, and we considered how to establish if the coastal experience was any different to other areas.

Awareness of HD was also a popular topic, and people starting actively considering how to life awareness of HD on the coast.

And of course, a really hot topic was the need for suitable Central Coast care facilities for Huntington's sufferers, including crisis support.

We also considered what future meetings could cover.

In addition to the general meetings where we can discuss a variety of topics, it was agreed that some guest speakers could possibly come to cover specific topics. The group has already listed quite a number of these, and we will work toward addressing these as we move forward.



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

Spring Cleaning

Finally we are in the last weeks of winter – spring with all its blossoms, warm sun and fresh breeze, is just around the corner. When we think of spring cleaning, we often think of cleaning out our cupboards and pantries, wiping down the bookshelves, vacuuming under the bed...but there comes a time when we should think about our own personal spring cleaning - that of our bodies and our minds.

We only have a certain amount of space in our minds, hearts, and even our schedules. When we spend our time thinking, doing and reacting to things in the past or even anticipating the future, we are not focusing on the present. Think of your mind the same way we think of our closets. There is a common rule of thumb that for every one new item of clothing you buy, you donate two items. It's even harder to follow this rule when it comes to commitments - it's hard to say "no" and often times you'll find yourself juggling a million commitments at one time. This approach, although it keeps you busy, does not allow you any time just "being."

Take some time out for self-reflection, and try some of the following steps to feel "new" again this spring:



Exercise

It's good for your body and helps release stress. Don't worry about picking the "right" activity; do something you love so you're more likely to do it. Find an exercise buddy. Go for a walk. Ask around about yoga or Tai Chi classes.

Express yourself; ask for support

Talk with your friend. Hug your neighbour. Cuddle your kids. Cry with your sister. Share your feelings with your partner. Professional counselors, social workers and therapists can also offer support.

Embrace your own spirituality

Spirituality means different things to different people. Some find inspiration in nature, others in meditation or chanting, and others in their synagogue or church.

Think and act positively

Seek out people who are honest, trustworthy and supportive. Give yourself permission to temporarily or permanently distance yourself from people who are abusive or who make you feel badly about yourself.

***Positive
Thoughts!***

Cry when you need to

Let it out. Think of it as allowing negative emotions to flow out of you to make room for positive feelings to come in.

Find safe outlets for your anger

Talk it out or give yourself a "time out." Write letters you may or may not send. Vent with a trusted friend.

Pamper yourself

Take a hot bath, with candles, scents and nice music. Do your nails. Wear something comfortable. Invite a friend over for a video and popcorn.

Have fun!

Laugh at least once a day. Forgive yourself and others. Try not to waste precious energy being angry, bitter, jealous or resentful.

Eat safely

Avoid raw or undercooked meats/fish/eggs. Don't leave food out that should be refrigerated. Use separate cutting boards for raw meats and veggies. Don't take chances with spoiled food. "If in doubt, throw it out."

Journal writing

Write about how you're feeling or what you're learning. Don't worry about grammar or spelling. It's just for you.

Appreciate nature

Stop and smell the roses. Enjoy a sunset.





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

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