

# GATEWAY

Volume 11 No 1 Australian Huntington's Disease Association (NSW) Inc

Winter 2008

## Australian Huntington's Disease National Conference

"TURNING POINT" - Huntington's Disease in the 21<sup>st</sup> Century is the theme of this year's Australian Huntington's Disease National Conference which will be held between 18 - 19 September 2008 at Pavilion on the Park in South Terrace, Adelaide.

The Conference offers valuable insights into professional comprehensive health management and cutting edge research from around the world.

The theme of the conference reflects the growing need to engage others in the specialist work of providing accessible and relevant knowledge into the care, best practice management and research of all aspects of Huntington's Disease.

Key note speakers include; Dr David Craufurd, Neuro Psychiatrist, Medical Genetics, St Mary's Hospital, Manchester, UK - "Behavioural Management of Huntington's Disease" and Mr James Pollard, Service Provider, Best Practice Care facilities, USA "The Three Stages of Huntington's Disease".

There will also be opportunities to meet and share knowledge and experiences with other delegates from Huntington's Disease service providers, health professionals, researchers, educators, carers and family members.

For further information, please phone (08) 8271 2922, email [hdasa@senet.com.au](mailto:hdasa@senet.com.au) or visit the conference website at [www.huntingtonssa.org](http://www.huntingtonssa.org).



### From the Executive Officer

Dear Friends

I joined the Association as the Executive Officer June 17, 2008. I am honoured to be associated with AHDA and look forward to leading our team to serve the Association and the families it helps and supports.

Life is a journey that brings us both joy and pain. We cherish the joys and deal with the pain as best we can. It is mainly the support we get from others who care that makes life's pains more bearable. I personally understand pain.

I was born in Lebanon and went through a terrible civil war during my teenage years and experienced the pain of losing loved ones in that war. I am also acquainted with the pain of family sickness.

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## From the Executive Officer (cont.)

When I was nine years old, my father suffered a stroke that paralysed him on the right hand side until his death twenty two years later. My mother, who had been his carer all those years, later suffered from Alzheimer's disease the last several years of her life and died from that disease while I was at her bedside at hospital... I witnessed the devastating toll the disease took on my mother, on my sister and her family—her primary carer, and our family as well. I fully understand the pressure that such situations exert on all family members, their well-being, and relationships. As the Executive Officer of the Association, I will endeavour to do my utmost in leading our dedicated staff to do our part in helping such families.

I am married to Leila and we have two beautiful adopted children. My daughter Grace (7) was born in China and my son Eric (6) was born in Kazakhstan. They surely are the joy of our lives. After a brief four year career in engineering and engineering management in the mid 80s, and for the past two decades since then, I have been involved in leadership type roles with non-profit organizations which mainly focus on helping people. I am also presently finishing my doctorate with a "leadership" emphasis that is specifically tailored for executives of non-profit organizations.

In our AHDA brochures, I came across this statement that seems to say it all: "The Australian Huntington's Disease Association (NSW) Inc. exists to advance the welfare of people with Huntington's Disease, their carers and families." To me this role is not just a job, nor just another chance to exercise leadership skills and pursue the career path. This role is indeed about advancing the welfare of valuable people with acute needs whether those suffering from the disease, their carers, or their families. I look forward to doing my part in that.

In friendship

Walid Nassar

Executive Officer



## Renew Your Membership!



Your membership of the Association is due for renewal on 1 July 2008, unless you have pre-paid for the 2008/09 membership year, and a membership form is enclosed with the newsletter.

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

# Huntington Happenings

## Staff Update

It is with sadness that we advise you that Maria Mackell, our Carer Support Coordinator, is seriously ill and had major surgery in early June. At this stage it is uncertain when she will return to work. In the meantime, Judy Fullston (see below) will be available to handle enquiries from family members and carers.

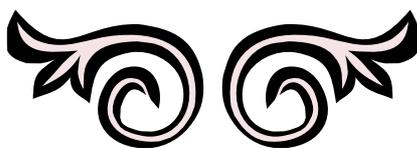
Maria's illness followed hard on the heels of the death of a close family member, and we express our sincere sympathy to her and her family for their loss. We also send our warmest wishes to her for a speedy recovery from her operation.

We are very pleased to advise you that Walid Nassar has been employed as Executive Officer (part-time) of the Association and has written the editorial for this issue.

Robert Curran retired (for the second time) last April and has been replaced as Administration Officer by Sharnie Mineeff. Sharnie's background is in Aged Care and Community Services with past work experience in community transport, aged care placements and information services.

Judy Fullston joined us in April to assist Maria Mackell with the Carer Support Program until the end of June 2008, although in the light of Maria's illness she may be with us for a longer period.

Judy has worked in the Community Welfare area for over twenty years. She co-ordinated a Dementia Program throughout Far North Queensland for seven years before moving to NSW in 2006. Prior to this she was working for the Queensland Dept of Health as well as working 12 hours a week as a Welfare Officer for the Queensland Huntington's Disease Association. Other fields in which she has worked are as a Correctional Counsellor, a Community Development role in the drug and alcohol field as well as in Aged Care and Mental Health fields. Judy has written more in the carers pages.



## Participation of Country Members

Whilst any member of the Association is eligible for election to the board of management this is a somewhat unrealistic option for country members due to the travelling time and expense involved in attending meetings in Sydney. At its June meeting, the board agreed to investigate medium-term options for facilitating the involvement of country members on the board. This may involve looking at things such as telephone and video conferencing.

Later this year the board will be holding a "planning day" to develop objectives and strategies for the following year's work. This will probably be held on a Saturday or Sunday in Sydney. The board is prepared to pay the travelling expenses of one or two country members who would like to participate in this planning day.

If you feel that you can contribute to the planning day (whether you live in Sydney, Canberra or the country) you are invited to register your interest by contacting the Executive Officer.

# Huntington Happenings



## Family Detectives Wanted for HD in Australia: a Social History

My name is Terese Alting. I am a neuropsychologist, and member of the Association, doing research into the social history of Huntington's Disease in Australia as part of a postgraduate thesis through the Unit for the History and Philosophy of Science at the University of Sydney, under the supervision of Dr Rachel Ankeny.

In addition to looking at the history of HD from the perspective of the doctors and researchers who have written about it, we want to find more about how families thought about and managed HD prior to the formation of the state HD Associations in the 1970s. What difficulties did families face? What kind of discrimination did they experience? What support was available? How did the wider community react to families affected by HD?

The project will explore the way HD was described in the medical literature, but we also want to learn more about the experiences of people with HD. One method is to look through medical records of those who were admitted to mental health facilities. The earliest arrival we know of is 1842, but perhaps there were others earlier.

We can do some of the research from currently published sources, but in order to more fully explore the past experiences of HD families we need to find out who the people were. If you have looked into your family history, or would be happy for me to help trace your family's HD background, we would greatly appreciate hearing from you.

Privacy concerns are extremely important in this project, and when this information is collated, no names or other identifying information will be published. We will not be collecting information on any living person without their written permission.

If you would like to help out with this research, or would like to find out more, please contact Therese Alting by phoning her on 0410 113 499 or 9767 7673, emailing [talt5191@usyd.edu.au](mailto:talt5191@usyd.edu.au) or posting your information to Therese Alting, Unit for the History and Philosophy of Science, Carlaw F07, University of Sydney, 2006

After you contact me I will send out an Information Sheet and Consent form if you wish to be involved. Thanks for your interest.

## Happy Holiday

Eight people with Huntington's Disease and four carers attended the holiday Camp at Camp Breakaway between the 1<sup>st</sup> and 4<sup>th</sup> of April. As usual, a great time was had by both clients and the staff. The camp was a little less demanding of the staff than previously as we utilised the services of Camp Breakaway for the catering for the first time.

Special thanks go to: Karen Bevan, who came as a volunteer to perform her previous role as organiser of the camp activities, and Heather Armstrong who also volunteered her time to this camp.

# Research News



## What is Creatine?

You probably know of creatine as a supplement for muscle builders. But creatine has also been shown to have some interesting properties that have HD researchers excited.

Creatine is a compound which has been found to slow disease progression and increase survival time in the R6/2 mouse model of HD. It has been found to be safe and well tolerated in Huntington's patients and is currently in clinical trials. Creatine addresses two sources of pathology in Huntington's Disease. Mitochondrial dysfunction results in energy impairment; creatine boosts cellular energy. In addition, oxidative stress occurs with aging and neurodegenerative disorders including Huntington's; creatine is an antioxidant.

Need more information? Check with your doctor.

## The Impact of Neurological illness on Marital Relationships

Some members of the Association will have participated in the recent study investigating the economic and psychological well-being of patients and families living with neurological illness. This study was conducted in Victoria by Deakin University and the University of Melbourne under the sponsorship of a number of associations including Motor Neuron Disease of Victoria, Parkinson's Victoria, Australian Huntington's Disease Association and Multiple Sclerosis Australia.

The following is an abstract of a recently published report resulting from the study, and highlights particular disadvantage for people with Huntington's disease and their carers. Please contact the Association if you would like to see a copy of the full report.

"The current study investigated the impact of neurological illness on marital relationship satisfaction. Participants numbered 423 patients and 335 carers from motor neurone disease (MND), Huntington's disease- (HD), Parkinson's, and multiple sclerosis (MS). The results demonstrated that patients and carers with HD had a significantly lower level of relationship satisfaction and sex life satisfaction than the other three illness groups. Further, patients with HD indicated a significantly higher level of relationship satisfaction than their carers. For MS and MND patients, social support predicted marital relationship satisfaction, and for Parkinson's patients, social support and sex life satisfaction predicted marital relationship satisfaction."

Citation: Elodie J. O'Connor, Marita P. McCabe & Lucy Firth. *The Impact of Neurological illness on Marital Relationships*. *Journal of Sex & Marital Therapy*, 34:115-132, 2008.

# Research News

## Mental and physical exercise delays dementia in HD

Scientists at Melbourne's Howard Florey Institute have discovered that mental and physical stimulation delays the onset of dementia in the fatal genetic disease, Huntington's disease.

This Australian research opens up new therapeutic possibilities for other devastating and difficult to treat brain diseases, including Alzheimer's disease where dementia is a key component.

The Florey's Dr Jess Nithianantharajah and Dr Anthony Hannan showed mice with the Huntington's disease gene displayed impairments on learning and memory tests at an early stage of the disease, prior to the obvious signs of movement problems. This closely correlates with observations in Huntington's disease patients.

However, Dr Jess Nithianantharajah said by providing the mice with an enriched environment that enhanced their mental and physical stimulation, the mice performed better on these memory tests.

"This discovery is quite remarkable because we have shown that an enriched environment not only delayed the onset of dementia, but it also slowed the progression of memory loss in these mice," Dr Jess Nithianantharajah said.

"We also showed that in the Huntington's disease mice, specific molecular changes occur that relate to communication between brain cells (synapses) in a region of the brain called the hippocampus, which plays a significant role in the formation of memories."

"The Huntington's disease mice without increased mental and physical activity showed decreased levels of specific proteins that are expressed at the synapse, which are essential for normal brain function.

"But the Huntington's disease mice exposed to increased mental and physical activity did not show this decrease," she said.

Huntington's is a very powerful model for nature-versus-nurture investigations. This discovery implies that gene-environment interactions and how they affect changes in the brain's pathways is important for all brain diseases.

Treatments for complex psychiatric disorders, like depression and schizophrenia, may also benefit from these research efforts.

This research was recently published in the international journal *Neurobiology of Disease* and involved collaborations between the Howard Florey Institute and the University of Melbourne.

The Howard Florey Institute is Australia's largest brain research centre. We continue to grow as we amalgamate with the Brain Research Institute and National Stroke Research Institute to form the Florey Neuroscience Institutes. Our united effort is creating a critical mass of skilled researchers from different disciplines focused exclusively on the brain. This will accelerate discoveries to benefit those affected directly and indirectly by brain disorders. The Florey's research areas cover a range of brain and mind disorders including Parkinson's disease, stroke, motor neuron disease, addiction, epilepsy, multiple sclerosis, and dementia. (Source: Press release from the Howard Florey Institute)

# Research News

## A Word of Warning from the Huntington's Disease Association of America (HDSA)

"Recently there have been reports of stem cell treatments for people with Huntington's Disease in the People's Republic of China. HDSA's medical/scientific advisors have not received any data to confirm the claims made in these reports. Of great concern is that websites making fundraising efforts for the stated purpose of sending people to China for these treatments are using without authority the Huntington's Disease Society of America's name, logo, and logos of HDSA fundraising programs.

HDSA has had no prior knowledge of and does not endorse or support these fundraising efforts. The Society is actively pursuing the removal of our name and logos from these sites and will do so with any other website or other unauthorized usage found.

HDSA goes to great efforts to support and report all legitimate research and therapeutic programs of potential benefit to the Huntington's Disease Community. We take our mission seriously. We believe that all information we provide is accurate and reliable."

(Source: Huntington's Disease Society of America)

### Sydney West Area Health Service - Huntington Disease Outreach Service

#### Workshop for Health Professionals – Huntington's Disease – Sharing the Caring

Wednesday August 27, 2008 8.30am – 3.45pm at Lottie Stewart Hospital, 40 Stewart Street Dundas.

Enquiries: Angela Lownie, CNC

Phone: 9804 5863 Fax: 9804 5858 Email: [angela\\_lownie@wsahs.nsw.gov.au](mailto:angela_lownie@wsahs.nsw.gov.au)

Cost: \$35.00 must be paid with application.

This day is for all professionals working with people affected by Huntington Disease.

It has been designed to assist participants to achieve the following goals:

- Increasing skills in assessing for HD care needs
- Increasing ability/confidence in making HD referrals
- Increasing ability/confidence in implementing appropriate strategies for those with HD

The program includes presentations as well as smaller interactive workshops.

Handouts will reinforce the information. Each participant will be assigned to 3 workshops based on their stated preferences.

Morning and afternoon tea and a light lunch will be provided.

# Powers of Attorney

## Powers of Attorney - Financial Management

by Ruth Pollard, principal legal officer, Public Trustee NSW

### What is a power of attorney?

It is a legal document which allows you to appoint another person called the attorney to take care of your financial, property and legal affairs. This covers things like banking, paying bills, buying and selling property, signing documents and undertaking legal proceedings.

There are two main types: a general power of attorney and an enduring power of attorney. The main difference between them is that the general one ceases to operate if you lose mental capacity but it is handy for short term work such as if you are travelling overseas and need someone to handle your finances.

An enduring power of attorney operates even after you suffer loss of mental capacity. An enduring power of attorney is a safeguard - it is a godsend if you become frail or lose your mental capacity. your attorney takes the burden of handling your financial affairs.

Both general and enduring powers of attorney cease to operate when you die.

### How does it help?

If you give specific directions in your power of attorney your attorney will be empowered to use your assets for the benefit of the person you care for. Your funds can be accessed to pay for their food, accommodation, education, transport and medical treatment. Any payments made must be reasonable and take into account the amount of your funds and balance this against your needs. While the law restricts your attorney to using your funds for these items only it does provide a means of support for the major needs in life of your dependant.

It is important to discuss these specific directions in your power of attorney form with your legal advisor.

### Who do you appoint as attorney?

you may wish to make a power of attorney appointing your spouse or partner, but it is wise to also appoint substitute attorneys should they die or become incapacitated. You may choose another family member or appoint an independent attorney such as the Public Trustee NSW or a trustee company.

If you do not make a power of attorney and management of your affairs is required it may be necessary for an application to be made to the Guardianship Tribunal or Supreme Court to appoint either a private financial manager or the Protective Commissioner to manage your affairs. It is very important to appoint an attorney who is trustworthy, financially savvy and who understands your needs and those of your dependant. Your attorney has a duty to act in your best interests and must avoid any conflict between your interests and their own. Your solicitor, Public Trustee NSW, a private trustee company, and Registrars of the Local Courts are all able to help you prepare a power of attorney that suits your particular circumstances.

### Further information

If you would like further information or to make an appointment with Public Trustee NSW please call 1300 364 103 or visit [www.pt.nsw.gov.au](http://www.pt.nsw.gov.au).

# Carer News

## A Message from Judy Fullston

My name is Judy Fullston and I am the recently appointed Family Support Officer. I work very closely with Maria, the Carer Support Coordinator. I enjoy working with people, providing them with support, advocacy and information so that they can make an informed decision and choose an option which satisfies their individual need/s in a way that assists to fulfil their potential.

I have worked in the Community Welfare area for over twenty years. I co-ordinated a Dementia Program throughout Far North Queensland for seven years before moving to NSW in 2006. Prior to this I was working for the Queensland Department of Health as well as working 12 hours a week as the Welfare Officer for the Australian Huntington's Disease Assoc. (Qld) Inc.

Throughout my working career I have gained a wealth of knowledge, experience and skills. Other fields in which I have worked are as a Correctional Counsellor; a Community Development role in the drug and alcohol field as well as in Aged Care and Mental Health fields.

The Family and Carer Support program is here to assist and support you but you need to inform us of your needs, your likes and dislikes. What types of programs would assist you? Is it education? Is it recreational? If so, what type? What about quality time out? Are you having your breaks. Those of you who assist in providing care are not expected to do it alone without some type of support. We are here to assist you in meeting your needs as well as those of your loved ones. The only way we can continuously improve our services is through you identifying your needs and feeding this back to us.

It is that time of the year when we begin planning for the next financial year. So put your creative hat on and send us some suggestions. We need to be aware of what families require from the Family & Carer Support program. I wait in anticipation for your written comments.

Cheers for now,

Judy

## Resources for Carers

The Carers Australia website includes links to several information sheets on topics of interest to carers such as:

- Taking care of yourself
- Services for you
- Safety at home
- Managing health care and medications
- Legal arrangements
- Managing money
- Loss and Grief
- Palliative care and emergency care plan
- Caring for and supporting your parent or partner as they age



Visit the 'Information & Resources' ' at <http://www.carersaustralia.com.au> for details.

# Carer News

## Future Carer Support Groups?

The Association would like to start planning for regular Carer Support groups in both Sydney and regional areas. In order to do this we need to know if you want to participate in such a group? Some questions for you to answer before you pick up the phone to enquire further:

- Do you sometimes feel alone or isolated?
- Do you sometimes feel no one understands what you are going through?
- Would you like to meet other carers looking after people with Huntington's?
- Would you feel comfortable discussing your issues/concerns with another carer who can really identify what you are going through?
- Would you like to go out for lunch; learn a new activity; explore opportunities you only think about?
- Do you just need some quality time out?
- If you live outside the Sydney metropolitan area and not in a regional city, what is the most accessible city or large town from where you live?
- If you are geographically or otherwise isolated, would you be interested in a telephone link up with a support group?

I wait in anticipation to hear from you. So please don't hesitate to contact me either by phone or email. Remember we are here for you.

Judy Fullston

Carer Support Officer

Phone: 02 9874 9777 or Freecall 1800 244 735 (regional NSW only)

Email: [judy@ahdansw.asn.au](mailto:judy@ahdansw.asn.au)



# Carer News

## Better Support for Carers

You may be aware that the new Commonwealth Government is conducting an inquiry to determine how to better meet the needs of Carers who care for those with chronic illness, disability and frailty.

Unfortunately, this newsletter will reach you after the closing date for submissions. However why not take the opportunity to contact your own Federal and State parliamentary representatives and make them aware of your perspective on what carers need.

The Committee is seeking a better understanding of the situation for Carers in Australia. Use any or all of the following starting points to help you write your letter:

- I feel that my role is ....
- I contribute to Australian society by ...
- I face the following problems ...
- I can't fully participate in social life because ...
- I am financially struggling because of ...
- I would like to work (full-time or part-time) but have the following issues to deal with ...
- I worry about my future because ...
- The things that stress me the most about being a carer are ...

Remember that it will help the Committee to understand your point if you can support it with examples from your own experience.

The Committee would also like to hear of any ideas, solutions or strategies that will support you in providing care. Use any or all of the following suggestions for getting started:

- I need help with *[insert problem or issue here]* and think that *[insert idea]* would be the best solution for me.
- I need to have *[insert a practical help or support here]* and this would help me because it would enable me to ...
- I think the Government can better help carers by ...

Remember that it will help the Committee to understand your idea if you can support it with reasons that it will work or examples of things it will help you to achieve.

## Gateway

'Gateway' is the newsletter of the Australian Huntington's Disease Association (NSW) Inc.

### 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.

### Committee 07/08

President: Mark Bevan  
 Vice President: Anne Low  
 Secretary: Keith Dingeldei  
 Treasurer: Richard Bobbitt  
 Members: Jim Finn  
 Elaine Sammut  
 Ian White

## Australian Huntington's Disease Association (NSW) Inc

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 STD Free Call: 1800 244 735 (Country NSW only)  
 Web Site: [www.ahdansw.asn.au](http://www.ahdansw.asn.au)

### Association and Other Useful Contacts

**Walid Nassar**  
 Executive Officer

**Sharnie Mineeff**  
 Administration Officer

**Maria Mackell**  
 Family and Carer Support  
 Coordinator

**Judy Fullston**  
 Family and Carer Support Officer

**Lily Ma**  
 Administration and Activities  
 Assistant

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

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

**Outreach Service**  
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 Social Worker,  
 Westmead Hospital  
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**Vacant**  
 Social Worker,  
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**Angela Lownie**  
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**Joan Stewart**  
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**Nursing Staff**  
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**Predictive Testing**  
**Fiona Richards**  
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**Hunter HD Service**  
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 Hunter Genetics,  
 (02) 4985 3100