
GATEWAY

Volume 10 No 1

Australian Huntington's Disease Association (NSW) Inc

Summer/Autumn 2007

The End of an Era

Executive Officer, Robyn Kapp, announced her retirement at the end of last year, after 28 years of involvement with the Association. She forwarded this farewell message to members and colleagues.



Dear Friends

As many of you are aware, I was on long service leave and annual leave from my position as the Executive Officer for 2006. During that time I was studying at Moore Theological College in Sydney, undertaking a one-year diploma course.

It was my original intention to return to the Association in early December 2006. However after much deliberation and prayer I have decided to retire and, therefore, to resign my position with the Association. I do believe the Association is in very good hands and I am sure it will benefit enormously from an injection of new ideas, and a fresh enthusiasm and passion.

Over the past twenty-eight years, many people here in Sydney and NSW, around Australia and throughout the world have been very supportive of me and have encouraged me enormously in my work with the Association. There are far too many to name individually however I am particularly indebted to the various management committees of the NSW Association for their trust and commitment; our dedicated and enthusiastic staff; friends and colleagues from all state and international HD Associations; the researchers who are so passionate about finding an effective treatment and cure; and the health professionals who are committed to the care of families affected by HD. I extend a very special note of thanks to all our HD families for their inspiration – their strength and resilience in dealing with HD never ceases to amaze me. It humbles me to know so many wonderful people and it has been an honour and a privilege to work with and to serve you all.

I am also very grateful to my family – my daughter, Jenny; my mother Essie Swales; my brother Stewart and members of my extended family for their love, support and encouragement. Finally I would like to acknowledge my dear friend and colleague, Fiona Richards, who has been a wonderful, faithful mentor for over two and a half decades.

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From the Executive Officer

Elsewhere in this issue we announce the retirement of our long-serving Executive Officer, Robyn Kapp, as well as the resignation of Chris Dixon, our rural outreach nurse for NSW. By the time you read this the Association should have a new Executive Officer so this will probably be the last time I write as editor.

Since April last year we have been making representations to the Minister for Health seeking to have the Huntington Disease Service, and particularly its Outreach component, funded to a level that enables it to deliver services equally throughout the state. So far, we have achieved nothing beyond accumulating a file of letters.

With the state election not far off, there is an opportunity for you to make contact with the candidates in your state electorate asking for justice for country families struggling with the impact of Huntington's Disease on their lives.

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The End of an Era cont.

And what am I going to do in my retirement? Well, I have enjoyed my one-year at college so much that I have transferred to the three-year degree course in theology (B.Th) which means another two years of study. As a Christian, I do have a strong desire to learn more about God and the Bible and a passion to tell others about the good news of Jesus.

My best wishes to you all for the future – you can be assured of my continual prayer that a treatment or cure for HD will be found in the not too distant future.

Love and friendship,

Robyn Kapp

From The Executive Officer cont.

Here are a few points you can make:

- NSW Health acknowledges equity of access to health services as a fundamental principle;
- The NSW Huntington Disease Service is a best-practice, comprehensive service for the support of people with Huntington's Disease;
- In terms of NSW Health's equity policy, the Service should be available to clients wherever they live in NSW;
- The Service is currently focused on providing services in the Greater Sydney area so those in country NSW miss out;
- NSW Health's policy obligates it address this inequity but it shows no inclination to do so;
- The costs of extending the Huntington Disease Service with the capability to deliver an Outreach component outside the Greater Sydney area are likely to be modest, comprising mainly additional labour and travelling costs.

In Friendship,

Robert Curran



Welcome Alex!



**Social work student
Alex Vanegas**

"My name is Alexandria Vanegas, I am a third year Social Work and Arts Student at the University of NSW. I am currently undertaking a placement with the Australian Huntington's Disease Association (NSW). Through this work experience, I would like to gain more knowledge and awareness about the difficulties that families, carers and people with Huntington's Disease experience, especially when they attempt to access health or other services.

I am also interested in the diversity of strengths of people with Huntington's Disease, as well as their carers and families. I will be working with AHDA staff and some of our partners from February to June. I hope to meet some you during this time."

Farewell to Robyn Kapp

Senior HD Social Worker, Fiona Richards, pays tribute to her long-time friend and colleague, Robyn Kapp.

"It is with very mixed feelings that I write this farewell and tribute to Robyn Kapp, whom I have known since commencing work at Lidcombe Hospital in 1981. I have already greatly missed Robyn's presence at the NSW HD Association, and will continue to miss her, but I realise that for everyone there comes a time to move on. Robyn has recognised that it was time for her to take on new experiences and challenges in her life, and I fully support her decision.

My relationship with Robyn has been a special friendship arising from our mutual interest in and commitment to supporting families affected by Huntington disease. Over the years Robyn and I communicated often about aspects of our work, with a particular focus on how to improve services for HD families in NSW. I believe that all the Association's achievements over the past 30 years were largely due to Robyn's skills and persistence in dealing with the appropriate people and agencies on behalf of HD families, beginning with Dr Carter, CEO of Lidcombe Hospital where the HD clinic and residential facility were established in the 1980s. I feel privileged to have participated in these achievements, and to have shared with Robyn the excitement of other highlights such as the discovery of the first chromosome 4 marker for HD in 1983, and the identification of the HD mutation in 1993 (although we can't claim credit for these!!).

Robyn's compassion and respect for people with HD and their families, combined with her wisdom and common sense, were always evident in her work with the HD Association. Her sense of humour, particularly in her interactions with those with HD, is undoubtedly one of her great strengths. I also greatly admired her organisational skills and her ability to communicate effectively with both families and professionals. These skills were unmistakable in Toronto in 2003 when the inaugural World Congress on HD was cancelled due to a widespread blackout in NE Canada and USA! As 100 or so delegates had already arrived in Toronto, Robyn single-handedly took on the task of organising a new program, with those who had brought posters scheduled to present these orally, together with those who had prepared a talk agreeing to present without audiovisual assistance! It was a complex and challenging task but Robyn accomplished it, in 24 hours, with great professionalism and good humour and the Congress went ahead, much to the satisfaction of those present.

Over the years, through attending international HD meetings, I have witnessed Robyn's genuine communication on all levels with both professionals and members of HD families world wide, and the profound warmth and respect with which she is regarded by all. This, of course, also applies here in Australia. I know her involvement will be greatly missed in both the international and national arenas, and especially here in NSW.

It was through my contact with Robyn and others involved in the HD Association that I learned, early in my career, the value of health professionals working closely with the family support/advocacy group for conditions such as HD. Apart from being the best way to learn about the illness and its impact on individuals and families, this contact is a constant reminder for professionals not to lose their focus on the experiences of those for whom the Associations and HD services exist.

I wish Robyn happiness and fulfillment in her future endeavours, and I look forward to celebrating with her the advances in treatment for HD which we all hope will be achieved as soon as possible."

Huntington Happenings

Young People in Nursing Homes Urgent Update

We expect that the NSW Department of Ageing, Disability and Home Care (DADHC) will be calling for applications for assistance under their new program shortly. The program is called *Younger People in Residential Aged Care (YPIRAC)*. The equivalent Department in the ACT will also be calling for applications shortly.

If you have a family member under the age of 65 either in a nursing home (residential aged care facility) or who has been approved for entry to a nursing home or hostel by an Aged Care Assessment Team (ACAT) they are eligible to apply, although initially priority will be given to those under the age of 50.

DADHC will be writing to eligible people under the age of 50 currently living in a nursing home or hospital and inviting them to apply. Others will have to obtain the application form and lodge their own application. Eligible people will need assistance from family, guardian or an advocate to complete the application form.

Assistance envisaged includes:

- Support services to enable the person to remain in their own home;
- Moving to a group home or nursing facility specifically for younger people; and
- For those who elect to remain in an aged care facility, additional support services.

If you have a family member in the above-mentioned categories **please register with us now** and we will provide you with information about the application process as soon as it is released. Just write, telephone or email and provide your name, mailing address, email address and state of residence of the family member. Please be aware that, as with all such programs, funds are limited and there are no guarantees that an application will lead to assistance being given.

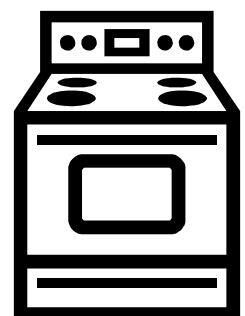
Do You Need a Stove?

The Association is disposing of a Roden "Two O Nine" electric stove formerly used for cooking for the lunch clubs. It includes a combined griller/hotplates and oven. This model of stove can be connected to a normal domestic power outlet and does not have to be "hard-wired".

The stove is being offered free of charge to a person with Huntington's Disease. If interested, please contact Robert at the Association.

The successful applicant will need to arrange removal of the stove from the Association's office at West Ryde.

Although we believe the stove to be fully serviceable, it does not come with a current electrical "safety tag" and the successful applicant will need to make their own arrangements in that regard.



Huntington Happenings

Farewell Chris Dixon



Chris Dixon, the Association's part-time Rural Outreach Nurse for southern NSW and the ACT has resigned, with effect from mid- January 2007.

Chris, who took up her position at the beginning of November 2001, came with a background in oncology, palliative care (as a clinical nurse consultant at the Royal North Shore Hospital) and Huntington's Disease.

During her time with us, Chris established a model of rural outreach based on a combination of visits and telephone support as the need dictated. Working closely with the NSW Huntington Disease Service, Chris's aim was always to produce sustainable support by linking the client to services available within their local community. To this end, "making the links" and providing in-service training to accommodation and other care providers was an important part of her work. This model has proved both effective and economical – the latter an important consideration given that the Association has no grant funding for the position.

Chris also enjoyed assisting with the holiday camps for people with Huntington's Disease where her special abilities in fields artistic added to the richness of the camp experience. She has also provided a special level of support to a client with juvenile Huntington's Disease.

Chris endeared herself to clients, their families and her work colleagues, for her expertise, professionalism, compassion and energy. In regard to the latter, Chris regularly travelled long (and lonely) distances in the course of her work, clocking up some 13,000 kilometres of driving last year.

We salute you, Chris, for your wonderful contribution to our country families over the past five years, and wish you every happiness hereafter!

Although we are saying farewell to Chris as Rural Outreach Nurse, we are hopeful that she will still be available from time to time when the Association needs her expertise for special projects.

Arrangements for Chris's replacement will be announced at a later date.

Community Chest Raffle Tickets 2007

Tickets for the 2007 Rotary Community Chest raffle are now available to sell to your friends, colleagues or family members. Simply fill in the ticket order form enclosed with this newsletter and you or a friend could win a new car or jewellery.

Tickets cost \$2.00 each and the Association receives \$1.60 for every ticket sold.

Community Chest is an annual Rotary project, helping community groups like AHDA (NSW) to raise funds for themselves.



Research Reports

Does Environmental Enrichment Have A Future As A HD treatment?

By our volunteer science writer, Alana Shepherd

The manifestation of the Huntington's Disease (HD) gene mutation occurs primarily in the cortical and striatal regions of the brain, interrupting the transmission of both cognitive and motor information from the cortex. The late stages of the disease are characterised by cortical and striatal degradation, however the early symptoms are more likely to be attributed to neuron (nerve cell) dysfunction rather than death.

A number of potential targets for disease treatment in humans have been identified for further study through the use of mouse models. R6 transgenic HD mice provide one of the most clinically accurate animal models for the disease: essentially they develop similar symptoms at a correspondingly progressive rate. (1, 5, 6.)

One theory that has been gaining a great deal of support is the idea of environmental enrichment for the treatment of both motor and cognitive HD symptoms. Environmental enrichment is essentially the use of sensory, cognitive and motor stimuli to actively engage the parts of the brain affected by HD. In mice, sensory stimulation includes visual, auditory and olfactory stimuli while cognitive stimulation relates to spatial maps and object recognition. Motor stimuli include both fine and gross motor skills (4). The findings indicated by environmental enrichment studies have many potential applications in clinical therapy.

Manipulation of the environment can be used to identify cause-and-effect relationships between factors influencing the onset and progression of the disease, contributing to the growing list of potential therapeutic targets for treatment.

Tested in mice, environmental enrichment has been shown to relieve symptoms such as motor deficits; loss of spatial memory; reduced cortical volume; and decreased neurogenesis: in the bigger picture, working to delay the overall onset and progression of HD (1-6).

A noteworthy area of potential is that of 'enviromimetics': the idea that drugs can be administered to emulate the effects of environmental stimulation.

Evidence supports one such drug, fluoxetine, a selective serotonin reuptake inhibitor (SRI) currently used as an antidepressant. Several of the psychiatric symptoms of HD have been linked to the hippocampus, in particular the dentate gyrus, as HD mice show decreased cell proliferation in this area. Both environmental enrichment and fluoxetine have been shown to increase neurogenesis (neuron growth) in the dentate gyrus, thus improving cognitive function, behavioural symptoms and psychiatric symptoms, particularly depression, in mice (1).

Before any conclusions can be made with respect to potential therapeutic benefit for humans, a great deal more study is needed with mouse models to answer the multitude of questions that has arisen from the current studies. It is clear that, in mice, provision of a complex environment provides the optimal conditions for delaying onset and slowing disease progression. However, exactly how the environment elicits changes to molecular disease mechanisms is still largely a mystery, the resolution of which will provide both understanding into HD pathogenesis as well as potential targets for treatment.

The standardisation of the complex environment also needs to be addressed. Although many studies have examined the effect of stimulating surroundings, there is limited consistency between these studies. Lack of standardisation means most studies have differed in the components of an enriched (with stimulation) and a standard (unenriched comparison) environment, as well as having a great deal of variation in both the age and the duration of exposure. All studies have in common key aspects of an enriched environment (novelty and complexity with motor, sensory and cognitive components) however there is no consensus on which aspects of the environment provide maximum benefit. Moreover, the differential effect of age needs to be examined: whether exposure during development or after maturation exerts distinct degrees of effect (4).

Continued next page

Research Reports

Continued from Page 6 If the relevance for humans can be justified by

Furthermore, extensive research is needed to examine the individual effects of each component of the environment. Studies so far have indicated that the maximum benefit is to be obtained from application of a complex environment combining motor, sensory and cognitive stimulus. However, examination of each component individually could illustrate the discrete effects and the molecular mechanisms behind each.

further research, the use of environmental enrichment as a therapy for the treatment of HD could have enormous implications for both sufferers of the disease and their families and carers, not only in terms of life expectancy, but also for quality of life.

Many questions need to be answered before this practice has therapeutic viability, most significantly the issue of relevance to humans: does a demonstrated effect in mice validate human testing?

Although the studies into environmental enrichment have shown great promise, the benefit for humans with HD has not been conclusively supported. There is evidence to suggest HD is affected by environmental factors, including studies of monozygotic twins with HD where each twin has an identical CAG length but elicits different clinical symptoms and behavioural abilities. The absence of genetic difference clearly indicates an environmental role (2). There have also been studies involving small numbers of human HD patients that have demonstrated improved physical and cognitive functioning in a proportion of the patients (4), however larger scale trials are required before any therapy can be recommended as clinically beneficial. Environmental enrichment has already shown to be effective in preventing aspects of other neurodegenerative diseases (6), including Parkinson's disease and Alzheimer's disease.

Many questions need to be answered before this practice has therapeutic viability, most significantly the issue of relevance to humans: does a demonstrated effect in mice validate human testing? Although HD mice provide an anatomical model for the disease, there is enormous difference in natural environmental complexity between mice and humans (4).

References

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6. Spires, T.L., Grote, H.E., Varshney, N.K., Cordery, P.M., van Dellen, A., Blakemore, C. Hannan, A. (2004). *Environmental enrichment rescues protein deficits in a mouse model of Huntington's Disease, indicating a possible disease mechanism*. Journal of Neuroscience. 24(9): 2270-2276.

AHDA National Conference

Carer Support Co-ordinator, Maria Mackell, attended the AHDA National Conference on behalf of the NSW Association last November. Below is her conference report, including an overview of some of the keynote speakers.

The title of the AHDA National Conference, held in Melbourne, 15 – 17 November 2006 was 'Another Piece of the Puzzle'. This represents the ongoing, piece by piece search for knowledge, and the fitting together of the many different parts of the puzzle that is Huntington's Disease. **But the title cannot do justice, to the vibrant, varied and committed participation of the many players who attended this Conference.** It was a truly inspiring and interesting event, attended by people affected by HD, people working to find a cure, people devoted to supporting those for whom a cure will come too late, and those who support the HD Associations throughout Australia as members, volunteers and staff.

An example of this diversity came from NSW, with Fiona Richards, of the Predictive Testing Program at Westmead Hospital presenting a paper, members of the HDS Outreach team attending, staff from AHDA (NSW) attending and three of our long-term carers Elaine Sammut, Beth Smith and June Mitchell attending.

Dr Tony Hannan from the Howard Florey Institute was the first keynote speaker at the Conference. Beginning with a quick sketch of the history of HD research, he presented a very informative "Update on Transgenic Research" including the recent emphasis on the impact of environmental enrichment. Dr Hannan's presentation showed how various motor tests in mice could demonstrate changes in the expression of their genetic material. These changes were attributed to environmental enrichment factors such as physical and mental activity, and the use of anti-depressants. These forms of enrichment were shown to encourage neurogenesis in the adult hippocampus. This may delay the onset of memory problems caused by the disruption in communication of information.

This topic will be on the agenda for the one-day Satellite Seminar on Huntington's Disease, that will be part of the World Congress of Neuro Science to be held in Melbourne in July 2007.

"Becoming and Being Parents in Families Facing HD" was the topic of the address by Dr Claudia Downing from Cambridge University. Dr Downing covered results from research that looked at how the decision-making process was shaped by values formed in early life that affect identity and relationships. The decision-making involved in becoming a parent became much more complex, when the possibility for HD was mapped onto the process. Apart from negotiating the risks that are pre-determined (HD gene) and making choices (will I have children) the concerns about "risks for my children" and uncertainty about "sustaining a parenting role" as well as dealing with the options available (having a child normally, or using IVF).

Some of the key findings noted by Dr Downing included: reproductive goals vary, most people either have or intend to have a child, few use genetic testing or IVF, and the decision about additional children is different from the decision-making around the first child.

Dr Downing stated that "the concern of reproductive decision-making is about generating a story about responsibility". This story included decision-making, generating a model of responsibility, enacting responsibility, and refining parental responsibility. Apart from all the issues, and the lack of an ordered sequence, Dr Downing also added that with the responsibility story..." there is no one single script".

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Carer News

Legal Services for People with Huntington's Disease



The Association has come to an understanding with the legal firm DLA Phillips Fox regarding *pro bono* (i.e. free or at reduced cost) legal services for people with Huntington's Disease.

The National *Pro Bono* Director for DLA Phillips Fox has advised that they are "happy to assist people with Huntington's disease with any legal issues or matters that they may have under the firm's *pro bono* programme. If there are instances where DLA Phillips Fox is unable to assist due to lack of expertise or resources, DLA Phillips Fox will liaise with other firms doing *pro bono* work in an attempt to find a firm that can assist."

This service could apply, for example to problems such as discrimination in employment or access to services, refusal of insurance, breach of privacy or guardianship issues.

If you wish to use this service please contact the Association and we will provide you with a letter of introduction to DLA Phillips Fox.

Regional Carer Support Groups

Canberra and Southern NSW

On **Saturday 3 March 2007** family members and carers will get together for a lunch in Canberra. This is a great way to catch up with other families who are affected by HD and to share stories and experience in a relaxed and friendly environment.

The group plans to meet bi-monthly – on the first Saturday of the month at 12.00 midday. Dates for the year are: 3 March, 5 May, 7 July, 1 September, 3 November. Bring along some lunch, a drink and a hat.

Contact Felicity O'Neil for more information on (02) 6287 1552.

Newcastle and the Hunter Region

A morning tea or afternoon tea for family members and carers from around the Hunter area is held on the third Thursday of each month. Thanks go to the Hunter Genetics team for this opportunity for carers and family members to catch up, discuss some of the issues affecting their families and to share their advice with other HD families.

Contact John Conaghan on (02) 4985 3100 if you'd like to attend.

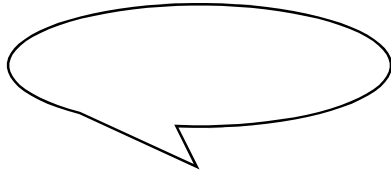
AHDA National Conference cont.

Other sessions on the first day of the conference included: "Managing Challenging Behaviors" (Dr Jane Paulsen) "Legal Aspects of Genetic Disorders" (Hall & Wilcox) and "Living Positively with the HD Gene" (Judy MacKenzie, Tony Mims, Eva Lynch). The second day included sessions on "Clinical Dilemmas Arising in the Predictive and HD Clinics" (Dr Dennis Velakoulis), "The Economic Impact of HD on Well-Being" (Candice Roberts), "Maturity of Judgement in Decision Making for Predictive Testing" (Fiona Richards) and "Maintaining Quality of Life: A person Centred Approach". Overseas presentations on the second day included "Juvenile Huntington's Disease and the work of the European Huntington's Disease Network by Helen Brewer of the UK and "Amaryllis House - Two years On" by Margaret Simmons of NZ.

A report on the Conference would not be complete without reference to the dynamic Victorian HD team who put the Conference together. Not only were the topics and speakers well chosen but the networking around events and the wonderful Gala Dinner spoke of hard work and a dedication to solving the puzzle of Huntington's Disease.

Carer News

City and Country Carers: Have Your Say About The Carer Support Project



An invitation is extended to all carers to meet the Carer Support Project Management Committee and to join them for a meal at their first meeting for 2007 in March.

The Carer Support Project Management Committee directs the work of the Project and to reports to the AHDA (NSW) Management Committee. They have an important role in terms of AHDA meeting your needs as carers as well as meeting the funding requirements for the Carer Support Grant from NSW Health.

The Committee members are:

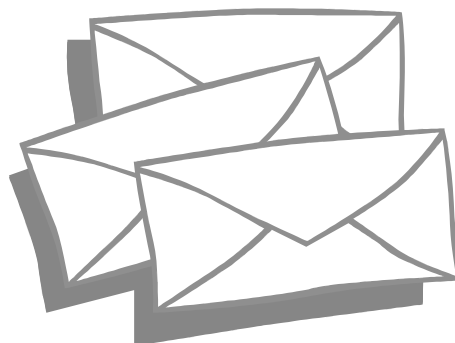
Ms Heather Armstrong – Carer Representative (country)
Dr Ian White – Carer Representative (city)
Ms Melanie Astridge – AHDA Committee Representative
Ms Josie Loche – Health Professional Representative

They meet quarterly to discuss how the Carer Support Program is going, and to suggest new activities or ideas. They would love to hear from any carer who wishes to be part of their team – either as a meeting visitor or even as an alternate member.

They want to ensure the Carer Support Project continues to meet the needs of all carers. They particularly want to hear from **country carers** so that your issues and ideas are included. The Committee is also looking at tele-conferencing, or having the meetings in different areas, if people wish to be involved, but can't travel to Sydney.

Country carers, you can also drop the Committee a line to share your thoughts. The address is:
The Management Committee, Carer Support Program, AHDA (NSW) Inc., PO Box 178, West Ryde NSW 1685.

Please ring Maria Mackell – Carer Support on 9874 9777 or STD Freecall 1800 244 735 to confirm the meeting venue and date.



Carer News

Carers – Are You MoneyMinded?

Attend MoneyMinded, a free, short, daytime workshop and find out how your money management skills measure up.

You'll discover how to:

- Increase your confidence in managing your money.
- Understand the financial risk.
- Understand the long-term benefits of saving.
- Apply a positive attitude to financial planning.

This special MoneyMinded Workshop is exclusively for AHDA Carers and will be presented by a Salvation Army Financial Literacy Adviser. AHDA (NSW) will provide morning tea and a light lunch.



The workshop runs from 10:00 am – 3:00 pm and covers:

- Goal setting strategies.
- How to prepare a personal Money Plan.
- How to calculate the true cost of credit.
- Your financial rights and options.

You will also receive:

- A Certificate of Participation upon completion.
- A free calculator.
- MoneyMinded satchel to store your savings plans.
- Support to help you apply the techniques.

If you are interested but live outside Sydney, please let us know and, we will organise something closer to where you live.

For more information, ring Maria Mackell (Carer Support) at AHDA on (02) 9874 9777 or STD Freecall 1800 244 735.

Planning Ahead: Do It Now

Come to a free 'Community Service and Accommodation Options Workshop' on Tuesday 13 March at Ryde Eastwood Leagues Club and increase your knowledge of the community support services available for carers. You'll also learn about accommodation bonds, respite, nursing home and hostel fees.

The workshop will be held at Ryde Eastwood Leagues Club, 117 Ryedale Road, West Ryde.

Guest speakers will be:

10:00 am - 12:00 noon TARS
(The Aged-care Rights Service)

1:00 pm - 3:00 pm Centrelink Financial Information Service Officer

You'll also be able to take a free bus tour to visit:

- a local respite care day centre.
- a local residential aged care facility.
- the Alzheimer's Australia NSW library.

To register your interest contact Natalie at Mercy Community Care on (02) 9479 3307.



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 06/07

President: Mark Bevan
 Vice President: Anne Low
 Secretary: Keith Dingeldei
 Treasurer: Melanie Astridge
 Members: Jim Finn
 Lynn Parker
 Richard Bobbit

Acting Executive Officer: Robert Curran

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 Acting Executive Officer

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 Coordinator, Carer Support

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 Administration Officer

Other Useful Contacts

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

Huntington's Lodge
Pauline Kelly
 Nursing Unit Manager,
 Lottie Stewart Hospital
 (02) 9804 5854
Nursing Staff
 (02) 9804 5803

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

Predictive Testing
Fiona Richards
 Social Worker,
 The Children's Hospital, Westmead
 (02) 9845 3273

Outreach Service
Suzie Docherty, Virginia
Munro and Roslyn Curran
 Social Workers,
 Westmead Hospital
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Hunter HD Service
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