

GATEWAY

Volume 10 No 2

Australian Huntington's Disease Association (NSW) Inc

Autumn/Winter 2007

Rural Outreach and Carer Support – the Future

You may be aware that Chris Dixon, our first (and only) rural outreach nurse, resigned last January and has not been replaced. At its May meeting the Association's committee decided that the Rural Outreach program would not be continued. Instead, the committee is aiming to implement a revised Carer Support program that contains a stronger focus on support to individual carers throughout NSW and the ACT.

Understanding this decision requires some background on the evolution of the Rural Outreach program, our current financial situation and the status of the Carer Support program.

The Rural Outreach Program

The program initially comprised a direct financial subsidy to the NSW Huntington Disease Service (HDS) to enable country travel by its staff. For operational reasons, this changed in 2001 whereby the Association employed Chris Dixon to deliver a rural outreach service. However Chris received most of her referrals from, and reported, in a professional sense, to the HDS.

Over the last year we made representations to the Minister for Health asking that the HDS be properly funded as a statewide health service. These representations have been to no effect, with the Minister stating:

"... the HDS will continue to be funded by SWAHS at current levels, and services will continue to be provided to people who live outside the Area boundaries..." (emphasis added)

The annual cost of the Rural Outreach program was about \$45,000, however this was only sufficient to service the southern half of NSW. We are currently holding \$23,000 that was raised specifically for services in northern NSW but this amount is less than 20% of what would be required to fund a 3-year program in the north of the state. As we did not have a dedicated funding source for the program it has since its inception been funded, along with some other activities, by deficit budgeting. In other words, as we did not receive sufficient income each year from charitable fundraising, the costs were met from reserves built up in earlier years or from windfall income such as bequests.

Continued on Page 2

From the President

I am pleased to announce that Jacqueline Bohm has been appointed as the Executive Officer, replacing Robyn Kapp, who retired at the end of 2006.

Jacqueline will be commencing on Monday the 2nd of July.

The committee and I look forward to working with Jacqueline to further the interests of Huntington's families throughout NSW and the ACT.

Inside this issue

- It's time to renew!
- HD Australia Internet Forum
- HDSA Convention Research Update
- Carers! Get gardening, manage your money and relax at the beach!

Continued from Page 1

Rural Outreach and Carer Support – the Future (cont.)

Unfortunately, we no longer have sufficient reserves to continue this – we have not had a bequest for general purposes since November 2003 and income from our telemarketing venture has declined by about 1/3 since 2002/03.

Our Financial Situation

At first glance, the Association's account might be read as showing significant financial reserves. This is true in an overall sense, however the majority of these reserves comprise money (currently about \$307,000) that has been bequeathed to us specifically for research and which cannot be used for service delivery.

If windfall income from bequests is ignored, we have operated at an annual average loss of about \$26,500 over the last 6 financial years (i.e. from 2000/01 onwards), not including this year which will also record a loss. (The Carer Support grant is not included in these calculations as it is held separately from other Association funds).

We therefore need to significantly improve our recurring income from fundraising and grants over the next 12 months if we are to continue operating at past levels. This will be a priority task for the committee and the new Executive Officer.

The Carer Support Program

This 3-year program was due to conclude at the end of 2007 although due to a delayed start there is just sufficient funding to carry it through to June 2008. In recent negotiations with NSW Health we received some assurance that we would be able to carry on to June 2008 as well as change the focus of the program based on experience to date. There will also likely be an opportunity to seek a 2-year extension to the program in the new year, that is until June 2010.

The Way Ahead

Over the last few years the percentage of the Association's funding that comes from tied grant funding has risen from about 20% to 36% and it is now the single biggest component of our income. Whilst this is welcome, it does mean that we have less discretion in how we use our funds. It is not an option to use our grant funding to subsidise the HDS.

The committee have therefore decided that an expanded and refocused Carer Support program offers the best opportunity for the Association to deliver support in regional areas of NSW and the ACT. Subject to approval by the Minister for Health of changes negotiated with NSW Health we will, and in consultation with stakeholders, including the HDS, be working over the next 12 months or so towards a carer support concept that:

- is funded partly by the NSW Health carers grant and partly by the Association;
- is clearly demarcated from and avoids overlap with the HDS;
- provides equivalent service to both northern and southern NSW and the ACT;
- works with both individual carers and groups of carers;
- involves at least 2 part-time workers working collaboratively but each with responsibility for a defined geographical territory.

Huntington Happenings



It's Membership Renewal Time!

Your membership of the Association is due for renewal on 1 July, unless you have pre-paid for the 2007/08 membership year. A membership renewal form is enclosed with the newsletter.

The membership fee was increased by members at the Annual General Meeting last year to \$22.00 including GST. This is the first increase, apart from an increase of \$1.00 when GST was introduced, since the Association was founded and is intended to ensure that the fee meets the costs of processing your membership and printing and mailing the newsletter.

It is important in lobbying and advocacy for the Association to have a membership that is representative as possible of Huntington's families and there is a "no fee" option for those who are on a pension or otherwise unable to pay the 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. This will help us identify the people we should be helping.

If there are multiple members in a household, there is a new option on the renewal form (in Section E) to indicate that only one copy of the newsletter and other circulars are required.

We have also given members the option (in Section D) of further identifying themselves in relation to their disease risk, stage or caring role. This is entirely optional, but will help us to target specific groups when advertising events or opportunities.

Planning the Transition from Hospital to Home



NSW Health recently promulgated a new standard titled *Discharge Planning: Responsive Standards (Revised May 2007)*. This includes, at annex D, a Patient Information Brochure titled *Planning for your transition from hospital to home*.

This brochure is a useful checklist of things to raise with hospital when the person you care for is close to being discharged. It will help you with the questions you need to ask of the GP and hospital staff before the person you care for is discharged from hospital. Please contact us

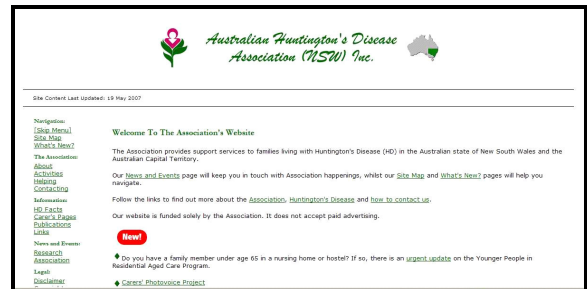
if you would like a copy.

Huntington Happenings

Have You Visited The Association's Website Recently?

The Association's website at www.ahdansw.asn.au provides the latest information about our activities for people with HD and their carers, as well as research updates factsheets and links to other relevant HD-related sites. You can also download a membership form from the site if you need one.

Best of all, the site has been endorsed by HonCode and linked to HealthInsite so you're always assured of finding high-quality, current and topical information about Huntington's Disease.



Holiday Camp

A holiday for 6 residents of the Huntington's Unit at Lottie Stewart Hospital was held at Camp Breakaway between the 23rd and 25th of May, with Karen Bevan again weaving her magic to bring laughter and fun to a very rewarding group of campers. You haven't lived until you've played 'Beat the Joker' with Karen and the crew! Our thanks to volunteers Alex Vanegas and Anne Barry for their assistance in bringing this to fruition; also to hospital nursing staff Alex and Monika for giving of their time to ensure that the camp could happen.



A helping hand at Camp Breakaway

HD Australia

An Internet Forum for all Australians affected by Huntington's Disease

An internet forum has been established for all families living with the realities of Huntington's Disease. Two young women, whose lives have been affected by this disease, have created this site for all families, relatives and friends affected by Huntington's Disease. It is a place to meet others, share experiences, ask questions and be able to share the valuable knowledge that families hold in regards to living with this disease.

The Internet forum will also be a way of accessing new research articles, providing links about Huntington's Disease and sharing up to date information.

All you need to do is go to the home page at www.hdaustralia.org ... go to the board navigation section and click on forum, register yourself in the registrations section and you are part of an online HD group!

You can read the personal stories of the two founders below.

Michelle's story

My name is Michelle and I am 28 years old.

I live in rural NSW. I am very excited to have been a part of creating this forum and hope it offers families a safe place to share their journeys with Huntington's Disease.

Huntington's Disease has always been a part of my family. My grandmother who had HD lived with us for a while when I was growing up and my mum cared for her. When my mum wasn't caring for her the realities of this disease were always in our home. My mum's pain of losing her mum and her aunty to HD, as well as her own fear of what this disease would bring into her future, was always present.

My mum is now 52 and has Huntington's Disease. She has lived in a nursing home for six years. My mum was diagnosed when I was 16 years old. In this same week I found out I was pregnant, so I can remember there where many tears shed that week...that was 12 years ago now and its been a very long and painful journey and one that I am still on. I have three brothers and myself who are at risk (two who are gene positive) and I have four children who are also at risk. We now face the reality that this could be our future.

My journey with HD has been a rather lonely one...losing my mum very slowly over the years has been heartbreaking and at times very devastating to my family. I have however learnt a lot along the way and in my search to connect with others facing similar issues I joined an online Internet forum www.hdac.org.

This forum is for all people effected by Huntington's Disease all over the world. They have become like my little extended family and I have learnt a lot through talking with others and hearing there stories. The strongest thing I have received from this group is a sense of connection. A connection over great sadness and loss...yet a powerful connection which has offered me a space to learn, share and build friendships. Hearing other people's stories and sharing in their journey relieved me from feeling alone and isolated...as I wasn't alone anymore.

When I met Renee on the forum we both had a passion to do something proactive for the HD community and we soon came up with an idea to establish an Internet Forum for Australians. We hope to offer others the chance to make these connections and provide a space where friendships and information can be shared.

"My journey with HD has been a rather lonely one...losing my mum very slowly over the years has been heartbreaking and at times very devastating to my family."

HD Australia (cont.)

Continued from Page 5

Renee's Story

My name is Renee, I am 27 years old and I live in Sydney. My journey with Huntington's Disease is just in its infancy with my step father diagnosed only 3 years ago. His diagnosis was the first we had heard of Huntington's Disease, let alone that it was in our family.

Since my father's diagnosis we haven't really known what to expect. We've seen many ups and downs and it's been an enormous learning curve for us all.

My mum cares for my dad, who is turning 50 next month. I have a brother and sister who are both at risk, but have decided not to be tested at this stage. I'm the only one in the family who isn't directly affected by HD; I'm not a carer or at risk of inheriting the disease so it's taken me a while to determine what role I would have in a family that has changed forever.

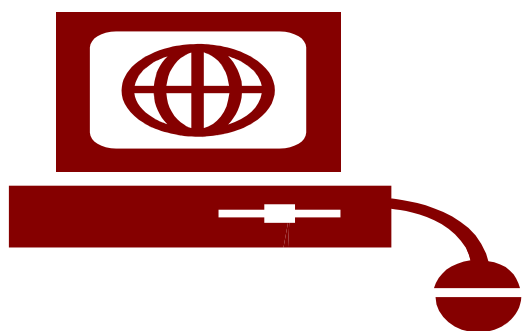
Recently I have felt like I have found my place. I see myself being able to provide emotional support for my mum and siblings. Although I can't always relate to the emotional strain of being a carer or having an at risk status, I can provide an objective point of view and a shoulder to cry on in the hard times ... and boy will there be hard times!

My next step was to go in search of as much information and resources as I could find that would help as my dad's disease progressed. The most helpful resource I found was the HD Advocacy Centre website (www.hdac.org). I believe the wealth of knowledge and support that people in similar situations can provide each other has been so helpful. Connecting with people, sharing experiences and stories has helped me to realise that there are other people out there in the community who are going through the same things and that we aren't alone ... even though we all feel like it sometimes.

Michelle and I decided that we wanted to localise this knowledge and support in Australia. It is something that we feel most passionate about.

It is my hope that we can help people recognise, as we did, that there are others out there going through similar experiences. We developed HD Australia to provide an online forum for people to find people who they can relate to, find a shoulder to lean on, to share the good and not so good times, and access relevant advice. We know that although doctors, nurses and specialists provide invaluable support, it is the stories and experiences of those affected by HD that can sometimes be the best resource of all.

Please join us at www.hdaustralia.org



Note: Whilst the Association is pleased to publicise this forum, you should be aware that it is not moderated by health professionals. This is not meant to discourage you from participating in the forum, but to alert you to take this into consideration when you assess the validity of health information or advice that you may encounter there.

Research News

Research Update from the 2007 HDSA Convention: Part One

Robert Pacifici, James Gusella, and other researchers report solid progress since last year.
Part One of Two.

Editor's Comment:

Attendees at the 2007 HDSA convention received some encouraging reports on progress on the research front. Dr. James Gusella (R) discussed the strategic plan for basic research, which is still needed since Huntington's Disease has yet to yield all of its secrets. Dr. Robert Pacifici (L) discussed progress on the strategic plan for developing treatments for the HD community. We also learned from Neurosearch that ACR 16 will be going into Phase III clinical trials at the end of the year, and from Avicena that creatine will be going into Phase III trials at the beginning of 2008.

Dr. Gusella gave a talk on "Clinical Trial Research: the Culmination of the Drug Development Pipeline" during the Saturday morning research forum. The goal of the research is to determine whether drugs or other interventions are safe and effective in treating Huntington's Disease. The FDA requires data which shows that a compound is both safe and effective before it will approve it for a specific medical condition.

Treating HD has different meanings depending on the stage of the disease and the purpose of the treatment. Potential treatment goals for the presymptomatic are to either 1) prevent the disease or 2) delay clinical onset. Treatment goals for the symptomatic are to 1) halt the disease process, 2) delay disease progression or 3) alleviate symptoms even if there is no delay in progression.

The shape of the HD protein hasn't been fully delineated yet but it seems to look something like a slinky. The extra CAG repeats cause problems with folding at the upper end. The mutant huntingtin's protein causes the debilitation of the cell and then cell death. At the time of clinical diagnosis, 30 percent of cells in the caudate nucleus are dead.

We can also think of treatments in regard to the cell. Treatments can be designed for the healthy cell, the sick cell, the dying cell, or after the cell has already died.

To begin to determine if a potential treatment is safe, the researchers need to conduct a Phase I trial. Typically this involves a small number of participants to determine whether the drug has obvious adverse effects.

Determining whether the potential treatment is effective in producing the desired clinical outcome requires first a Phase II and then a Phase III clinical trial. They involve increasing numbers of participants. The researchers must compare subjects who receive the potential treatment with subjects who do not (either historical or simultaneous data) for some pre-specified measure.

For the presymptomatic, the hope is to prevent or at least delay clinical onset of the disease. How can effectiveness be measured without waiting years and years? One possibility is to use biomarkers and another is to use brain imaging.

Continued on Page 8

Research News (cont.)

Continued from Page 7

For treatments which do not prevent the disease but rather delay it, age of onset can also be used as a measure of effectiveness.

For treatments during the symptomatic phase which halt or delay disease progression, measures of progression can be used. For treatments that alleviate symptoms, the symptoms themselves need to be measured.

"Dr. Gusella urged everyone to sign up for COHORT. This is an observational study being conducted in North America and Australia."

Studies such as Predict-HD and COHORT are very important for the development of treatments for the presymptomatic since they will identify and validate biomarkers which appear before onset and delineate the rate of change in both biomarkers and the brain as onset approaches.

Dr. Gusella urged everyone to sign up for COHORT. This is an observational study being conducted in North America and Australia. Participants include adults and children with clinically diagnosed HD as well as HD family members, including those at risk and spouses of people with the disease. The study requires one visit each year which will involve a clinical assessment, family history, research genotyping, and the collection of biological samples. So far 683 people have enrolled and the goal is unlimited.

A list of the 40 participating sites can be found on the Huntington Study Group website:
<http://www.huntington-study-group.org/COHORTSites.htm>

Dr. Gusella also spoke about the Coalition for the Cure. The fundamental goals of the coalition are to "1) discover the biochemical differences that occur in HD." and "2) to define which ones are critical in the disease process." These will be the targets for CHDI's translational research.

Team two is looking at folding, aggregation, and clearance of the HD protein.

Team three is looking at huntingtin proteolysis and postranslational modification.

Team four is looking at transcription.

Team five is looking at the function of the huntingtin's protein.

Dr. Gusella told the audience that The Coalition for the Cure is "closely aligned with CHDI to order to capitalize quickly on the basic research findings."

Our thanks to the HdLighthouse, the source of this article (<http://www.hdlighthouse.org/>)

Carer News

Carers! Here's your chance to relax at the beach — for free!



Join other carers and HD family members for a short holiday at Aquila Beach House for Carers in Hawks Nest between Monday, 27th of August and Friday, 31st of August, 2007.

Aquila is a family-owned holiday house that has been made available for carers to have a relaxed, affordable holiday where they can enjoy some time alone, rest and recharge their batteries or join other carers for relaxing, social activities.

The house is located at Hawks Nest, about an hour's drive north of Newcastle. Situated just off the Myall River, the house is an easy stroll to Jimmy's Beach. It is also close to bush walks and a short drive to the Myall Lakes or a ferry ride to Nelson Bay. Hawks Nest and the neighbouring Tea Gardens include a range of cafes, restaurants and shops. The house is fully equipped and sleeps up to 8 people.

The house is easily accessible by sealed roads but wheelchair access is limited and the house is on two levels. AHDA (NSW) will cover costs of the holiday. (The Carer Support Program is supported by NSW Health Statewide Carers Grant.)

Places are limited, so please contact, Maria Mackell, as soon as possible, on 9874 9777 or regional NSW freecall 1800 244 735, if you'd like to join us. (We can also help you to organise respite care for the person you care for, if necessary.)

Money, Money Money



How 'money-minded' are you? Do you want to manage your money better?

The Salvation Army's 'Money-Minded' team run a financial literacy program that can be aimed at the specific needs of a group of people, for example, carers or family members of someone with a chronic illness. It's provided free of charge and can be held over either one or two days.

Each participant receives a calculator and a manual on financial matters. These meetings can be held in regional areas as well as city areas and the Association will provide lunch and refreshments at each workshop.

I recently attended a 'trial' two day workshop and found that it covered a whole lot of financial issues common to carers, families and anyone battling the daily inflow and outflow of money!

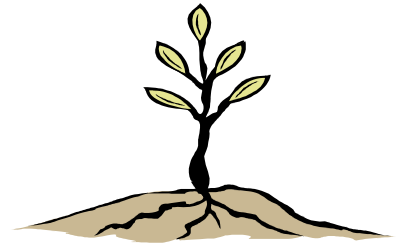
To find out more information about when and where the workshops will be held, please contact Carer Support Coordinator, Maria Mackell, on 9874 9777 or freecall 1800 244 735 from regional NSW.

Carer News

What is that growing over there?

Look! A new small green shoot has appeared...

We have recently held our first Carers Gardening Club meeting. Several carers and the Carer Support Worker attended a special Horticultural Therapy Workshop to get a sense of planning gardens and gardening activities. The emphasis was on activities and equipment that make gardening fun and easy and making gardens suitable for people who are frail, aging, or who have a disability.



How does our garden grow?

The idea is to start small, perhaps work on one garden and then, move onto another one. Perhaps carers would prefer to work on each others' gardens, getting those jobs done that need more than one person's green fingers to finish. (Dare we suggest having a nice lunch together when the garden is all done?)

What do we need?

You! Perhaps you have gardening skills that are not fully appreciated, spare plants and tools, a bucket full of ideas or a garden that's looking for some tender, loving care.

We plan to have our gardens growing beautifully for Carers Week in October, so we need to start now! We're also dreaming up other activities like perhaps designing a cottage garden at Elsie Court Cottage for families, clients and carers to enjoy.

Please register your name, your area of interest, or tell us how you'd like to be involved by calling Carer Support Coordinator, Maria Mackell on 9874 9777.

Congratulations!



The Carers Photo Voice Exhibition Lucky Draw winners are:

Marie Osterberg of North Curl Curl (metropolitan winner) and Ken Turnbull of Dondingalong near Coffs Harbour (regional winner).

Marie and Ken have each won a \$30 book voucher. Prizes are donated by gleebooks at 49 Glebe Point Rd, Glebe.

The Carers' Photo Voice Exhibition: Making the Invisible World of Carers Visible

The Carers Photo Voice Exhibition is a most unusual photo exhibition. It is the work of six carers of people with Huntington's Disease, who decided to make the invisible world of caring, more visible to others.

The carers set out to photograph things or issues within their everyday life. To safeguard the privacy of the person they cared for, and the privacy of other family members, it was agreed by the group that the photos would not include people. The **photos** show issues that affect carers, with a special degree of detail not found in other ways of collecting information.

The words are the '**voices**' offered by the photographer to explain how or why a photo expresses some aspect of their every day life. Words accompany the photos as equal partners, but are used in different ways, shown either with the photos or separately. The exhibition is a resource for working with carers in several ways to:

Highlight carers' individual experiences. The process can help through identifying and expressing issues, ideas and positive and negative aspects of every day life.

Help carers share experiences with each other. We know carers really value and develop from the advice and support of other carers. We see this as a valuable a resource for our work with geographically or socially isolated carers, in group work or work with individual carers.

Raise awareness in the wider community about the quality of life for carers. Words can be presented with the photographs. In this way, they directly share incredible detail of the carer's experience with others who want or need to know. Or they may be kept separate, allowing for many different reactions to the world of a carer.

The exhibition is now 'on tour' and it may be coming to a town near you!

Quite a few members in regional areas expressed a wish to see the exhibition, but were unable to come to the launch and exhibition in Sydney. In May, we took the exhibition with us on our regional visits to Newcastle, Taree, Port Macquarie and Coffs Harbour. Over 40 people viewed the exhibition, and most filled in a 'comments' form, giving us a real sense of what people found useful or illuminating.

We're continuing to learn about the invisible world of caring through these photos and the words that accompany them and we plan to take them with us on our upcoming country visits. Please contact us if you would like to be advised of future times or venues where Photo Voice will be on display.

The exhibition is also on our website: www.ahdansw.asn.au.



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; carer support 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 Bobbitt

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