



# Gateway

News from Huntington's New South Wales

Volume 15 No 2

Autumn 2012

## Strategic Planning Day

On Saturday 26 May the Board and our Manager, Robyn Kapp, held a strategic planning day at West Ryde to think about, and plan for, the next couple of years. We were joined by Mark Bevan and had an outside facilitator to guide us through the day.

We focused our discussions on what it means to support and serve the HD community in NSW. We looked at the kinds of things we should be doing to complement the health system's services, and to advocate for more equitable access to services.

We have identified key issues that will direct our activities over the next two or three years; for example:

- We particularly recognise that, the further you are from the major metropolitan areas, the more difficult it is to access services.
- We want to help more people affected by HD overcome the isolation that can become part of daily living.
- We want to engage more younger people with Huntington's NSW so the Association retains a strong and representative voice on behalf of the HD community in the years ahead.

We are facing times when governments are trying to save money and charity funding is getting harder to attract. However, we are confident that, with your support, involvement and input we can continue to have a positive impact on the lives of members of the HD community across NSW.

*Brian Rumbold*  
Vice President



## Annual General Meeting

*The AGM of Huntington's NSW will be held on Saturday 27th October 2012 at 2pm at 21 Chatham Road, West Ryde*

## Camp Breakaway 2012

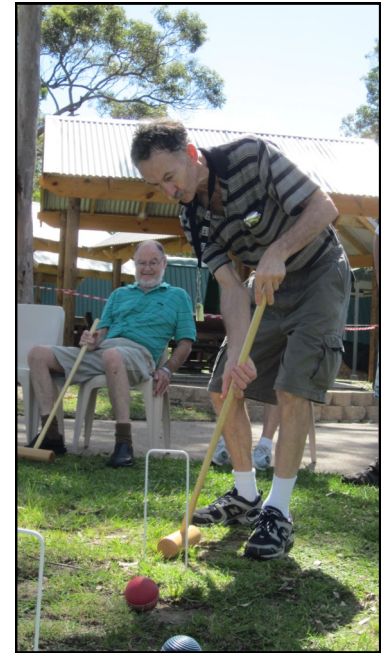
In March, I again had the privilege of attending a holiday camp at Camp Breakaway with eight delightful participants and one lovely carer.

We all had such a great time with lots of fun things to do which had been organised by the HD staff... a big thank you to each one who made our time away so memorable.

Our walk everyday by the lake in such picturesque surroundings was a highlight for all and with perfect weather - who could ask for more? For the record, there has never been a wet camp yet. We have been truly blessed.



Sharing meals together is another highlight and Robyn as usual cooked up a storm and kept us well fed and looking forward to each special meal. I don't know about anyone else but I always gain a few pounds while on camp – Thanks Robyn!



With great conversation and even greater company one could not help but have a great time. Craft was a big hit with each participant taking home some precious memories of their holiday which they had created, lots of talent displayed in their creativity – all gifted with a great eye for colour.

Who could forget the outdoor activities each day as everyone shared in lots of fun and laughter participating in games such as croquet, bowls, putt-putt and hooky?

Each night the competitive spirit was aroused with trivia, team games and of course the usual theme night for our last night. On this occasion, it was the Olympics, which of course brought out the winner in all of us, not sure who won - I think we were all winners at one game or another. I find it a privilege having the opportunity to spend a week with such delightful and special men and women who, even though affected by HD, have embraced life and are willing to share so much of themselves and their journey with others.



The friendships that are formed and the lessons they have taught me along the way make this time together invaluable and I would not want to miss this special time.

*Karen Bevan*

## It's time to renew your membership!!

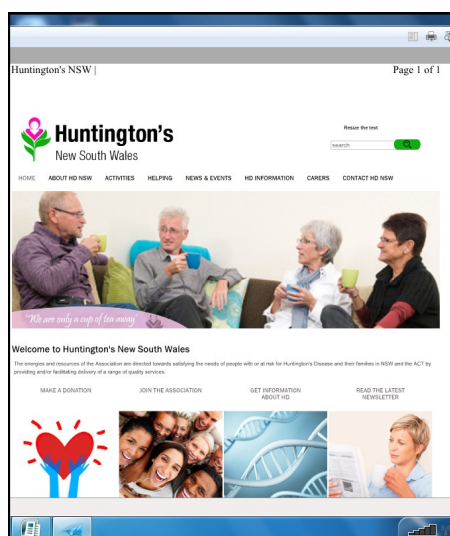
Yes it's that time of year again. Membership renewals for 2012/2013 are now due. For \$22 per year (including GST) you will continue to receive research news, practical advice and updates in *Gateway* and have unlimited access to new publications, special events and formal and informal support networks offered by the HD community.

A strong membership will ensure that the Association continues to be representative of, and relevant to, people affected by HD in NSW and Australia. So why not encourage another family member or friend to join?

A membership form is enclosed for you to complete and return with your cheque/money order/credit card details. Donations are always appreciated and are also tax deductible.



## We have a new website!!



Huntington's NSW has a new website which we hope you will find easy to access. We aim to keep it up-to-date with information about Huntington's Disease and the activities of the Association. Please take a moment to visit it and let us know what you think.

For the time being we will still have the same web address which is [www.ahdansw.asn.au](http://www.ahdansw.asn.au).

We are very grateful to Jason Turnbull, from DigiScape Productions, for so generously designing our website at no charge. Thank you Jason.

If you need a web site developed then do contact Jason and discuss your requirements with him.  
[enquiries@digiscape.com.au](mailto:enquiries@digiscape.com.au)

## Do you like this Newsletter?

Tell us what you do and don't like about this newsletter so we can keep on improving it.

You can call us at the Association offices or email Robyn on [robyn.kapp@ahdansw.asn.au](mailto:robyn.kapp@ahdansw.asn.au)



## Things that make you smile inside ....

After a year of extremely challenging events in my life, including at 51 being pre-menopausal, I was unable to cope with the day to day stuff, let alone Christmas. In late November I spoke to some lovely people in the Mental Health Area and decided to put myself into Katoomba Hospital's Mental Health Unit. Under the care of professionals who gave me access to doctors, counsellors and a social worker, the nursing staff gave me both the personal space just to be still, and sit in the sun, but also an ear when I did need to talk (non-judgemental). While I was in there, my "tics" as one doctor called them were quite pronounced, as they had been for that last year. I thought this is it I am on the slippery slide down to my doom.

Fast forward to March 2012, and I am gradually getting physically, emotionally and mentally stronger. I have written letters to *Gateway* before and mentioned the regular swimming I do to keep my muscles strong. Over the last few months I have been far more aware of what I eat and also how often. Having been an irregular eater all my life, I am now grazing regularly through the day. If I need to sleep through the day I do, as night sleep is still irregular.

What I also have been doing to help me keep myself strong is having my pink MP3 player in my bag all the time and if I feel a bit frazzled or need cheering up I put the earplugs in. I patiently went through all my CDs and my daughter helped to put them on my computer, then onto my MP3. I have also discovered iTunes cards, and I can buy all the daggy old music I used to listen to that still makes me happy.

Last but not least I strongly believe in something in the Universe (I do not call myself Christian), that IS there for me and I am learning to slow down and meditate. I have actually noticed (as have others) that the more disciplined I am at slowing down and meditating, my "tics" are less pronounced and I have just been taught by my daughter how to communicate on Facebook. So my 51 year old brain with HD is still capable of learning new information.

For a long time I have been dying inside and what I am trying to do now is put as much focus on what I can do. I can still drive, and I am having a ball "borrowing" my daughters little Getz and buzzing around the Blue Mountains where I live. I want to build a veggie garden in my backyard, and I discovered yesterday I can still throw the lawn mower around my backyard. I love music and my cats Serenity, Artemus and Rango.

This is an awful disease, but don't do what I did and let it be the complete focus of who you are. Instead, find things you are passionate about and things that make you smile inside, and fill your life with them.

*Janet Smith*

### Do you have a Story to Share?

If you have a contribution that you wish to make to the Newsletter please send it to us at the Association offices (see details on the back page) or by email to Robyn at [robyn.kapp@ahdansw.asn.au](mailto:robyn.kapp@ahdansw.asn.au)

## No Bitterness over Abercorn

Jim Stewart, who lost both legs in the IRA's bombing of the Abercorn Restaurant in Belfast in 1972, could be forgiven if he looked back with a burning sense of bitterness. He has also suffered a succession of heart attacks and is now a victim of the debilitating Huntington's Disease. But Jim, with a profound Christian faith and "a wonderful family that the Lord has bestowed upon me", feels only compassion and forgiveness, even though nobody has been brought to justice for the atrocity which killed two young women - Belfast friends Frances Owens, 22, and 21-year-old Janet Bereen - and injured 70 others.

Tomorrow marks the 40th anniversary of the explosion, which took place in the packed restaurant in the heart of Belfast at 4.30pm on Saturday, March 4, 1972. The coroner at the inquest of Ms Owens described the incident as "pathological murder of the most depraved kind".

With Huntington's having ravaged his thoughts and his ability to communicate, Jim has nothing but thankfulness for the way that wife Florrie has cared for him since that terrible act of barbarism, considered one of the worst of the Troubles. Florrie told the News Letter: "Jim was a sheet metal worker in Mackie's when the Abercorn was bombed. He remembers seeing a flash from the side of his eye and he was blown onto his back. He didn't feel the pain but he wondered why he couldn't get up."

With the stress of the horrific injuries Jim suffered, many a young woman would have ended the relationship – but Florrie felt that God had brought them together to journey through life. They originally lived in the Woodvale area of east Belfast, but they now live in a specially-adapted bungalow in Glengormley and are the parents of two sons and grandparents of four.

"Bitterness has never entered this home," said Florrie. "It destroys people and it destroys families."

Jim spent three months in the Royal Victoria Hospital and was then transferred to Musgrave. He had two artificial legs fitted, and returned to Mackie's two-and-a-half years after the blast. "The men at Mackie's couldn't have been better,"

Jim remembers. "They couldn't have done enough for me, and it was great to be back."

But life changed when he was made redundant in 1991, the first of his heart attacks shook him the following year and later he was struck down with Huntington's and is now confined to a wheelchair.

"With all his problems, he is wonderful to live with," said Florrie. "He remains cheerful and a delight to be with, and while he can't get to our church [Glengormley Baptist] very much these days, they are with us all the way, and that means a lot. We think of the girls who were killed and the many who were injured in the bombing. We pray for the bombers and know that God will deal with them in his own way. That's the right way."

One of the first reporters on the scene was Gloria Hunniford, now a famous TV and radio presenter and working with BBC Belfast at the time. "It was the first report I filed to England," she said yesterday from her home in Kent. "It was horrific. I recall seeing limbs and handbags and toys scattered all over the street, as well as the driving licence of one of the young women who was killed. It was burned at the corner. That scene has remained with me throughout the years."

*Acknowledgement: <http://www.newsletter.co.uk/lifestyle/features/no-bitterness-over-aberncorn-bombers-1-3588814>*



## Interview: CHDI's Scientific Team

HDBuzz interviews the top scientists from CHDI, the largest funder of Huntington's disease research in the world.

By Dr Ed Wild, Edited by Dr Jeff Carroll

*The 2012 Huntington's Disease Therapeutics Conference brought a hefty dose of news, excitement and optimism for people desperately waiting for effective treatments for HD. HDBuzz interviewed some of the leading scientific minds behind the Conference's organizer, CHDI Foundation, Inc.*

### What is CHDI?

It's a continuous source of surprise to us that many people from HD-affected families haven't heard of CHDI, considering they are, by a long way, the largest funder of Huntington's disease research around the world.

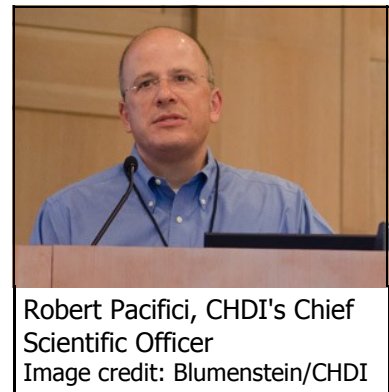
CHDI's structure and mission are highly unusual — not just within Huntington's disease, but in any area of research. In many ways, CHDI resembles a commercial drug company — it has a management structure, has a pipeline of 'targets' and employs drug-hunting scientists, many with experience in the pharmaceutical industry. Yet CHDI is a non-profit organization, funded entirely from donations, with no need to deliver a financial return to shareholders. CHDI's main motivation is time, not money. Uniquely, CHDI is committed entirely to developing treatments for one disease — Huntington's — and, equally unusually, has no physical laboratories of its own, instead driving HD research through collaborations with academic and commercial researchers.

### An exciting time for drugs

As our tweets and reports from the Conference show, there's a real feeling that 2012 will mark the beginning of a new era in Huntington's disease drug development. Several long-awaited human trials of gene silencing are being planned, and CHDI's parallel efforts to produce

new drugs specifically targeting different problems in HD have advanced dramatically.

We started by asking Robert Pacifici, CHDI's Chief Scientific Officer, what was different about these upcoming trials from what we've seen before. Three things make him optimistic, he replied. "The first is the number of shots on goal. We have a lot of things in the hopper that are at a very advanced stage. The second thing is diversity. If we were only focusing on one approach, I'd be really nervous, but we're not — there's diversity there."



Pacifici and his chemistry and biology leads, Celia Dominguez and Ignacio Muñoz-Sanjuan, are rightly proud of the drugs they've painstakingly designed and tested. One thing that distinguishes the next generation of experimental drugs is that they were designed specifically for Huntington's disease rather than re-tooled from other diseases — or as Dominguez puts it, "these molecules were hand-crafted for HD from the get-go."

The third change CHDI is aiming for goes to the very heart of what motivates researchers to run a clinical trial. "We've got things designed in a way that there's every chance of success — but if they fail", says Pacifici, "they're still informative. Everything is going to give a definitive result."

***"There's every chance of success - but if the trials fail, they're still informative. Everything is going to give a definitive result."***

That requires two fundamental adjustments to the way trials are run. First, there has to be exhaustive testing of the drug before it reaches a human trial, to make sure it does what it's supposed to. Second, the trial has to be designed in a way that allows the results to make sense, whether

positive or negative.

Given the financial and time cost of trials, says Pacifici, it's not enough to get a negative result and not know why. CHDI's trial designs use three layers of 'biomarkers' to track the effects of a drug from hitting its target to having a "meaningful biological effect" on the disease. "It's still possible, even with those three things, that the drug doesn't fix Huntington's, but if I know I've hit the target, and it doesn't fix HD, I know that target is one to walk away from."

As an example of CHDI's approach, Pacifici cites caspase-6, an enzyme thought to be important for snipping the mutant huntingtin protein into poisonous fragments. CHDI worked intensively to study the enzyme, and to develop drugs to reduce its activity. But the more they discovered, the less promising it seemed as a treatment approach, and the hard decision was taken to discontinue the program. But CHDI didn't just walk away from caspase-6, Pacifici points out. "We made sure we closed out the project properly and we're publishing our findings, so that anyone else who was interested could pick it up. We're happy to be proved wrong."

### A new approach

With gene silencing exciting drugs like phosphodiesterase (PDE) inhibitors and KMO inhibitors rapidly moving towards clinical trials, if CHDI were a regular pharmaceutical company this might be the time to pause its efforts to discover new targets and develop new molecules. Instead, the Foundation has just unveiled a new approach to the problem of studying and developing treatments for HD — using systems biology.

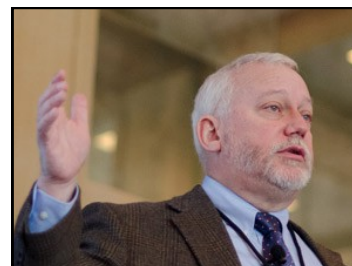
Keith Elliston is CHDI's newly appointed Vice President for Systems Biology. "Biological systems," explains Elliston, "have a particular nature to themselves that you cannot understand by looking at single parts one at a time. We have to look at the collection of parts as a whole, rather than individual components."

It sounds so sensible, we wonder briefly why anyone would do anything differently. Elliston switches to history mode. "The molecular biology revolution fundamentally changed the way we

think about biology. It took us from a state where we looked at whole systems as they function, to where we could tear them down to their atomic components. But it's very clear that biological systems are much more complex than that."

Fair enough, but isn't Huntington's disease basically a simple problem — a single genetic stutter, that causes the death of brain cells? Not quite, says Elliston. A cell with the HD mutation has "changed its nature — it's not dead, it's still alive, but it's fundamentally altered. The challenge is to find out how it's been altered, then how can we nudge the system back to a more favorable state".

Elliston believes that systems biology presents a new way of approaching drug development. "Conventional wisdom says that if we make a drug that alters a single point in the system, we can change the way the system works. But drugs have many different effects, and it may be the collection of effects that nudge the system one way or another."



Keith Elliston, CHDI's new Vice President for Systems Biology.  
Image credit: Blumenstein/CHDI

***"Our strategy has been to make sure that nothing that's on the critical path is beyond our control"***

In a sense, then, it seems like systems biology is about realizing that we've always been dealing with systems, perhaps without realizing it. Elliston has a neat analogy. "If I take a pin and push it against a balloon, I pop it. If I take a hand and push it at many

points, it changes shape. It's the same thing with biology. The more gently I push it, the more likely I am to move it from one state to another."

Openness and sharing are important aspects of CHDI's move towards systems biology. The Foundation has many academic and industry partners, and aims to bridge gaps where those traditional ways of working don't always do well. "The key thing that CHDI can do is build the database — what are the right models we need, what are the mechanisms of disease — when we put these things together and package them up,

we can basically kick off HD programs across the pharmaceutical industry, because we've done the biology."

### "Big pharma"

It's been a mixed year for the pharmaceutical industry and Huntington's disease. HD families were understandably disappointed when Novartis announced they were pulling the plug on their neurodegenerative disease program, including their HD work.

Meanwhile another drug giant, Pfizer, announced great preliminary results from its collaboration with CHDI, to develop PDE drugs to improve the functioning of the synaptic connections between neurons. Pfizer is now planning a drug trial which could begin as early as 2013.

Pacifici remains positive about the sometimes unpredictable involvement of commercial drug companies in HD research. "Because CHDI has the luxury of the long term and the financial resources," he says, "we can rise above it. It's disappointing when a company de-prioritizes things, but our strategy has been to make sure that nothing that's on the critical path is beyond our control."

### From small seeds

CHDI has reinvented itself this year with a new logo — a tree made from connected structures — representing the chemistry of drug molecules, or possibly Elliston's biological systems. It's an apt image, since the seedlings that CHDI has been planting and nurturing these past seven years have oftentimes proved fragile and difficult to cultivate. But there's a real sense, both within the Foundation and in the global community of HD researchers, that their efforts will be rewarded and every reason to believe that the forthcoming trials of drugs "designed specifically with HD in mind" will bear fruit. Or, at the very least, provide some shelter from the storm.

*Acknowledgements: By Dr Ed Wild, Edited by Dr Jeff Carroll  
HD Buzz, <http://hdbuzz.net>*

## Family & Friends Support Group

Our family and friends support group meets on **Wednesdays** each month at **10.30am**.

The venue is the Association's office,  
21 Chatham Rd West Ryde,  
and we would welcome new members.

*It's a great time to get together  
with other carers who, like  
yourself, are caring for a partner, a  
family member or a  
friend with HD.*

*Come along and join us as we  
share our chatter, laughter, tears  
and experiences.*

### 2012 Sessions

11 July  
22 August  
26 September  
24 October  
21 November  
7 December, End-of-Year  
Get-Together - TBC

To RSVP and for further  
information,  
please contact:

**Jet Aserios: (02) 9845 6699**  
Social Work Department  
Westmead Hospital





## Running for Huntington's NSW

We are delighted that once again a team is running in the City2Surf on Sunday 12th August to raise funds for the Association. Sincere thanks to Belinda Asquith-Forth, her family and friends who have formed the team 'Racing to Fight HD'.

If you would like to join the team and participate in this iconic event all you need to do is go to [www.city2surf.com.au](http://www.city2surf.com.au), select 'Enter Now' and then search for the 'Racing to Fight HD' team. If you would like sponsor this team visit the Everyday Hero web site, [www.everydayhero.com.au](http://www.everydayhero.com.au), select 'Heroes' and search for the 'Racing to Fight HD' team.

Last year Kathleen Cardona and her team (*see right*) raised over \$7,000 for Huntington's NSW through sponsorship, fundraising events and participating in the City2Surf.



In the Canberra Marathon in April this year, Alison Oates and Anthony Buckley made Huntington's their cause and raised in excess of \$1,800.

*We are so grateful to those all who have participated in these events and for the generosity of their supporters and donors.*

## Southern Sojourning

As promised in the last *Gateway*, Mark has now started working with families in the southern areas of the state, and in the ACT.

During April, Mark had the pleasure of travelling to a number of towns on the south coast, and also visiting the ACT.

The week started with meeting a number of people in Kiama over a coffee (decaf of course). From there, on to a home visit in the Illawarra area, and then to an Aged Care Facility to meet some more people.

The following day, Mark headed further south, to Batemans Bay area, and then on to beautiful Narooma (see photo - although with the rain bucketing down, it was no time for sightseeing), meeting with family members in both locations.

The next morning, Mark was off to the ACT via Braidwood, for a wonderful family meeting over a meal at Ainslie Football Club. He was fortunate to meet some great people there, and reports that they do a very good job organising support meetings which draw together family members who have been impacted by Huntington's in various ways. They would welcome other people at their informal get-togethers, and that includes people from outside the ACT. Mark said that the trip back from the ACT was interesting as he drove through Nerriga on what the sign said was 5km of dirt road – seems there may have been a zero missing from the sign – but he survived.

Mark is also travelling to the south western area of the state in the last week of June, so please let him know if you are connected with a Huntington's family in those areas. If you want to talk about arranging a visit when he is in your area, or if you want to talk about any Huntington's related issues, just contact him. It is as easy as calling Mark on 0410 629 850 or emailing him at [mark@ahdansw.asn.au](mailto:mark@ahdansw.asn.au). He would certainly love to hear from you.

## Closing the care gap: new guidelines for HD

*Huntington's disease may be incurable - but it's far from untreatable. But the care patients receive from professionals can be inconsistent. Now, a series of recently published internationally-agreed guidelines will help 'level up' everyone's care to the best standards.*

### Mind the gap

The Huntington's Disease Association of England and Wales has as its slogan **Hunting for a cure, with care**, while the HD Society of America promises **Help for today. Hope for tomorrow**.

Rightly, these organizations recognize that scientific research into new drugs to prevent or slow Huntington's disease is not enough. Without proper clinical care, even a perfect drug cannot do any good. Scientific research and care must go hand-in-hand.

Huntington's is often described as 'untreatable' — but that's simply not true. It may be incurable, but in fact, **many** treatments exist that can help people with HD. Drugs can improve many symptoms of HD, and non-drug treatments like physiotherapy and dietary supplements can often provide dramatic benefits.

For many people, the greatest barrier to living well with HD is not that treatments don't exist — it's that the professionals looking after them aren't fully aware of the best way to help Huntington's disease patients.

That's not to say that these professionals are negligent — even for clinicians who are expert in managing neurological and psychiatric conditions, it can be surprisingly difficult to keep fully up to date with the latest research into caring for patients. And quite often, even the experts can't agree on what the "best" care is.

### Levelling up

Thankfully, people affected by Huntington's disease are part of a uniquely connected global community of families, care professionals and scientists. The HD community is really good at working together to share ideas and best practices.

The past few months have seen several

initiatives aimed at improving standards of care in HD. They've all come from collaborative groups of professionals, working with patients and family members, to try to produce practical guidelines that have a sound basis in scientific research.

### Standards of care

The European HD Network — EHDN — recently published a comprehensive set of guidelines for clinicians caring for HD-affected people. Each guideline is the end product of several years of intensive effort by 'working groups' of professionals, guided by their own expertise and the wealth of research into HD.

The guidelines include straightforward advice on physiotherapy, nutrition, feeding, oral care, speech and communication, and occupational therapy.

Helpfully, EHDN worked with the journal *Neurodegenerative Disease Management* to publish the guidelines as 'open access', so anyone can download them, free of charge.

### Treatment algorithms

Open access is a key ingredient of another recent initiative — a series of publications aimed at assisting doctors in making decisions about drug treatments in Huntington's disease.

Many doctors, especially those who aren't expert in managing patients with HD, are either unaware of the range of drugs that can be used to help control symptoms, or have difficulty making rational decisions about the best treatment in a particular situation. Because treating HD often follows a 'trial and error' approach, there are big differences in approaches to treatment in different parts of the world.

In an attempt to bring some clarity to the situation, Dr LaVonne Goodman assembled an international panel of doctors considered world

experts in the field of HD. Goodman chose three HD symptoms that are most challenging for non-experts to manage: chorea (the involuntary movements experienced by most HD patients), irritability and obsessive-compulsive symptoms.

For each symptom, a survey was used to produce a snapshot of treatment patterns. The answers were then pulled together to create 'treatment algorithms' — essentially, step-by-step decision-making tools.

The algorithms were published in the innovative online journal PLoS Currents: Huntington's Disease and, again, can be downloaded free of charge by anyone.

### Quantity of quality

Nobody knows how much time we'll have on this earth, but — to misquote top wizard Gandalf — "all we have to decide is how to make the most of the time that is given to us".

Fundamentally, the aim of all Huntington's disease research is giving HD-affected people the maximum number of years of good quality life.

But what is quality of life, and how do we know whether we're improving it? A surprisingly difficult question — but one that's crucial to answer. Not only is it important in its own right, but government agencies often require evidence that a drug improves quality of life before they'll approve them for use.

Thankfully this is another area where we've seen significant progress. EHDN's Quality of Life Working Group, led by Dr Aileen Ho, recently produced the **HDQoL** — the Huntington's Disease Health-related Quality of Life questionnaire, and published it in the journal Clinical Genetics.

The process began with interviews with patients and carers to identify the most important things in people's lives that HD affects. A large set of questions about these things was then produced and boiled down to the final set, through a rigorous process of repeated interviews.

The end result is a tool that will hopefully enable us to assess the real impact of any drug or other intervention for HD.

### It never stops

These developments, which have all taken place in the past few months, demonstrate how communication, care and science can work together to improve the lives of HD-affected people.

Of course, everyone's different, so no guideline or algorithm can replace expertise and effective communication between professionals and patients. But having internationally-agreed guidelines in place gives every professional a scientifically-sound basis for the tricky business of helping HD-affected people.

So, don't be afraid to point the professionals involved in your care in the direction of these guidelines. Any clinician who's up to scratch will be glad to be made aware of them.

And — as we're fond of pointing out — science never stops. These guidelines will be reviewed, added to and improved. The more we learn about HD, in the lab and in the clinic, the better we get at caring.

*Acknowledgements: By Dr Ed Wild, Edited by Dr Jeff Carroll; HD Buzz, <http://hdbuzz.net>*

*The guidelines can be found at [www.futuremedicine.com/toc/nmt/2/1](http://www.futuremedicine.com/toc/nmt/2/1)*



Like a fine cognac, these new publications distill a wealth of knowledge and expertise into easy-to-swallow guidelines.



## Huntington's New South Wales

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### AHDA (NSW) Inc

The Australian Huntington's Disease Association (NSW) Inc is a not-for-profit organisation established in 1975.

### Our Mission

The energies and resources of the Australian Huntington's Disease Association (NSW) Inc are directed towards satisfying the needs of people with or at risk for Huntington's Disease and their families in NSW and the ACT by providing and/or facilitating delivery of a range of quality services.

### Our Philosophy

People with Huntington's Disease and their families are individuals with equal value to all other members of Australian society, with the right to treatment and care by knowledgeable professionals and care givers, the right to appropriate support services and the right to have the best quality of life possible.

### Our Services

These include education and information; advocacy; counselling and referral; holiday programs; family support; rural outreach and client services.

### Our Board

President: Don Ayres

Vice President: Brian Rumbold

Treasurer: Richard Bobbitt

Secretary: Judy Rough

Karen Bevan

John Conaghan

Keith Dingeldei

Ann Lowe

## Association and Other Useful Contacts

### Association Staff

**Robyn Kapp OAM**  
Manager

**Lily Shu Yue Ma**  
Administration and  
Activities Assistant

**Toni Ling Zhang**  
Administration Officer

**Ramona Watts**  
Family Support Worker

**Mark Bevan**  
Rural Family Support  
Worker

### Huntington Disease Service

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**Dr Sam Kim**  
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**Research Queries**  
**Dr Elizabeth McCusker**  
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**HD Clinic Appointments**  
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