



# Gateway

News from Huntington's New South Wales

Volume 16 No 1

Autumn 2013



## HDYO's First Anniversary!

Dear Rob

HDYO is now officially 1-year-old (!!!) So we wanted to take the time to say a massive thank you to all our HDYO users for your support and feedback during our first year. Doesn't a year go by fast? This is a little summary of HDYO's success in 2012:

- Closing in on 500,000 website views! (That's half a million views!)
- HDYO's educational content has been shared over 3,000 times
- HDYO's forum has almost 600 posts from young people on it
- HDYO's website is now available in 5 languages (English, German, Spanish, Portuguese and Dutch)!
- Over 5,000 facebook fans
- HDYO's videos have been viewed over 15,000 times
- 15 HD Associations worldwide now officially support HDYO and contribute to our projects

The first 12 months have been a good start but we want to keep improving and providing more for young people impacted by HD around the world. We have projects in the pipeline for 2013 in many regions of the world, but if you have any feedback about what you think HDYO should do we would love to hear it.

Take care,

Matt Ellison, Project Coordinator

HDYO [www.hdyo.org](http://www.hdyo.org)

## From the Executive Officer

*This edition of Gateway contains a wide variety of articles which I hope you will find both interesting and informative.*

*In preparing the newsletter I was struck by the differences between two of them. On this page you'll read about the wonderful success of HDYO in its first year. While on pages 10 and 11 you'll read about those who have been or were involved with Huntington's Disease in the early days of establishing associations and initiating research.*

*These two articles represent history and the present. It's important that we remember the history—much can be learned from it—the mistakes we've made and the successes of which we can be very proud.*

*However, we must move forward, keeping in mind the history and ensuring what we are doing now in the present is well done, given our resources.*

*And what of the future? We must keep striving to improve the quality of life for all families impacted in any way by Huntington's Disease.*

*In friendship*

*Robyn Kapp*

## Congratulations to ...

**Professor David Sillence AM** on being appointed a Member of the Order of Australia (AM) in the recent Australia Day Honours, for "significant service to medicine in the field of clinical genetics".

This is a fitting recognition of David's tireless commitment to teaching and training in medical genetics and the enormous contribution he has made to the field of clinical genetics.

Professor Sillence, along with Fiona Richards and others, was instrumental in establishing the Predictive Testing Program for Huntington's Disease in NSW after it was announced (in November 1983) that a gene 'marker' for HD had been located on chromosome 4. It took many meetings and correspondence to get the program set up, however David's persistence and dedication paid off and for this we are most grateful.



**Clinical Associate Professor Elizabeth McCusker** who has been appointed a Clinical Associate Professor by the University of Sydney.

Dr McCusker founded the Huntington Disease Service at Lidcombe Hospital and following the closure of the hospital, she advocated for, and oversaw the establishment in 1995 of a new and much more comprehensive service in Western Sydney. This included the Outreach Program which is a multidisciplinary model of care in Huntington's Disease.

Dr McCusker was Director of Huntington Disease Service until her retirement in 2008. However her interest in and passion for Huntington's Disease continues in her role as Research Neurologist in Huntington's Disease at Westmead Hospital. Her leadership in research is much appreciated by families throughout NSW.

### *Thank you*

*Long term Board Member has Anne Low has announced her retirement from the Board. Anne has given many, many years to the Association and has served in a variety of capacities on the Board including President, Vice President and Secretary.*

*Anne's wisdom, commitment and dedication will always be appreciated and we wish her well in her future endeavours.*

## Welcome to ...

Our new Board Member, **Deborah Cockrell**. Deb is a registered Oral Surgeon who currently practices and lives on the Central Coast of NSW. She moved from the UK to Australia in 1996 and since that time she has held senior academic appointments in dentistry and oral health, at the University of Sydney and the University of Newcastle. Deb has a PhD in dentistry and recently obtained an MBA. She is currently a Councillor of the Australian Dental Association (NSW Branch) and Vice-President of the Dental Council of NSW. Deb's mum, Pat, was affected by HD so Deb looks forward to using her skills, expertise and personal family experience on the Board.



**Colleen McKinnon** who has been appointed the Clinical Nurse Consultant for the HD Service at Westmead Hospital. Colleen has over thirty years experience as a nurse across the continuum of care. This has included the contexts of Community, Aged Care Facilities and Acute Care. The last nine years have been as the Dementia/Delirium Clinical Nurse Consultant for the hospitals in the South Eastern Sydney Local Health District. Colleen has extensive experience in nursing assessment and evaluation, carer support, provision of education to health professionals and research. Recent research interest has been related to implementation of strategies to reduce carer burden. This paper was presented in the UK in September last year. Colleen is looking forward to being a part of the team of professionals who make up the Huntingtons Outreach Service.

**Mark Cirillo** has been an RN for three years now. He brings to the HD Outreach Service experience in both general, traumatic and acquired rehabilitation nursing at Royal Ryde Rehabilitation centre and experience in aged care in dementia. Mark has what he feels is the maturity and empathy valuable to improving the quality of life of people with HD and their families. He looks forward to this challenge.



# IMPORTANT INFORMATION ABOUT NURSING HOME FEES AND CENTRELINK PENSIONS

It is a sad reality of conditions such as Huntington's disease (HD) that the person with HD will eventually require a level of care that the family is no longer able to provide. They will then need to go to a residential care facility, for which fees have to be paid. In some situations this will occur when the person's spouse or partner still needs to work and may still have children to support. In these situations it is important to be aware of the two different ways that Centrelink assesses the person's and family's income regarding eligibility for a Disability Support pension which can cover the cost of the care fees. It may seem logical that in this situation the couple would be classified under 'illness separated couple'. However in the guide to the Social Security Act ([http://guidesacts.fahcsia.gov.au/guides\\_acts/ssg/ssguide-2.s/ssguide-2.2.5/ssguide-2.2.5.60](http://guidesacts.fahcsia.gov.au/guides_acts/ssg/ssguide-2.s/ssguide-2.2.5/ssguide-2.2.5.60)) this classification assumes that the couple relationship is still intact and that they only have to separate because one partner needs residential care. In this case the well partner's income and the couple's joint assets will be assessed, which often means that the person needing care is not eligible for a pension. The couple are then faced with having to pay care fees, as well as maintain the family home and possibly also the care of dependent children. For most families this would create severe financial stress or be impossible.

There is another category which is actually more appropriate for people with HD, and under which the guide to the Social Security Act actually states Huntington's disease as one of the eligible conditions ([http://guidesacts.fahcsia.gov.au/guides\\_acts/ssg/ssguide-2.s/ssguide-2.2.5/ssguide-2.2.5.20](http://guidesacts.fahcsia.gov.au/guides_acts/ssg/ssguide-2.s/ssguide-2.2.5/ssguide-2.2.5.20)). It is referred to as 'Living separately & apart – one member of a couple institutionalised due to a severe & debilitating illness'. Under this category it is assumed that due to the nature of the illness eg. Huntington's disease or advanced Alzheimer's disease, the partner with the illness is '...totally and permanently incapable of providing their partner

with such things as companionship, comfort,



**centrelink**

physical, intellectual or emotional support.' In this situation the person with the illness will be deemed to be single and their partner's income will NOT be taken into account. This means that unless that person has an independent income, such as an insurance pension, they will be eligible for a Disability Support pension which would cover the cost of their care fees. The person's assets will be assessed as half the value of their joint assets, but the family home will be exempt as long as the partner and/or children remain living in the home.

Under this category the well partner may still visit the person with HD on a regular basis, provide financial support and does not have to obtain a divorce.

When dealing with Centrelink in this situation is important to make the Centrelink officer aware of this category as they may assume you come under the 'illness separated couple' category, and may not even be aware of the 'living separately & apart' category. You can refer them to the online guide (reference above) and insist that HD is one of the illnesses that fits the category of 'living separately and apart'.

If you have any questions or encounter difficulties dealing with Centrelink in this situation please contact the social workers with the HD Outreach service at Westmead Hospital (Jet Aserios and Cecelia Lincoln) on (02) 9845 6699, John Conaghan at Hunter Genetics on (02) 49853100 or Fiona Richards on the number below.

Fiona Richards  
Senior Social Worker  
Department of Clinical Genetics  
The Children's Hospital at Westmead  
Telephone: (02) 9845 3212



# Huntington's Disease and Sleep

*Why do many Huntington's disease patients have trouble sleeping, and what can be done about it?*

*Many Huntington's disease patients have problems with sleep and in the control of daily or 'circadian' rhythms. These problems may actually be part of the range of symptoms in HD, and managing or treating them directly may be beneficial. In this special HDBuzz feature, sleep expert Prof Jenny Morton looks at the science behind sleep problems and solutions in Huntington's disease. Coming soon, part 2: Prof Morton's 'Simple Rules for a Good Night's Sleep'.*

After a long day, many of us look forward to the bliss that comes with a good night's sleep. But not everyone who is tired is guaranteed a peaceful night's sleep. For those to whom sleep does not come, the night can seem a lonely and sometimes anguished exile. And more often than not, those who live with the sleepless share the burden. Unfortunately for the person with a neurological disease like Huntington's, the consequences of sleep disturbance may not only be distressing and disruptive, but may also contribute significantly to their symptoms.

## We all need sleep

There is no doubt that sleep is an essential and beneficial part of a daily pattern of life. Short-term sleep deprivation causes no lasting damage, but unquestionably impacts mood. Without adequate sleep, people become irritable and unable to sustain attention. They also become unreasonable and short-tempered.

Most people can bounce back after a couple of good night's sleep. But what if you have Huntington's disease

Evidence is emerging that HD patients frequently suffer from abnormalities in both sleep and in the control of daily or 'circadian' rhythms. It is possible that sleep and circadian dysfunction may actually be part of the range of symptoms in HD. If this is the case, it is important that it is recognized, because sleep and circadian disturbances have negative impact on people's daily lives, even in people without a neurological problem. So, sleep and circadian disturbance in HD patients are likely to

contribute to HD symptoms that are worsened by sleep deprivation, such as irritability and anxiety.

Chances are, if you have Huntington's disease and sleep poorly, it will not be solely due to your

disease. A significant percentage of the general population suffers sleep disruption due to personal habits, lifestyle or environment. We stay up too late - we get up too early. We take drugs that interfere with sleep, we over-stimulate ourselves with late-night activities such as work or television. HD patients are no exception to this. The difference is that HD patients may not have the reserves that allow a neurologically healthy person to cope with sleep deprivation.

Chronic sleep deprivation is damaging to health in normal people, so it's possible that chronic sleep-wake deficits could actually contribute to mental decline in HD. If this is the case, then treating sleep deficits might delay cognitive and emotional decline in HD.

## Is there a difference between sleep and circadian rhythms?

Circadian rhythms and sleep are two different processes, although the terms are often used interchangeably. Circadian rhythms are biological processes that change roughly every 24 hours. They are orchestrated by a small part of the brain known as the suprachiasmatic nucleus or SCN. The SCN is known as the body's 'master clock'. It regulates all your daily activities, including when you wake up and when you want to go to bed.

Sleep is a very obvious 'circadian behavior', because the onset of sleep typically happens once a day. But it is just one of many circadian behaviors that are controlled by the master clock. Others include heart rate, hormone secretion, blood pressure and body temperature.



*Sleep problems are common in the general population. People with Huntington's disease may have extra reasons to have sleeping difficulties, too*

So, sleep is a circadian behavior that is influenced by the SCN, but it is not generated there. Sleep is a very complex thing, and the process of going to sleep, maintaining sleep and waking up are all controlled by different parts of the brain.

There are multiple stages of sleep that can be identified by looking at the brain's electrical activity. The mechanisms that generate sleep and control movement between these different sleep stages are not fully understood. It is not even known why we sleep, although there is growing evidence that sleep is important for learning and forming lasting memories. We may even do some 'brain housework' while we sleep - by reviewing experiences that have occurred during the day.

### **Neurological disease causes sleep problems**

Sleep abnormalities and disorders of circadian rhythm are already recognized as symptoms in a number of other neurodegenerative diseases, particularly Parkinson's disease and Alzheimer's disease. In fact, sleep disruption in Alzheimer's patients is reportedly the main reason for their institutionalization. This is probably because when an Alzheimer's patient has disrupted sleep, this becomes a problem not only for the patient, but also for their carer.

More research is needed before we will know if sleep or circadian rhythm disruption is part of the complex repertoire of Huntington's disease symptoms, or if it is just a 'knock-on' effect of having HD. But whatever the cause, we should recognize that even mild sleep abnormalities could worsen neurological symptoms in HD patients. Knock-on effects of sleep abnormalities in HD may be critical for determining the care-plan of patients. And, if they worsen thinking and mood disturbances, they may also end up having a greater impact on quality of life than other symptoms like involuntary movements.

### **Circadian abnormalities in Huntington's disease**

The first clue that sleep or circadian rhythms might be abnormal in HD patients came from a study showing subtle changes in circadian activity profiles, measured by wrist-mounted movement monitors.

Circadian rhythms are difficult to measure accurately in humans, because the rhythm can be masked by other activities such as work and social life. But they are easy to measure in mice, and direct measurement of circadian rhythms in one HD mouse model showed clear abnormalities in circadian behavior.

These mice showed a progressive disintegration of the normal rhythm of rest and activity. That disturbance was mirrored in the HD patients wearing the activity monitors. In the HD mice, there was also disruption in activity levels of genes that controlled the circadian clock in the SCN. These circadian abnormalities in HD mice have now been confirmed by three different laboratories.

Importantly, the breakdown in circadian rhythms in the mice were linked to their decline in thinking function - and restoring good circadian rhythms delayed the thinking decline.

This suggests that some of the thinking problems in the mice were caused by the disruption of sleep and circadian rhythm. If the same thing happens in humans, then improving sleep and circadian function might have a beneficial effect on cognitive and emotional problems in people with Huntington's disease.

### **What causes sleep disturbance in Huntington's disease?**

The most common causes of sleep disturbance in healthy people are depression, stimulant drugs like caffeine and nicotine, and disruptive lifestyles like going to bed late, getting up late and taking naps during the day. So, it is likely that these same culprits are responsible for some sleep disturbance in Huntington's disease patients.

But it's also possible that sleep and circadian abnormalities are direct symptoms of HD, in the same way that chorea is a symptom. There is evidence for sleep disturbance in early symptomatic HD patients who are not taking any medication and not depressed.

So, we don't know yet if there are sleep and circadian abnormalities that are caused directly by the HD mutation, or if it is simply that some patients have disrupted sleep and circadian behavior because they have symptoms of HD.

More research is needed to address this question. But it is interesting that many of the subtle symptoms of early HD are similar to those experienced by normal individuals after sleep deprivation.

### Can we treat sleep or circadian disturbances in HD?

If you have Huntington's disease, you don't want to add the consequences of sleep deprivation to your symptomatic burden. But there is good news: there are already well-established treatments for sleep disturbance.

If disrupted sleep is interfering with your daily life, you should **talk to your doctor**. He or she may be able to prescribe a drug treatment that will help you. This does not have to be a long-term treatment - sometimes a short period of treatment is enough to help you re-establish good sleeping patterns.

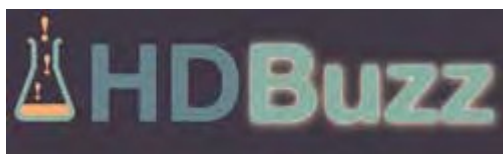
If you think you might be **depressed**, you should also talk to your doctor about depression and sleep problems. Depression is the enemy of sleep, but effective treatments are available.

Remember, too, that many **medications** that can cause sleeplessness as a side effect. Ask your doctor or pharmacist if the medication you are taking can lead to sleeplessness. Don't stop taking the medication, even if you think it might be interfering with your sleep. Always seek the advice of your physician and other healthcare professionals before changing your medications.

*Acknowledgement: By Prof Jenny Morton, Edited by Dr Ed Wild; HD Buzz, <http://hdbuzz.net>*



*Studies in mice models have helped us understand sleep problems in HD patients. Encouragingly, restoring normal sleep in HD mice helped with their thinking performance.*



## Family & Friends Support Group

Our family & 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.*

### 2013 Sessions

24th April  
29th May  
19th June  
10th July  
14th August  
25th September  
16th October  
13th November  
Friday 6th or 13th December  
Christmas Get Together TBC

To RSVP and for further information,  
please contact:

**Jet Aserios** or  
**Cecelia Lincoln**  
**(02) 9845 6699**

Social Work Department  
Westmead Hospital

## One day at a time

Larry and Suzanne Csordas have faced some tough times over the years. First, there were the battles with alcoholism, although both have now been sober for more than 25 years. Next came a 1990 aneurysm that left Larry relearning how to speak and walk. Then, in 1998, Larry was diagnosed with HD.

Suzanne was devastated when they got the news. Although one of Larry's sisters had died of the disease, the family didn't realize it was hereditary. "It was a total shock to me," she says. "I took it really, really, hard as I knew what the family had just been through with Larry's sister. She was in a nursing home at the age for 40 with Huntington disease and passed away at the age for 53 from the disease. I had a lot of fear because so much was unknown."

Early on, Larry suffered from temper outbursts. On one occasion, his difficulties writing a few thank-you cards sent him into a towering rage, only to tearfully apologize to Suzanne the next morning.

"From that point on, we both realized we have to work together on this," she recalls. "One person can't do it on their own."

Larry's family has rallied around, going to the Huntington Society of Canada's local chapter meetings, raising money and escorting him to activities. His sister Margie has dedicated over 50 volunteer hours with HSC in a single year, earning a \$500 donation from her employer.

The local HSC support group was a "godsend," helping them understand and cope with the disease. "We are so thankful to Maike, our local HSC Resource Centre Director, who is so dedicated and rallies for our well being". Meanwhile, medication has helped Larry keep his emotions under control and calmed his involuntary movements.

Today, the Ontario couple fills their days with laughs, hugs, movie dates and a long list of activities to keep Larry busy.

Retired from his career as a postal carrier, Larry

walks their dog two or three times a day to keep fit. He works part-time as a groundskeeper and serves breakfast to the needy every month. He enjoys cribbage and bowling in winter and a steady diet of crosswords and word searches year-round.



On top of that, he's active in their church and regularly goes to events at the local Alzheimer's Society. He and Suzanne are stalwart members of HSC's Niagara Chapter support group, helping newcomers face all the challenges they have overcome.

Best of all, says Larry, are the monthly potlucks with his brothers and sister, followed by poker nights.

Sure, sometimes car keys and can openers go missing. "My left hand doesn't know what the right hand is doing," he laughs. As the years go by, HD will take its toll.

But Larry just focuses on his mantra: stay active and be positive. "One day at a time," he says. "You have to beat it one day at a time."

*Acknowledgement: "Horizon", Huntingtons Society of Canada, No. 138, Fall 2012*



## What is unawareness and how do I deal with it ?

Unawareness of Huntington disease (HD) symptoms is a difficult concept for many to understand. How is it possible that someone with HD who has had trouble keeping their balance, to the point of often running into things, has no awareness of their symptoms? Or maybe more subtly, the person with HD who has had some fender benders but doesn't seem to equate these accidents with their declining ability to drive. The term "unawareness" is used when talking about HD symptoms because it is more accurate and very different than denial.

Sometimes, unawareness is confused with denial. Denial is the psychological inability to cope with distressing events. Psychologists typically use this term when someone has experienced a death of someone close to them or a loss. You might think denial would apply to a person with HD; that they might want to deliberately put out of their mind that they will or do have disease symptoms. But we have some control over our denial and it seems to fade over time. Unawareness, on the other hand, is a part of the disease process and typically becomes more pronounced as the disease progresses.

The unawareness that occurs in HD is not intentional and is typically caused by damages to circuits in the frontal lobes of the brain. Another term for this unawareness is *anosognosia*. People with diseases like Parkinson's or Alzheimer's have similar unawareness problems because of disruptions in the same section of the brain. In more advanced HD, these brain disruptions can be characterized by the term *dementia*. Examples of dementia symptoms include slowing of mental processing (for example, the former cashier who has difficulty making change), forgetfulness, having trouble organizing events or tasks that once seemed easy, apathy and depression. A person with HD may have trouble evaluating his/her own behavior or performance and may have trouble understanding someone else's point of view.

Now that you understand that unawareness is a symptom of HD, how do you deal with things that seem so obvious to you but are not recognized by your loved one?

- There is not one standard way to avoid problems of unawareness. Knowing your loved one and having a set of strategies that work in different situations is best.
- Try to avoid power struggles. Attempting to get your loved one to have insight into their problems will probably create more frustration.
- Unawareness is a part of the disease and there may never be the moment of insight that the person with HD understands his/her deficits.
- Try the use of a "contract" to achieve compliance and don't assume that non-compliance is intentional. Maybe there is one person who is best at getting the person with HD to comply. This could be another family member or a caregiver at a facility. Utilize that person to help your loved one to comply with necessary tasks.
- Pick your battles. Is it more important to attend a family gathering or is it more important that he/she wears a clean shirt?
- Safety first. Allowing your loved one to have access to his/her car keys when the doctor advised no driving creates a dangerous situation for your loved one and others on the road. It may be necessary for you to help your loved one keep himself/herself safe by enforcing your doctor's recommendations.

*Acknowledgement: By Anne Leserman, MSW, LISW, HDSA Regional Social Worker, Mid-Atlantic Region. Huntington's Disease Society of America Support Group Newsletter, Issue 7, December 2012, [www.hdsa.org](http://www.hdsa.org)*

## MAKING THIS A LAND FOR YOU AND ME

*Francis Collins, M.D., Ph.D., Director, National Institutes of Health in the United States, wrote a recent blog entry in honour of Rare Disease Day on 28th February 2013. Please read his touching words below. To read it online – and to listen to Woody Guthrie perform one version of "This Land" – visit Francis's blog: <http://directorsblog.nih.gov/making-this-a-land-for-you-and-me/#more-672>.*

Today is International Rare Disease Day. In honour of the occasion, I'd like to pay tribute to a few real-life heroes whose struggles have forever changed the landscape of rare disease research.

Folk singer Woody Guthrie is best known for his song, "This Land Is Your Land." Written more than 70 years ago, "This Land" has taken its place among our nation's great anthems, setting forth a vision of inclusiveness that has inspired generations of Americans to "sing along." But the last couple of verses are often omitted. Here's a version of one of them:

As I was walkin'—I saw a sign there  
And that sign said—no trespassin'  
But on the other side ... it didn't say nothin'!  
Now that side was made for you and me!



These verses brought into the foreground those whom society had marginalized. "This Land" reminded us of their existence, challenged us to live up to our ideals—and include all people in our best vision of ourselves.

To hear Woody perform one version of "This Land," check out this archival recording: <http://www.youtube.com/watch?v=wxiMrvDbq3s>

Even as he was singing about inclusiveness, Woody Guthrie was starting a long battle against a disease that increasingly cast him outside mainstream society: Huntington's disease. In most cases—and as was indeed the case for Woody—symptoms of Huntington's disease do not appear until adulthood. Gradually, this rare, inherited neurological disorder seizes control of its sufferer's body, mind—and even voice. In 1965, 13 years after he was diagnosed, Woody fell mute. He had long since lost his ability to play guitar. Two years later, he died at the age of 55.



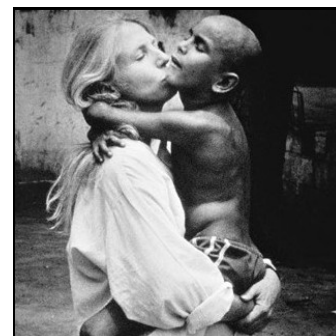
Fortunately for Woody and for all of us, his second wife, Marjorie, was by his side as he struggled with his failing health. Marjorie Guthrie responded to her husband's death by founding what is now the Huntington's Disease Society of America. Over the years, Marjorie raised our country's awareness, not just of Huntington's, but of all kinds of rare diseases. She made her case in Washington, DC—and right here in Bethesda, where she encouraged NIH to expand its efforts to understand rare diseases. Her foundation worked with NIH to support such research. And she was involved in the movement that eventually led to the passage of the Orphan Drug Act in 1983—the year she died. In its 30 year history, the Orphan Drug Act has greatly encouraged the development of drugs

for rare diseases. While we have a long way to go—there are an estimated 7000 rare diseases, and there are drugs available for approximately 300 of those—there remains great cause for hope. The founding of the Therapeutics for Rare and Neglected Diseases (TRND) program at NIH, now located in the new National Center for Advancing Translational Sciences, is just one of many steps that seek to build a bridge from a veritable deluge of recent discoveries about the causes of rare diseases to new and effective treatments.



At the same time Marjorie Guthrie was setting up her society, Dr. Milton Wexler was establishing the Hereditary Disease Foundation (HDF) in response to his wife's struggles with Huntington's disease. Soon his daughter Nancy joined her father's campaign. A clinical psychologist by training, Nancy Wexler learned genetics from the ground up. She was part of the group that, in 1983, successfully discovered the general location of the Huntington's gene, on the short arm of chromosome 4. The HDF helped support that research. So did NIH.

Nancy then pulled together a research team—including my own research lab at the University of Michigan—to search for the causative gene. Nancy's leadership led to an unprecedented collaborative model, where research groups that would normally have competed with each other agreed to work together. With the support of NIH and HDF, discovery of the HD gene was published in March, 1993, just about exactly 20 years ago. That gene discovery has directed new research aimed at developing treatments for Huntington's: a quest that continues to this day, with growing confidence that it will ultimately succeed.



Shortly after being diagnosed with Huntington's, Woody Guthrie wrote a poem, entitled "No Help Known" <sup>[1]</sup>

*Huntington's Chorea  
Means there's no help known  
In the science of medicine  
For me ...  
All look at me and say  
By your words or by your looks  
Or maybe by your whispers  
There's just not no hope....*

Today, I contend that, precisely because of the efforts of folks like Woody, Marjorie, and Nancy, there is help, and there is hope. The landscape of many rare diseases is no longer uncharted. These heroes, and so many others, have helped make this a land for you and me.

Reference:

<sup>[1]</sup> Tracing Woody Guthrie and Huntington's disease. Arévalo J, Wojcieszek J, Conneally PM. Semin Neurol. 2001 Jun;21(2):209-23.



## Huntington's New South Wales

PO Box 178, West Ryde, NSW 1685

21 Chatham Road, West Ryde, NSW 2114

Telephone: (02) 9874 9777 Facsimile: (02) 9874 9177

STD Free Call: 1800 244 735 (Country NSW only)

Email: [hdassoc@huntingtonsnsw.org.au](mailto:hdassoc@huntingtonsnsw.org.au)

Web Site: [www.huntingtonsnsw.org.au](http://www.huntingtonsnsw.org.au)

### AHDA (NSW) Inc

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

### Our Mission

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

### Our Philosophy

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

### Our Services

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

### Our Board

President: Brian Rumbold

Vice President: Don Ayres

Treasurer: Richard Bobbitt

Secretary: Judy Rough

Deb Cockrell

Amanda Dickey

Keith Dingeldei

## Association and Other Useful Contacts

### Association Staff

**Robyn Kapp** OAM  
Executive Officer

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

**Mark Bevan**  
Regional Family Support  
Worker

### Huntington Disease Service

**Dr Clement Loy**  
Director  
Westmead Hospital  
(02) 9845 6793

**Dr Sam Kim**  
Neurologist  
Westmead Hospital  
(02) 9845 6793

**Research Queries**  
**Dr Elizabeth McCusker**  
(02) 9845 6793

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

**Jet Aserios**  
Social Worker  
Westmead Hospital  
(02) 9845 6699

**Cecelia Lincoln**  
Social Worker  
Westmead Hospital  
(02) 9845 6699

**Outreach Service**  
**Colleen McKinnon &  
Mark Cirillo**  
Westmead Hospital  
(02) 9845 9960

### Huntington's Lodge

Nursing Unit Manager  
Lottie Stewart Hospital  
(02) 9804 5854

**Nursing Staff**  
(02) 9804 5803

### Predictive Testing

**Fiona Richards**  
Social Worker  
The Children's Hospital  
Westmead  
(02) 9845 3273

### Hunter HD Service

**John Conaghan**  
Social Worker  
Hunter Genetics  
(02) 4985 3100