

## President's update

It has been a busy and exciting time for the service in recent weeks due to the recent sale and pending relocation of our office that I talked about in my last update. Leading the organization during this time stirs feelings of nostalgia as I look back at the journey travelled to bring HV to this point, trepidation as I guide our members, staff and service users into the next phase of our history and excitement as together we embark upon the future and the service that we collectively envisage.

We have secured a lease property in Hawthorn to enable us to begin to realize our vision to provide an accessible, inclusive and welcoming environment available to all people affected by HD in Victoria. Our hope is to create a community hub, from which we can deliver essential services to clients, encourage participation within our community and provide an avenue for raising awareness and educating people about HD.

The next two to three years will focus on building our capacity to more effectively meet community need. What we learn from community feedback and consultation during this time will assist us to make long-term

decisions about the location of the service to assist us to achieve our goals.

As chairperson and a member of the HD community I am truly excited about what the future holds for HV; its members, clients and stakeholders. I endeavour to keep you abreast of developments to the service as they emerge within our new environment, and look forward to your involvement along the way. We will continue have a strong focus on the provision of accessible and quality services to individuals, families and professionals in the community. As always we welcome your involvement and feedback as we enter a new phase of HV.



Angela Weller  
President

## HV is moving!

After 10 years in Ashwood, the service is relocating to Hawthorn, just minutes from the city by public transport.

Read more on the back page!

## Trivia Time – everyone's invited!

Join some of HV's fantastic volunteers again at this year's Trivia Night. If you aren't a regular at this event, know you are guaranteed a great night full of laughter and games with other people that want to dig deep to support families affected by HD across Victoria. This year we are reaching further into the community with the aim of bringing together new people that would like to learn more about what we do, support a worthy cause and well... just have a blast! Come along and see for yourself what all the fuss is about.

## What you need to do...

Be Quick, tickets do sell out! Get 10 of your friends, family, colleagues or literally anyone together to fill a table. Contact Fi Mims on 0407 366 801 or [fi@mimsphtography.com.au](mailto:fi@mimsphtography.com.au) to book and pay \$250 for your table – that's only \$25 a head for a great night!

## What do I need to know?

**Date:** Saturday 7th August

**Time:** Games begin 7pm sharp

**Venue:** Holy Redeemer Hall,  
311 Mont Albert Rd,  
Surrey Hills

**BYO food**

**Alcohol sold at the venue**  
(tea and coffee free of charge)

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*Don't forget to complete and return your membership form.*



## Research participants needed

A team of leading Melbourne based clinicians and researchers are calling for volunteers in a study to assess the relationship of chemicals in the body to mood and thinking. Located at St George's Hospital, Kew, the research is seeking the involvement of people diagnosed with HD (diagnosis within the past 5 years approximately) and people with the HD gene who are not diagnosed. Participants will be required to attend an appointment of no more than 3 hours, where a blood sample will be taken and some basic pencil and paper tests carried out. We will also ask for some saliva samples. By taking part you will be making a significant contribution to the understanding of the early biological and behavioural changes that can occur in HD. All travel expenses will be reimbursed. If you are interested in volunteering or want to know more, please contact Chris Shirbin (0404 911 451) or contact your HD clinician.

## One-stop shop for respite services

Victorians living with a disability, their families and carers will now have easier access to respite online with the latest information about available services from all Commonwealth, State and local Government programs available at the click of a button. Until now, members and clients of HV have found that accessing information about respite was a complex and time consuming task. The Victorian Government says that their new website will provide a one-stop shop for detailed information about all available services. Carers will be able to find information about respite services that are available in an emergency, people with a disability can find day programs that are available and parents can find information about what out-of-school hours services are available. The service will be delivered as a part of a \$1 million Government commitment to improve online respite information services and improve access and coordination of respite services across the state. The new online service links eight existing regional websites and can be accessed at: [respitevictoria.org.au](http://respitevictoria.org.au)



## New physiotherapy guidance document for patients with HD

Physiotherapy is becoming more frequently recommended for people with HD but to date, there have been no specific implementation guidelines. The Physiotherapy Working Group of the European Huntington's Disease Network (EHDN) has developed a comprehensive Guidance Document for Physiotherapists. It aims to assist therapists in implementing a plan of care that is consistent with current best practice in physiotherapy provision to people at all stages of HD. The document will be reviewed and updated as new research becomes available. The current version is available free of charge for download at: <http://freedownloadbooks.net/ehdn-doc.html>

## Making the Connection – Conference 2010

The National Huntington's Disease Conference in collaboration with the Queensland Brain Institute, University of Queensland is to be held in Brisbane in September 2010. The theme "Making the Connection" reflects the meeting and sharing of knowledge and experiences with all those involved in the Huntington's field – family members, community services, researchers, allied health professionals, care workers and members and supporters of all HD Associations across Australia. Professor Gary Egan will be presenting a keynote address on Multi-modal MR Imaging of Neural Pathways in HD and a worldwide research update on HD. Jimmy Pollard, MA from the USA will be presenting two papers on aspects of caring for a person with HD, which will be particularly useful for families, care workers and health professionals.

For further information please contact Huntington's Queensland (07) 3391 8833 or email [admin@huntingtonsqld.com](mailto:admin@huntingtonsqld.com)

National Conference  
on Huntington's Disease  
Brisbane • 9-10 September 2010

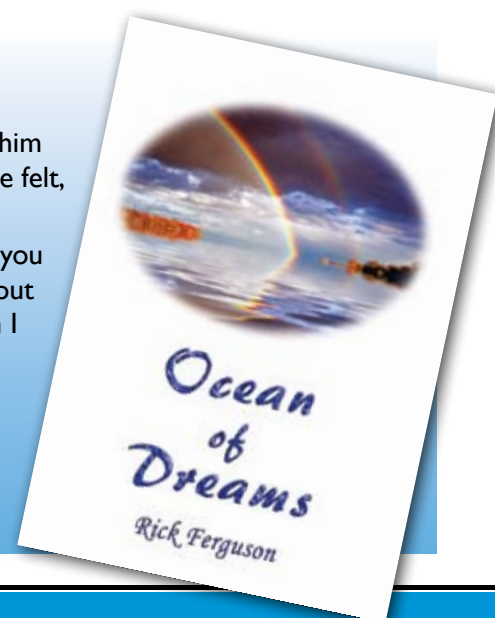
## Raising Awareness in Rural Victoria

Rick Ferguson believes that when one door closes another opens, which inspired him to write and publish a book of poetry *Ocean of Dreams*, which is based on love he felt, love he lost, and future promises of love.

Rick says "What happens when you are young and have the world in front of you, you take a simple blood test and find you inherited a mutated gene that will probably put you in the grave before your loved ones? I was 18, my life was just beginning when I was handed a death sentence. I had inherited Huntington's Disease."

Rick's book is not about HD, but he refers to HD and its effect on his life on his website. Rick, with Mary's help, is about to display his work at his library in Shepparton for a month to coincide with HD Awareness month in the US.

For more information or to buy a copy, go to [oceanofdreams-australia.com](http://oceanofdreams-australia.com)



# Thank you for your support

HV is constantly overwhelmed by the generosity of people like you who dig deep each year to assist our work with individuals, families and communities affected by HD across Victoria. Without your willingness to support us through membership, donations large and small, buying tickets to events, sponsoring people running marathons or volunteering your time; we would not be able to assist people, who turn to us for support almost every day of the year.

**These people are neither nameless nor faceless, they are people like Kylie, a 32 year old Melbourne mother who recently shared her story with us. We would like to now share her story with you so that you can measure for yourself the true value of your support in assisting people affected by HD.**

“To say that HD has had a huge effect on my life would be an understatement. When I first found out that HD was in our family and that I could be carrying the gene, I had no idea that it would take over my life as rapidly as it did. Only seven years ago, I was always on the go and loving my job as a hairdresser. I loved playing netball & basketball, at competition level, and almost took up a scholarship to go to America. Now I need a variety of medications and rely on others to help me with everyday tasks that I took for granted.

I have fond memories of my childhood in Shepparton; camping, swimming and playing in the great outdoors with my brother and sister. I loved the country life, spending time on the Murray River. I still go up there whenever I can to see family & friends. My Grandparents ran a business, and I remember helping out there regularly. My late teens, however, were quite disruptive. My parents separated when I was fifteen, I moved to Melbourne with my mother, brother and sister. Looking back, the strain that HD put on their relationship was just too hard for mum, and she had to do what she thought was best for the family. When I was eighteen & doing VCE, we found out that my dad had been diagnosed with HD. This came as a shock especially since we had no idea what it was, it did help us to understand some of what had gone on with dad in the past once we began to learn about the symptoms. I'm glad I was able to visit him when he moved to special accommodation in Melbourne & he was coping better then with treatment. Tragically, 3 years later, on New Year's Eve, dad was involved in a boating accident and drowned.

After my father's death, I decided to get the predictive gene test for HD. I found out I had the gene, so I knew I would someday develop HD.



**“I can honestly say that I would not have been able to cope without HV's assistance.**

I don't really remember how the diagnosis affected my thoughts at the time, I basically tried to put them to the back of my mind and get on with my life, otherwise it was too upsetting – that was my way of coping. It was a difficult time for Mum, as it began to hit home that all of her children could be carrying the gene. This is really hard for Mum who knows better than anyone what to expect as the disease progresses.

In my early 20's, I had finished my apprenticeship in hairdressing, I was working full time and enjoying the life that I had always wanted. I loved hairdressing, the contact with people. I had been in a relationship for about five years, and my boyfriend was supportive when I told him about HD in my family and that I was gene positive. He would often come to my appointments to give me moral support, which was a great help. Things began to change at work when I noticed I was losing concentration and it took me a lot longer to do everyday jobs. Nobody at work really noticed, but as my symptoms progressed I made the decision to leave work, I didn't tell anyone my reasons for leaving.

My partner and I moved to Queensland for two years and had a child together, before moving back to Victoria. It was at this time that a friend of mine said I should contact Huntington's Victoria. From the beginning this has been a very positive experience for me, mainly because of the practical support that means I have been able to get on with my life and be a mother. I can honestly say that I would not have been able to cope without HV's assistance. I am extremely blessed to have my six year old son and I enjoy every second of sharing my life with him. Being a Mum can be challenging and exhausting at times because of HD so I have my son at weekends and school holidays, but he is still such a big part of my life. He is just like any other six year old boy, he's so full on, always on the go, always talking. Although he isn't old enough to know about my condition, he still understands that I need a break sometimes. He says that I'm a “shaky mum”.

“HV has really helped me to continue to live a normal and enjoyable life, and I am just taking each day at a time...”

I recently attended a makeover day arranged by HV. It made me feel so special and beautiful to be pampered for almost six hours! But it also reminded me how much I miss hairdressing and the independence I once had. So much has happened over the last seven years, I have gone from being an active, sporty career woman to being constantly tired, having shaky movements and taking a variety of medications. Sometimes I find it hard to cope with the challenges that HD brings, but there are good and bad days. The message I have about living with HD is “you can do it”. There is always hope, always a way to keep going and remain positive. The important things still make life worth living, like seeing my son and spending time with family and friends. HV has really helped me to continue to live a normal and enjoyable life, and I am just taking each day at a time, in the hope that I can keep doing the things I love with the people I love for a long time to come.

**Our services are vital to people like Kylie, your ongoing generosity means that we can continue to be there for them when they need our support. By providing up-to-date information and education to the community and healthcare professionals, our staff ensure that people affected by HD can access the essential information, support and services they need.**

**Thank you for all of your support. You can continue to help people like Kylie by donating to our Tax Appeal today using the donation slip below.**

Please accept my gift to make a difference to people living with Huntington's Disease:

\$25    \$50    \$100    Other Amount \$ \_\_\_\_\_

Mr    Mrs    Ms    Miss    Dr

Name/Company Name: \_\_\_\_\_

Address: \_\_\_\_\_

Postcode: \_\_\_\_\_

Phone: \_\_\_\_\_ Mobile: \_\_\_\_\_

Email: \_\_\_\_\_

Payment Method:  Cheque    Money Order

(please make payable to Huntington's Victoria)

Or please debit my:  Mastercard    Visa

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Expiry:

## Dancing to make a difference

Property manager Jess Rice held a charity ball in April to raise awareness of HD, donating the proceeds to help others living with HD. The 250 guests that attended the glittering event enjoyed live auctions, silent auctions, raffles, a DJ and a sit-down dinner. The event raised a total of \$24,000 to assist the work of HV and Wesley Mission Victoria. “Jess is an amazing young woman” said Leanne Rayner, Fundraising Manager at HV. “We are delighted that she nominated us as one of her charities of choice and we will put the money to good use in supporting people across the state”.

Held in honour of her mum, Kerry, who is in the advanced stages of the disease, the event was an opportunity for Jess to speak out about the impact of HD on families like hers. “Not only does this disease affect my mum, her sister and family members, but my cousins, sisters and I are affected as we all have a 50-50 chance of inheriting the gene that causes HD”. Speaking fondly of her mum, aged 51, Jess says, “mum loved to go out and dance, have a drink and chat with her friends.” “Now she cannot walk or talk very well but remains the brave and caring person she has always been. I can honestly say mum would move the earth for us girls as we are her life and she is ours. My friends and family are a great support to me and my sisters; they really helped me to make the event a success too. If I can do it, anyone can give it a go!”

**For more information on holding a fundraising event, contact us or go to our website to download a fundraising kit.**



Giving it a go: Jess Rice is doing all she can to help others

## Community news

### Genetic discrimination – know your rights

In recent times, genetic science has opened major opportunities for medical advancement, but the ever increasing use of genetic testing and the related publicity has given rise to potential genetic discrimination. A recent research study by The Academic Unit for Psychiatry of Old Age at Melbourne University focused on the experiences of Australians who have a family history or who have undergone genetic testing for HD. Sixty participants completed a survey regarding their experience of genetic discrimination, adverse and unfair treatment, and knowledge about existing laws and policies surrounding genetic discrimination.

The findings revealed significant experiences of genetic discrimination and a concerning lack of knowledge of legal rights and avenues. "This inspired the production of a booklet and website, supported by a grant from the Legal Services Board, for people affected by genetic disorders, family members, caregivers and those professionals who give advice to these communities." Dr Anita Goh, Research Fellow explains, "The resources are not designed to replace legal advice, but to demystify and make accessible the relevant legislation and avenues for recourse for people that feel that they have experienced genetic discrimination. If members of the HD community feel they have been discriminated against, we recommend they seek advice from appropriate professionals."

For more information go to [respondgeneticdiscrimination.com](http://respondgeneticdiscrimination.com)

### Lifestyle can influence impact of HD

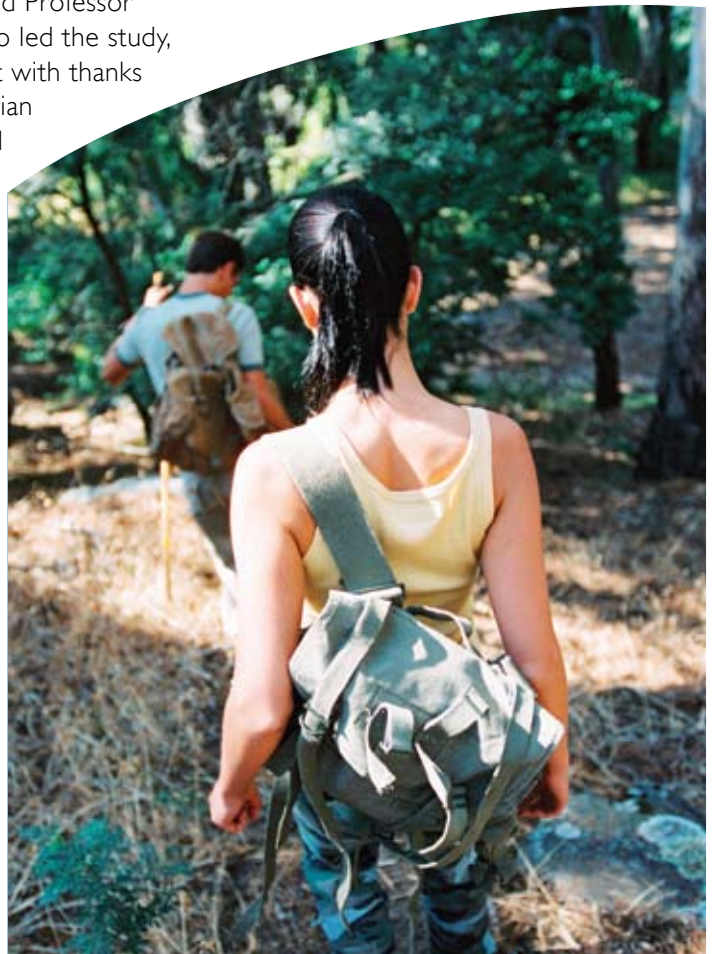
**Researchers at the Murdoch Children's Research Institute have found that individuals at risk of HD may be able to delay its onset by altering their lifestyle.**

In a study published in *Movement Disorders*, those with the genetic predisposition to HD who led a more passive lifestyle had an earlier age of onset than those who led a less passive life. Passive activities include watching television, talking on the phone, listening to music or undertaking sedentary occupations that lack intellectual challenge.

Dr Kaye Trembath and Professor Martin Delatycki, who led the study, recently told HV that with thanks to around 130 Victorian and 30 New Zealand HD patients who volunteered their time to be interviewed, the study produced results that provide a practical lifestyle choice for those at risk of HD. "We believe that those at risk of developing HD should minimise passive activities," said Dr Kaye Trembath. "We are not suggesting that people do no passive activities – we all enjoy these and they are important for down time," Professor Delatycki stated.

"What we are suggesting is that these passive activities are not dominant in the life of people who are at risk of developing HD. We encourage those at risk to have periods of physical and intellectual activity built into their daily regimen."

HV welcomes this research and sees it as a real opportunity to provide hope to those living with HD. "We are very excited about this research and we will be responding by advising our clients that there is something they can do to delay the onset of the disease that has such a major impact on their quality of life." Says Tammy Gardner, Client Services Manager.



We encourage those at risk to have periods of physical and intellectual activity built into their daily regimen

## Melbourne Fire Brigade encourages HV Supporters to 'Run Melbourne 2010'

If you missed out on the opportunity to take a challenge and support HV, we are again calling for people who want to make a difference to the lives of people affected by HD to join us on Sunday 18th July 2010 and Run Melbourne.

Presented by The Age, Run Melbourne is the community fitness event for everyone. With the right training, anyone, at any age and any fitness level can participate. Set yourself a 5km, 10km or half marathon challenge and start training today.

The Melbourne Fire Bridge Charity Running Team will again be running for HV and hosting the post event sausage sizzle, giving all HV supporters the opportunity to come together and celebrate their success. So, it's not only an opportunity to raise money for HV, but to meet like minded people who care about our cause. Greg Cotterill of the MFB told us 'HV is a charity close to the hearts of many runners in the squad. A long standing colleague and friend lost his battle to HD in 2008 and is sadly missed by is all. We want to do all we can to help other people living with this tragic disease, by taking part you can too!'

To sign up for the event go to [runmelbourne.com.au](http://runmelbourne.com.au)

If you want to be part of the HV team or need fundraising support, contact Leanne Rayner at [l.rayner@huntingtonsvic.org.au](mailto:l.rayner@huntingtonsvic.org.au), or on 1800 063 501



## We are moving

For more than a decade HV has operated from Warrigal Road, Ashwood. During this time many of our clients, partners and supporters have visited the site, accessed support and felt a sense of community. We acknowledge the importance of this space to many people and invite you to join us in the next chapter of the service, as we relocate to Hawthorn. In the coming months our vision for the future will begin to truly take shape – we appreciate your patience and understanding as we go through the essential transition and relocation. To enable us to relocate as efficiently as possible, we will provide a limited service between 23-30 June 2010. During this time, an answering service will be in place so please leave a message.

Our IT system will also be in transit, therefore emails will not be able to be accessed. The HV team will regularly review voice messages, however we will be restricted in our ability to respond to matters that are not deemed a priority during the move. All other business will be attended to when the office is fully operational from the 1st of July.

Don't forget to make a note of our updated contact details below.

If you require assistance during the relocation, please refer to the full emergency contact information list on our website, contact your GP, or call:

**Lifeline on 13 11 14 – 24 hour counselling support**

**CareLine 24 hours 1800 059 059 – support, advice and emergency respite**

## Contact Us

From 30th June we will be at our new premises

### Office Address:

16 Wakefield Street, Hawthorn, 3122

### Email:

[info@huntingtonsvic.org.au](mailto:info@huntingtonsvic.org.au)

### Web:

[www.huntingtonsvic.org.au](http://www.huntingtonsvic.org.au)

### Telephone:

03 9818 6333 or 1800 063 501 (Toll free)

### Fax:

03 9818 7333

