

## General Manager's Report



Welcome to the final newsletter for 2011. This has definitely been an eventful year for both the organisation and the HD community at large. In brief, some event highlights for the year included:

- Client support services were recognised by the International Social Work and Mental

Health community

- The first state wide HD Allied Health Meeting, hosted and facilitated by Huntington's Victoria.
- HV hosted a book launch on the Behavioural and Psychological Symptoms of HD .
- A number of educational seminars covering various topics were conducted throughout this year for example: A Will and Estate Planning seminar and building awareness of HD via participation in the Australian Physiotherapy Association Neuro-Special Interest Group.
- Establishment of the Meet and Greet group by community members which has been and continues to be well attended.
- Launch of our updated website with features that include an accessible homepage that provides short cuts and quick links to new sections within the website. These include a virtual library, family centre, online referral, younger person section, and living with HD section.
- HD community members were invited to participate as guest speakers to educate

genetic counselling students and scientists on the impact of HD and PTP on the individual as well as the family unit. This was well received and as such will be repeated next year.

The most prominent event of the year was the World Congress on HD as well as the IHA family day, both a resounding success. The IHA day attracted over 300 delegates who participated in the day, the most attendees at an IHA day yet. Attendees included national and international professionals groupings (i.e medical, scientists, researchers, academic, allied health, community sector) and various members of our national and international HD community.

Plans for 2012 will show to be an exciting and promising year for the organisation. We hope to bring you a pilot regional program to begin rebuilding the necessary links with our regional clients. HV has also begun discussions with relevant parties to address the community need for early access to superannuation and funding streams for IVF PGD. Finally we plan to co host the Inaugural Huntington's Victoria Gala Dinner with community member Jess Rice to be held at the Crown Palladium. However be assured that via our newsletter and our website you will be updated on any advancements.

Lastly on behalf of the board and staff of HV, I would like to wish everyone a Merry Christmas and a Happy New Year.

Tammy Gardner

General Manager

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## Quarter in Review

### IHA Day & World Congress on HD

In September 2011, Melbourne played host to the World Congress on Huntington's disease as well as the International Huntington's Association Family Day. Since its inauguration in 2009 at the World Congress on Huntington's Disease held in Vancouver, Canada the IHA Family day is now an integral part of the World Congress on Huntington's disease.

Both the World Congress and IHA Family Day attracted delegates from across the globe and provided the opportunity for the research and professional community to network with the HD community.

The IHA Family day provided the HD community with the opportunity to hear from national and international guest speakers and interact with them as well as panel members in relation to the topic areas outlined below:

- Youth living with HD
- Coping strategies
- Starting a family
- Integration of Multidisciplinary care in HD
- Relationships
- Living with HD

**International Huntington's Disease Association (IHA) Family Day**  
PROGRAM AND ABSTRACT GUIDE  
13 SEPTEMBER 2011

**TOPICS:**

- Youth Living with HD
- Coping Strategies
- Starting a family
- Integration of Multidisciplinary Care in HD
- Relationships
- Carers Living with HD

**THEME:**  
hope dignity awareness

2011 WORLD CONGRESS on Huntington's Disease  
Melbourne Convention and Exhibition Centre  
September 11-14, 2011

hope dignity awareness  
huntington's victoria

### International Allied Health Network

Huntington's Victoria as part of the WCHD hosted the inaugural International Allied Health Network Meeting with the aim of establishing a forum in which the global allied health community can provide peer support, collaborate on research and program initiatives, and be a point of reference for relevant knowledge and resources in relation to evidence based practice and research issues.

Following this meeting and at the conclusion of the WCHD, Huntington's Victoria via our website established an online forum where allied health professionals can register as a member and can utilise the discussion board or live chat to liaise with other allied health professionals. Since the launch of this forum in October, there have been approximately 40 participants who have registered. All allied health professionals working with people with HD are invited to register as a member. It is free to join and this can be done by following the link on the menu bar on the website.



#### Allied Health Network



"Evidence indicates that a team approach to care, in which health care professionals together consider all care options and develop an individual care plan for each client, can improve quality of life for the client."

Australian Government

#### Welcome!

Welcome to the Huntington's disease International Allied Health Network. The Network was established in September 2011 at the World Congress on Huntington's Disease 2011. The network provides allied health professionals with a common international platform by which to establish and develop the basis for closer working relationships across the international professional community.

This website provides a vital link to facilitate communication and share knowledge with colleagues within a professional context. The website features include these sections:

- About the International Allied Health Network
- List of Members
- Resources
- What's On - Professional Development
- Research Initiatives
- Discussion Board

#### Quick links

- What we do
- Frequently Asked Questions
- Glossary
- Join a HV Event

#### Member Login

Username   
Password   
 Remember Me

Log in »

### Genetic Support Network of Victoria- Patient Information Session

On Friday 2<sup>nd</sup> September two HD community members provided personal accounts of their own experience of predictive testing and the impact of growing up in a HD family to professionals and genetic counselling students. This talk was held at the Murdoch Institute at the Royal Children's and hosted by GSNV. The purpose was to educate both professionals and students on the 'human' elements of this process, and to encourage upcoming genetic counsellors to consider more than the CAG repeat and to remember the unique experiences of the individuals that played a role in their decision to undergo this process.

## Our Services

The Huntington's Victoria (HV) website continues to be improved and is now an integral portal for referrals to HV's client support service program and research updates. Huntington's Victoria is now a proud financial supporter of HDBuzz, an internet provider of high-quality news and information on laboratory and clinical research on Huntington's disease. The HV website receives direct live newsfeeds from HDBuzz that can be accessed directly on the HV website homepage or by following the link below.

<http://www.huntingtonsvic.org.au/research-update/hdbuzz>

During the first part of this quarter, Huntington's Victoria also launched the International Allied Health Network forum through the HV website. The network provides a common platform by which health professionals can establish and develop the basis for closer working relationships across the international professional community.

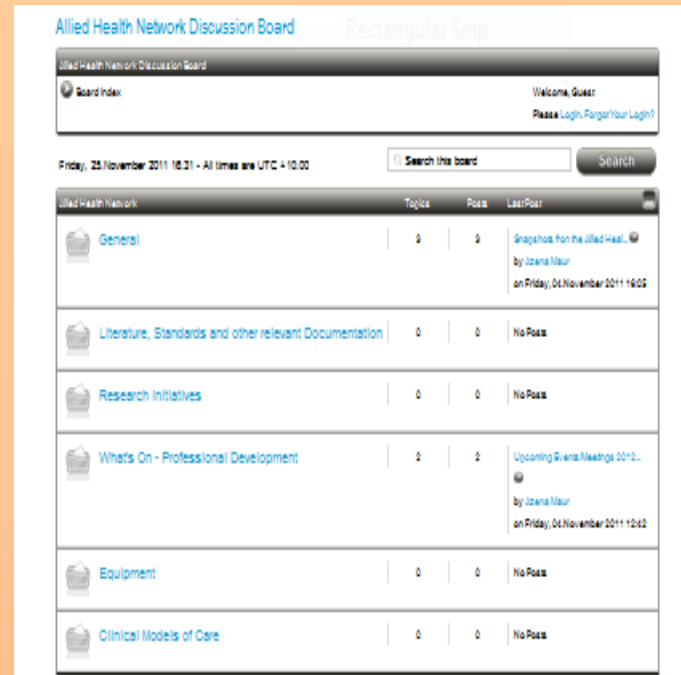
HV as an inaugural member of the network now hosts the Allied Health Network Discussion Board through our website. The HV website provides a vital link to facilitate communication and share knowledge with colleagues within a professional context. Some features of the website include the following

- About the International Allied Health Network
- Resources
- Research Initiatives
- What's On – Professional Development
- Discussion Board
- Live Chat

The Discussion Board and the Live Chat features of the website allows registered users to post new topics and comments, to access relevant information and to instantly send messages to other registered members who are online. If you are an Allied Health Professional and interested in learning and getting more involved with the HD Community and have not yet registered to become a member of the International Allied Health Network, please visit the HV website now and complete the registration form which can be accessed through this link <http://www.huntingtonsvic.org.au/allied-health-network/register>.

Upon registration, you will receive an email from a HV team member with your log-in details and password. To all members who have previously registered, please feel to use the discussion board and start sharing knowledge and information to our professional colleagues.

For further information about the International Allied Health Network, please contact Huntington's Victoria on 03 9818 6333



## Community Cabinet

On Wednesday 9th November staff from Huntington's Victoria attended a community cabinet meeting with the Prime Minister the Hon Julia Gillard MP as well as a number of Federal Ministers in attendance.

The community cabinet meeting provided the forum for the local community to ask questions of the ministers about issues of direct concern to them and the community they live in.

As part of this forum, HV had the opportunity to secure a private meeting with the Honourable Jenny Macklin MP minister for Families, Housing, Community Services & Indigenous Affairs in relation to matters that affects the HD community and the extended neurological community.

HV discussed the importance of having a representative from the neurodegenerative community as part of the advisory committee for the National Disability Insurance Scheme (NDIS). Every Australian Counts is the campaign behind this scheme whereby individuals, carers and families will have greater access to funds that will enable them greater independence and choice in regards to their supports. It will also provide a nationally consistent approach to disability ensuring a fair, efficient and effective system to funding allocation and access to supports.

HV also initiated discussion in regards to early access of Superannuation. HV has identified that for individuals with a neurodegenerative condition who due to illness cannot maintain employment and decide to access their superannuation early so to assist in funding of supports can be penalised 21% tax on drawing upon this early unless done by someone with expertise in this area.

IVF PGD was also a topic raised with the Hon Jenny Macklin MP in relation to exploring funding options such as Medicare for individuals wishing to consider IVF PGD so they can have a child free of genetic conditions such as HD. HV explained that whilst IVF has some coverage from Medicare, the PGD process which allows gene negative embryos to be implanted is not covered by Medicare or private health funds.



## Annual General Meeting

### Annual General Meeting

On October 26<sup>th</sup> 2011 Huntington's Victoria hosted their 38<sup>th</sup> AGM which was held at HV headquarters in Hawthorn. Following the formalities of the AGM, HV had 2 guest speakers present on the recent World Congress. Associate Professor Tony Hannan from the Howard Florey Neuroscience Institute provided an overview of the scientific presentations from the WCHD into a format that could be well understood by those outside of the research industry. Our second guest speaker was HD specialist Dr Andrew Churchyard (neurologist) who was one of the main organisers from the local organising committee for the WCHD. Dr Churchyard provided general feedback on the world congress and the interlink between the research/professional community and the 'lay' community.



## Our Partners

Huntington's Victoria in 2012 will be establishing a family therapy counseling program that will be accessible to all families under the Mental Health Care Plan as covered by Medicare. Huntington's Victoria has partnered with JoAnne Bevilacqua to run these sessions.



JoAnne Bevilacqua holds a BBSoc (La Trobe University); BSW (University of Melbourne); MaCIFT (La Trobe University) and is an Accredited Mental

Health Social Worker. She has been a practising social worker for 23 years. Whilst her early career was in the area of child protection and children's development, she moved into Adult Mental Health in 2003 when she commenced the social work position with the Neuropsychiatry Unit, based at the Royal Melbourne Hospital, North Western Mental Health.

JoAnne has always been committed to family involvement and inclusion in her work. Opportunity to meet with patients on the ward and their families promoted a desire to further advance her skills in the area of family engagement, and she undertook a Masters of Clinical Family Therapy, completed in 2006. She also established her private practice as an Accredited Mental Health Social Worker at that time.

In February 2011, JoAnne accepted a 9 month secondment to Alzheimer's Australia Vic, where she was working in Younger Onset Dementia. She holds firmly to the belief that Younger Onset conditions, such as Huntington's disease, and Dementia, directly impact not only the person with the condition, but the family members and the family functioning. She promotes family inclusion in all of her work, with family being both the family of origin, (parents/grandparents) and the family of creation (partners, children).

**If you are interested in utilizing this support please contact Huntington's Victoria to register your interest. Further information and details will be available in the new year.**

## Research Update

HV is a proud supporter and sponsor of HDBuzz a website dedicated to providing the most up to date research on HD in a format that can be understood by lay people. The research updates below are cited from the HDBuzz.net and for further information and to read the full article please access HDBuzz.net via the link on our website.

### Huntexil hits the headlines again

#### Dr Ed Wild on November 22, 2011

The results of the MermaiHD trial of Huntexil for movement problems in HD have been published in the scientific journal Lancet Neurology. Despite conflicting media reports, this doesn't change the need for a further trial before Huntexil can be approved for use in patients

### Safety trials add crucial piece to gene silencing jigsaw

#### Dr Ed Wild on November 14, 2011

Gene silencing drugs aim to slow down or prevent Huntington's disease by telling cells not to make the harmful protein. For the first time, a study has shown that gene silencing hits its target and is safe in the complex brains of rhesus monkeys.

### Melatonin treatment success in HD mice

#### Dr Ed Wild on October 31, 2011

Melatonin, a hormone produced by the pineal gland in the brain, is available in pill form and used to treat sleeping disorders. New research suggests that it can slow down Huntington's disease in model mice - great news, but it doesn't mean everyone should rush to take it.

### HD just got cilia

#### Dr Jeff Carroll on October 11, 2011

A better understanding of the normal role of the huntingtin protein would make developing treatments easier. Surprising new results from French researchers suggest that huntingtin influences tiny hair-like structures called 'cilia'. Now we need to figure out what it means for patients

### Huntexil hits the headlines again



Dr Ed Wild



Dr Jeff Carroll

#### IDBbuzz funding partners



## Get Updates from HV

Receive HV publications and email updates on events and HD research by updating and completing this form. All details provided will be confidential. Send completed forms to our office address detailed at the back of this publication.

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

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

State \_\_\_\_\_ Postcode \_\_\_\_\_

Phone \_\_\_\_\_

Mobile \_\_\_\_\_

Email \_\_\_\_\_

## Fundraising

### Car Rally

Maurie's Car Rally which was held on the 13th November was again another successful event. Maurie has been organising this event for a number of years, and each event is bigger and better than the last. This year Maurie and his family raised over \$2100.00 with the support of the community participation. HV would like to thank Maurie for his continued support of HV and the community at large. Money raised and donated to HV goes directly to service provision.



### Merchandise

HV have a number of items available for purchase and all proceeds go directly towards service provision. Items available for purchase include:

## Merchandise

**Huntington's Victoria Merchandise**

**Products available**

- T-shirt - \$25.00
- Kaleidoscope - \$20.00
- Key ring - \$4.00
- Calculator - \$4.00
- Lanyard - \$3.00
- Wristband - \$ 3.00
- Pens - \$2.00
- Bag - \$2.00

**Pack One: \$35.00**  
Includes: T-shirt plus all small items

**Pack Two: \$30.00**  
Includes: book (kaleidoscope) plus all small items

**hope dignity awareness**  
**huntington's victoria**

To purchase any of these items please visit our website and click on 'support us' and then follow the prompts.

## How to make a Donation

If you would like to make a donation to Huntington's Victoria please visit our

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

or simply complete the form on the left and send it back to us.

Donations over \$2 are tax-deductible.

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: □ □   □ □

## Diary Dates

### HV Christmas Closure

Huntington's Victoria will be closed over the Christmas and New Years Period. Our Office will be shut as of **5:00pm Thursday 22nd December and re-open Tuesday 3rd January at 9:00am.** Please refer to the attached **emergency contact list for support during this period.**

**Date:** Friday 23rd December - Monday 2nd January (re-open Tuesday 3rd January 2012)

### Carers Support Group

**Date:** 7th December 2011

**Time:** 2:00pm—3.30pm

**At:** Huntington's Victoria

**RSVP:** Glenys Johnson (03) 9818 6333

### Meet and Greet

**Date:** 13th December 2011

24th January 2012

6th March 2012.

**Time:** 7:00pm onwards

**At:** Huntington's Victoria

**RSVP:** Eleni 0431 084 297/ Mel 0421 799 747

## SAVE THE DATE— 2ND NOVEMBER 2012

### Huntington's Victoria Gala Dinner

**Date:** Friday 2nd November 2012

**Venue:** Crown Palladium

Huntington's Victoria in conjunction with community member Jess Rice will be co hosting an inaugural Gala Dinner at the Crown Palladium. This event will feature a 3 course dinner plus drinks, as well as entertainment, live auctions and raffles. For further information about the night please contact Jess Rice : j-rice05@hotmail.com.

or Huntington's Victoria if you would like to register your interest in attending.

## HELP HV AND THE ENVIRONMENT

### Are you environmentally friendly?

Huntington's Victoria would like your assistance to help the environment and keep our running costs to a minimum. To do this, all you need to do is to request to receive your newsletter via email. Not only is this better for our environment but it means more money can go directly into service provision.

To receive your quarterly newsletter electronically, please send an email to [info@huntingtonsvic.org.au](mailto:info@huntingtonsvic.org.au) and request 'electronic newsletter'. Please ensure to provide your contact name and details.



## Contact US

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

## **Our Mission**

To promote the needs and interests of people affected by Huntington's Disease.

## **Our Vision**

People affected by Huntington's disease living meaningful and hopeful lives as valued members of the community; with equitable, timely access to resources and empowered choices for care and support of the highest quality.

## **Through Our Service We:**

- Provide information and advice to help people with HD and their families make decisions about their care
- Connect people to the services and support they need
- Assist people with HD to live independently for as long as possible
- Provides support for carers and families
- Advocate to government policy makers and deliverers of services for improved access to services for people with HD
- Educate health professionals and direct care staff about how to support people with HD
- Increase understanding and knowledge of HD in the community
- Support research that improves the quality of life of people affected by HD

## **Contributions**

Huntington's Victoria welcome contributions from the community and service providers for our quarterly newsletter.

If you would like an article/event/photograph published in the next newsletter please contact Huntington's Victoria for deadlines.

We would like to extend our gratitude to those who have contributed to this issue of HV Contact.