

## General Manager's Report



Dear Community members,

It is with absolute pleasure that I submit my inaugural report to the community in my role as General Manager of Huntington's Victoria. During my two years at Huntington's Victoria I have been fortunate enough to meet and work with many members of the community however I would like to

take this opportunity to introduce myself to those of you who I have yet had the opportunity to meet. I am a trained social worker with a Masters Degree and over 10 years experience working in the health, aged care, mental health and disability sectors, as well as delivered various presentations at conference forums at state, national, and international levels.

My time at Huntington's Victoria thus far has been directed towards delivering an accountable, relevant and quality client based service that meets the changing needs of our community. In my role as General Manager I will now be responsible for the overall operations, management and strategic direction of Huntington's Victoria. With this focus in mind, I am committed to engaging with the community on a range of issues in relation to

- The provision of an update on existing funded client support services
- Discussions and identification of barriers/gaps in supporting the community
- The review and further development of the Community Advisory Committee (CAC) and Fundraising committees

A community consultation forum was proposed to occur on the 30th of November to discuss the current services provided by Huntington's Victoria and any gaps in service perceived by the community. However due to limited responses received we will endeavour to reschedule a more convenient time in the New Year after we have all recovered from our Christmas and New Year celebrations. I am also aware that our community members are extremely busy and that availability to participate in a forum may be limited. Consequently, I have arranged for varied types of participation to provide the community with additional avenues of contact and involvement, which include:

- Survey (written, telephone, email)
- Group discussion

Please contact us via Glenys Johnson at the office or email: [gjohnson@huntingtonsvic.org.au](mailto:gjohnson@huntingtonsvic.org.au) and let us know your preferred type of participation. If you select contact by telephone please also identify times and dates when you can be contacted.

I have recently had the opportunity to engage with other representatives of our community via our AGM. Our AGM was an enjoyable evening where staff, the board and members of the community had the opportunity to mingle in the surroundings of our new office. It also provided us a time for reflection, and to celebrate the contributions of Huntington's Victoria to the community as well as to the wider community throughout Australia. I look forward to meeting even more members of the community in the near future.



**Tammy Gardner**  
General Manager

### Inside:

<b>A Quarter in Review</b>	<b>2</b>	<b>Fundraising</b>	<b>4</b>	Huntington's Victoria Carers Group	4
The 2011 World Congress		Community Fundraising	4	Book Launch: The Behavioural and Psychological Symptoms of HD – A practical guide to assist in caring for a person with HD	4
Community Feedback	2	<b>Our Partners</b>	<b>4</b>	Contact Us	4
AGM	2	Macquarie Group Foundation	4		
National Conference	2	<b>Diary Dates:</b> Community Notice Board/Community Corner	4		
<b>Client Support Services</b>	<b>3</b>	2011 World Congress on Huntington's disease	4		
How to make a Donation	3				

# A Quarter in Review

## The 2011 World Congress Community Feedback

In September 2011 Melbourne will host the World Congress on Huntington's disease. Huntington's Victoria in collaboration with the National and International Huntington's Associations is currently planning and organizing a day for the community with the purpose to:

- Provide the community with a forum to discuss common issues with the broader communities
- Discuss practical strategies and accessible community services that can assist community members to manage with the disease in their everyday life.

In September of this year, Huntington's Victoria sent out to the community a feedback form that accompanied the newsletter requesting community involvement in deciding upon the **proposed purpose** and **topics** for the community day at the **World Congress**.

Huntington's Victoria believes community participation is essential in selecting the topics for this day as it is for you-the community.

Unfortunately from approximately 900 surveys sent out as part of the newsletter we received minimal response. Huntington's Victoria would like to take this opportunity to thank those members of the community who were able to respond for their time and effort, as the information collected has been invaluable.

The feedback received demonstrated, that all proposed topics are of importance to the community with particular focus on future planning with an emphasis on residential care and respite, and improving families resiliency and coping strategies when caring for persons with HD. Adapting to the changes in relationships between family members and the changing role of carer and the loss of intimacy between spouses, were also identified as areas of interest. If you would still like the opportunity to provide input into this day please contact Huntington's Victoria on 9818 6333.

## Annual General Meeting

Huntington's Victoria held its 37th AGM on Wednesday the 27th of October at our new office in Hawthorn. It was pleasing to see so many community members in attendance making this one of the most successful AGMs in recent years. We would like to recognise Judy Mackenzie who performed the role of chair and did so to perfection. The AGM was well supported with approximately 50 members of the community in attendance as well as professionals from Melbourne Health, MS Australia and the Department of Human Services. Points of discussion included:

- Our new building and its accessibility to our community being located in close proximity to public transport particularly trains and trams.

- Discussion of the financial report with particular reference to the Department of Human Services ongoing funding of our current Client Support Services programs
- The acknowledgment of Judy Mackenzie's retirement from the board. Judy has been a tireless volunteer for Huntington's Victoria for over decade serving in numerous capacities including fundraising as well as holding various board office bearer positions.
- The progression of the World Congress which will be held next year at the Melbourne Convention Centre.

We would also like to acknowledge and thank our much admired and respected community member and guest speaker of the evening Jan Ferguson. Jan spoke to the community with great eloquence about her experiences with HD and its impact. Jan spent some time answering questions from the audience and also referred to how Huntington's Victoria was able to offer her support and give her advice on where to go for help when it was needed.

## National Conference

The National Conference on Huntington's Disease was held at The Queensland Brain Institute at The University of Queensland in Brisbane on the 9th -10th of September 2010. Key note speakers included Professor Gary Egan and Jimmy Pollard, and other researchers such as Dr Trent Woodruff, Associate Professor Helen Cooper, Dr Valentine Hyland, Associate Professor Nellie Georgiou-Karistianis and Dr Jennifer Thompson. Community Members Michelle O'Brien and Naomi Van Dijk officially launched the "Our HD space" website ([www.ourhdspace.org](http://www.ourhdspace.org)). This website was developed in order to provide young people with an opportunity to easily access information, supports and communicate with other young people living in families affected by HD. Presentations were also given by each state association outlining current services provided to respective communities. You can access the state presentation for Victoria on the Huntington's Victoria website <http://www.huntingtonsvic.org.au>. A hard copy of all presentation materials is current being organised by the Australian Huntington's Disease Association (Qld) and will be available for \$15 in the near future. Huntington's Victoria would like to thank the Australian Huntington's Disease Association (Qld) particularly Barbara Gary and Gerry Doyle for their considerable time and effort given to the organisation and hosting of this national event.



# Client Support Services

## CASE MANAGEMENT PROGRAM

Huntington's Victoria Case Management Program provides support for people with Huntington's disease who are residing in the community and are not in receipt of any other case management services.

Our case management program provides person directed support to assist clients and their families to develop and achieve their goals, enabling them to continue residing in the community for longer; have greater community access, and/or address other health issues that are currently impacting on their overall wellbeing.

Huntington's Victoria would like to take this opportunity to introduce and welcome the most recent addition to the case management and ISP team Azena Maur. Azena completed a degree in social science followed by a Masters in social work at RMIT in 2009.

Azena joined the organisation as a locum in May 2010 and became a permanent staff member in September of this year. Azena joins Melanie Brinsmead and Lauren Lieberthal as part of this team.

When asked about her time here at Huntington's Victoria Azena commented how 'good it is to be part of a small organisation which provides a huge amount of support to its community' and how privileged she felt to 'be part of a team that makes a difference in the lives of people living with HD'.



New staff members from our AGM on the 27th October 2010  
(Left to Right) Azena Maur & Viv Davis

Azena's skill base stretches beyond that of case management, and she is currently the driving force behind the development of HV's new website that is due to be launched soon.

Azena is looking forward to meeting the community and providing case management to clients in need of this support.

If you would like further information on our case management program, or feel that this program would be of benefit to you please do not hesitate to contact Huntington's Victoria on **9818 6333** or toll free on **1800 063 501**.

## INFORMATION SUPPORT & EDUCATION SERVICES

Information Support & Education services is Huntington's Victoria longest running program, and continues to be the first point of contact for new clients, current clients, families, friends, professionals and the broader community who want to learn more about HD. You can access this service via the website and/or the telephone. The service is available via the telephone from Monday to Friday between 9:00am and 5:00pm. This service supports the community to access relevant information and education and provides an immediate response to client concern.

The Information, Support & Education (IS&E) team have also welcomed a new member of staff. Viv Davis joined the Huntington's Victoria team earlier this year and is thoroughly enjoying sharing the many challenges presented in the Information, Support and Education program with colleague Julia Caflich.

Viv Davis may be known to many members of the community in her previous role at Arthur Preston Centre. Prior to commencing at Huntington's Victoria, Viv was with Wesley for 9 years, four of which were at The Arthur Preston Centre where she worked within a multi disciplinary team to support many residents with HD to access the community, maintain independence, and enjoy quality of life.

With a well established background in Disability, Viv's focus has always been on advocacy and support for people within the community, and continually strives to raise awareness and educate people about Huntington's Disease.

To access this support please do not hesitate to contact Huntington's Victoria on **9818 6333** or toll free on **1800 063 501** to speak to either Julia or Viv who are both available for office based appointments.

## How to make a Donation

If you would like to make a donation to Huntington's Victoria and have internet access please visit our website [www.huntingtonsvic.org.au](http://www.huntingtonsvic.org.au) and click on the Donate Now button, or simply complete the form to the left and send it in. 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:

### Community Notice Board / Community Corner

#### 2011 WORLD CONGRESS ON HUNTINGTON'S DISEASE

**DATE:** 11-14 September 2011

**AT:** Melbourne Convention and Exhibition  
Centre

To keep informed on all developments  
relating to this conference please visit [www.  
worldcongress-hd2011.org](http://www.worldcongress-hd2011.org)

#### HUNTINGTON'S VICTORIA CARERS GROUP

**DATE:** 8th of December 2010

**AT:** 16 Wakefield Street, Hawthorn  
- See map below.

#### BOOK LAUNCH: THE BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF HD – A PRACTICAL GUIDE TO ASSIST IN CARING FOR A PERSON WITH HD

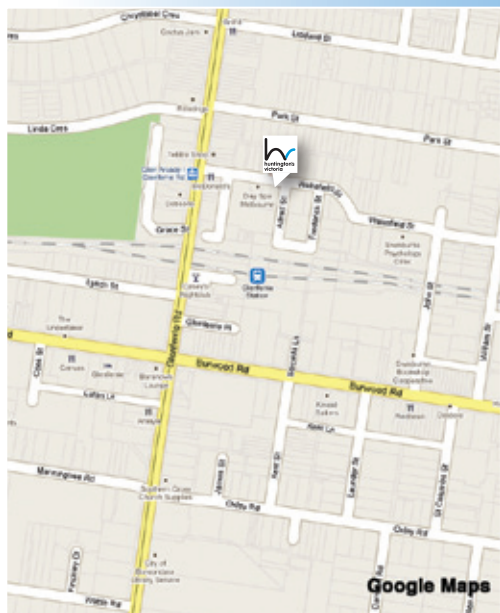
**AUTHOR:** Anita Goh

Research Fellow and Clinical Neuropsychologist  
The University Of Melbourne

**DATE:** Wednesday the 16th of February 2011

**AT:** 16 Wakefield Street, Hawthorn

**TIME:** 6pm



## Fundraising

### Community Fundraising

#### MAURIE'S CAR RALLY

Maurie Browne's Car Rally a regular fixture on the community's fundraising calendar occurred on the 7th of November 2010 in Narre Warren. Huntington's Victoria would like to acknowledge Maurie's boundless energy and determination in co-ordinating this event each year. I understand fun was had by all, and through a collaborative effort \$1134 was raised. Huntington's Victoria wish to express its gratitude to those who participated in this event and for their continued support of the HD community.

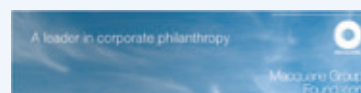
### Our Partners

The RACV Club recently selected Huntington's Victoria to be a recipient of a Rebel Sports Voucher worth \$1000. The RACV Club has a strong sense of community and is committed to improving the lives of Victorians through partnership, sponsorship programs and other community activities Huntington's Victoria wish to express our gratitude to the RACV Club for their continued support of our community.



#### MACQUARIE GROUP FOUNDATION

The Macquarie Group Foundation is one of Australia's oldest and largest corporate benefactors. The Macquarie Group Foundation actively supports Macquarie staff pursuing their own community interests and passions. Macquarie staff continues their financial support with the receipt of a \$1000 donation. Huntington's Victoria would like to recognise the Macquarie staff support of our community.



## Contact Us

**Office Address:** 16 Wakefield Street, Hawthorn, 3122

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

**Telephone:** 03 9818 6333 or 1800 063 501 (Toll free)

**Fax:** 03 9818 7333