

President's Update



Dear supporters,

I write to you this month with the news that we have finally moved into our new office and while we have experienced a few teething problems the team is settling in well. The new office is adjacent to the Glenferrie train station and the tram line is located a few feet

away from our front door. This particular location was chosen in order to provide the community with an accessible community space that currently includes a library as well as an operational social space. The location also affords the community ready access to our group room that can be booked out to members of Huntington's Victoria. For further details please contact Glenys Johnson on: (03) 9818 6333.

While it is still very early days we have also been encouraged to discover that our close proximity to public transport has enabled members of the community residing throughout Victoria more direct contact with the Client Support Services Team. So far the move has allowed Huntington's Victoria to provide a more accessible community space that we envisage will support the future development of a broader range of support services.

With this viewpoint in mind Huntington's Victoria will facilitate a community consultation forum in November with the purpose of engaging the community on a range of issues. Please refer to the Diary Dates section of this newsletter for further details.

It is also time for our Annual General Meeting (AGM), which will take place on the 27th of October so please note the date in your diaries. The AGM will be held at our new office and we look forward to seeing you at this event. The AGM will also be attended by our newly appointed General Manager. I am very pleased to announce that we have recently appointed Tammy Gardner to the position of General Manager of HV. Many of you will have had previous contact with Tammy during the last 2 years in which she fulfilled the position of Client Services Manager. We have recently created a broader role, in which Tammy will be responsible for the operations of the organisation as well as the overall management and strategic direction. Tammy has displayed an enormous commitment to HV and great energy while with us, so we are very excited that she will be undertaking the role of General Manager.

The year ahead is filled with possibilities for us with a new location, and opportunities to work collaboratively with you, our community, towards achieving better outcomes for families living with Huntington's disease.

I look forward to seeing many of you at the AGM.

The joys of moving!

The Huntington's Victoria team would like to report that the move has occurred and as with all relocations there have been a few unexpected bumps in the road. Supported by a large dose of chocolate and coffee we have weathered the storms – in some cases cyclones. We did experience

an unforeseen disruption to our ability to provide a direct service to the community due to unexpected breakdowns in our information technology and phone systems. We would like to apologise for any inconvenience this may have caused and assure you that all systems are now functional.

World Congress 2011 International Huntington's Association day

Huntington's Victoria in collaboration with the International Huntington's Association (IHA) will be hosting a community day at the World Congress 2011.

Huntington's Victoria is looking for expressions of interest from the community on topics to be presented on the day. Please see enclosed flyer for further information or contact Huntington's Victoria toll free on **1800 063 051** or **03 9818 6333** (if calling from a mobile).

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Community Round Up

Melbourne Fun Run

MELBOURNE FIRE BRIGADE (MFB) CHARITY RUNNING CLUB RAISES FUNDS FOR THE COMMUNITY

Once again Greg Cotterill and the MFB Charity Running Club have raised funds for the community. On a freezing cold Sunday morning when most of us are enjoying a sleep in or reading our morning newspaper over a hot coffee or chocolate, the MFB Charity running club were showing us all how it is done in memory of a well respected colleague who lost his battle with HD in 2008. Huntington's Victoria would like to take this opportunity to acknowledge the MFB Charity Running Club's continued support of the HV community.



Maurie's Car Rally

Maurie Browne's Car Rally has become a regular fixture of the community's efforts to raise much-needed funds. Due to its great success Laurie has organised another Car Rally on the 7th of November 2010 in Narre Warren. Entry fee will be \$25.

Please contact Julie for further details on 0418 566 206 or julzbrowne44@hotmail.com.

State-wide recognition of Carers: The Victorian Carer Card Program

The purpose of the Victorian Carer Card is to recognise and reward the unpaid role provided by carers throughout Victoria. Eligible carers may now apply for their Carer Card. Benefits available include:

- Discounts on a range of government and community venues, activities and services
- Free travel on public transport on Sundays and travel vouchers for two free return off-peak trips
- Benefits and discounts secured through the participation of corporate sponsors.

For further information on the Carer Card you can visit www.carercard.vic.gov.au or email carercard@dhs.vic.gov.au or call 1800 901 958 (toll free).

Do you have a concession card? Do you need help with Winter Energy Costs?

If you fall into any of the groups listed below:

- Disabled
- Visa holders
- Vision impaired
- People in crisis
- First home buyers
- Reside in regional Victoria
- Families
- Students
- Elderly
- Carers
- Veteran
- Parents

You may be eligible for concessions, benefits and assistance available to Victorians.

To find out more please visit www.dhs.vic.gov.au/concessions. The website includes eligibility information and how to apply, where appropriate.

Breakthrough in search for Huntington's treatment

Melbourne researchers believe they have made a breakthrough in the search for a treatment for Huntington's disease.

Dr Hatter from the University of Melbourne has discovered more about the mutant protein that is responsible for this condition. Dr Hatter believes this breakthrough will have implications for future therapeutic strategies in the treatment of Huntington's disease.

"Now that we can actually see these small clusters and we can measure how much of the protein is in these small clusters, it allows us to take our potential drugs that we might want to use to treat Huntington's disease and measure exactly how it's clustered," he said.

"It gives us a more direct handle on the exact processes that are occurring right inside the cells and I think this will be really quite important for future therapeutic strategies."

For further information please follow the link to <http://www.abc.net.au/news/stories/2010/07/28/2967082.htm>

Free community program in Regional Victoria

FREE RANGE SCIENCE

This program is designed to engage regional Victorian communities with science and technology.

If you'd like further information please visit www.riaus.org.au/freerangescience or contact Lisa Bailey Senior Programs Co-ordinator directly: lbailey@riaus.org.au or 0427 490 088.

Services Update

Client Support Services Team is recognised by the International Social Work Community



Huntington's Victoria Client Support Services Team was successful in submitting and presenting three papers for the 6th International Conference on Social Work and Mental Health that occurred from 28 June to 2 July 2010 in Dublin, Ireland. This conference focused on the challenges that are currently present within the health care and mental health care setting for practitioners, researchers and educators of social work on an international basis. These challenges identified changes in population groups, and the shift between a curative approach and interventions to health and maintenance of good health.

The three papers presented at this conference included:

- Client Self Directed Planning: A progressive approach to psychosocial care
- Innovative approaches to care a model of service delivery within a regional context of practice.
- Can case managers continue to meet the need of the client within parameters set by the current international climate?

These papers specifically highlighted the challenges Huntington's Victoria Client Support Services Team has encountered in providing person-directed services within the current economic environment and how this has directly impacted on overall service delivery to the HD community.

Quality of Life for Younger People in Residential Care

The Summer Foundation has been engaged by the Department of Human Services to undertake a Quality of Life evaluation for individuals receiving support services through the My Future My Choice (MFMC) initiative. A number of younger people in the HD community currently reside in residential aged care facilities and a small number are in receipt of a My Future My Choice package. This program aims to provide better living options for younger people in, or at risk of entry to, residential aged care facilities. The program's three strategic objectives include:

- To provide alternative supports
- To enhance disability supports within residential aged care
- To minimise future admissions to residential aged facilities.

This evaluation will assess whether there has been an improvement in the quality of life for young people in aged care, and will look at factors that foster or impede successful outcomes in order to inform future service delivery.

If you would like further information about this project please contact Nadine Holgate, Research Coordinator, at the Summer Foundation on (03) 9894 7006 or send an email to nadine.holgate@summerfoundation.org.au

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 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

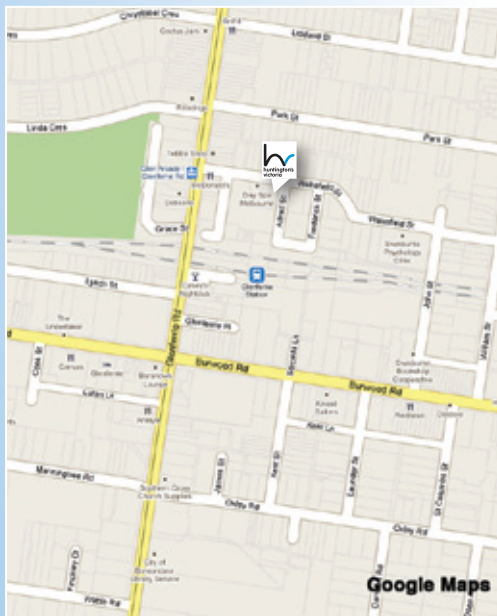
To keep informed on all developments relating to this conference please visit www.worldcongress-hd2011.org

HUNTINGTON'S VICTORIA AGM

DATE: Wednesday 27 October 2010

TIME: 7.00pm

AT: 16 Wakefield Street, Hawthorn
(Our New Location)



Contact Us

Office Address:

16 Wakefield Street,
Hawthorn, 3122

Email:

info@huntingtonsvic.org.au

Web:

www.huntingtonsvic.org.au

Telephone:

03 9818 6333 or
1800 063 501 (Toll free)

Fax:

03 9818 7333

HUNTINGTON'S VICTORIA CARERS GROUP

DATE: 29 September 2010

AT: 16 Wakefield Street, Hawthorn – See map below.

HUNTINGTON'S VICTORIA COMMUNITY CONSULTATION

This is an opportunity to provide the community with an update on existing funded client support services and discuss and identify barriers/gaps in supporting the community. We will also be reviewing the Community Advisory Committee (CAC) and consider how to continue to develop this forum into the future.

Types of participation:

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

DATE: 30 of November 2010

AT: 16 Wakefield Street, Hawthorn

EXPRESSION OF INTEREST:

If you are interested in participating in this forum please contact Glenys Johnson at the office or email: g.johnson@huntingtonsvic.org.au by close of business on 29 October.

Please identify your preferred type of participation – survey or group discussion. We look forward to hearing from you all.

CARER'S WEEK

DATE: 17–23 October 2010

Please contact Carers Victoria on (03) 9396 9500 or visit the Carer's Victoria website at <http://www.carersvic.org.au> to find out details about carer events that will be happening in your area.

Become a member of Carers Victoria

MEMBERSHIP BENEFITS

All members receive:

- Carers Victoria membership card
- 4 Carers in Victoria newsletters every year (read about current issues, helpful information and personal stories)
- Regular e-bulletins (for those with internet access)
- Invitations to special events and member forums
- Use of our library (with free mail out)
- Voting rights at the Annual General Meeting

Carer Support Group members also receive:

- 2 Carers Supporting Carers newsletters every year (read about issues and information that will help you run your carer support group)

COST OF MEMBERSHIP

- FREE for carers or former carers
- FREE for carer support groups
- \$20 per year for other interested persons
- \$100 per year for organisations

Contact member services at Carers Victoria to find out more on the numbers above.