

Diary Dates

2011 WORLD CONGRESS on HUNTINGTON'S DISEASE

Date: 11–14 September 2011
At: Melbourne Convention and Exhibition Centre
 For more information visit :
www.worldcongress-hd2011.org

HUNTINGTON'S DISEASE AWARENESS WEEK

At: 16 Wakefield Street, Hawthorn

Date: March 22nd, 2011

Time: 2:00pm—4:00pm

What: HV CARER'S SUPPORT GROUP

(Guest Speaker Stephanie Hansen– Family Relationship Services for Carer's; see attached flyer)

Date: March 23th, 2011

Time: 6:00PM– 8:00 PM

What: BOOK LAUNCH by Dr. Anita Goh

The Behavioural and Psychological Symptoms of Huntington's disease

Date: March 25th 2011

Time: 10:00AM—3:00PM

What: HV OFFICE OPEN DAY

Save this day to visit our new office or to have a chat with our Client Support Services Staff who will be available on the day. Our collection of information resources about HD will be available for loan as well as access to the internet and opportunity to provide feedback to our new website prior to its launch in April.

Cuppa and biscuits will be provided...



Community Notice Board

Maurie's Car Boot Sale

Maurie is having a car boot sale on Wednesday 16th March 2011 to raise funds for Huntington's Victoria.

Maurie is looking for anything in working order and in good condition to sell on this date. Items requested for example are: toasters, vacuum cleaners, tools etc.



To assist Maurie with his car boot sale please contact Maurie directly on ph (03) 97931587 or (m) 0438910555. Maurie is happy to collect items.

Advertise with HV



Contact HV Office for sale items, groups, activities and support groups that may be relevant to the HD community for a chance to advertise in our quarterly newsletter.

For further information contact Lauren Lieberthal on (03) 9818 6333.

Space is limited so, please notify us in advance.

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



CONTACT

Quarterly news for the community and supporters of Huntington's Victoria

No. 48, March 2011

General Manager's Report



It is with great pleasure that I write my first report for 2011 and wish current and new members a happy New Year.

Last year was a successful year for Huntington's Victoria and the HD community and as such I would like to take this opportunity to reflect on some of the many achievements of 2010 which include the following:

The relocation of Huntington's Victoria to Hawthorn

Huntington's Victoria relocated to its new premises in Hawthorn during the months of June/July 2010. As with any relocation it was not all smooth sailing however we all survived the move and now have settled into the new office. I have also been very pleased to see community members utilising the office as a drop in community hub. This location is providing the broader community and professional agencies with greater access to our staff and relevant information about HD. Indeed Huntington's Victoria is now able to host relevant professional network meetings that have enabled another avenue by which to build awareness of HD. The office location was chosen due to its central position, close proximity to public transport (trains and trams), to our freeways and to HD specialist clinics. I have been delighted to note visits from regionally based clients either pre or post clinic appointments.

Welcoming of New staff members to Client Support Services

Last year we welcomed two new staff members to the Client Support Services team. Viv Davis joined the Information, Support & Education program and Azena Maur joined our Case Management/ ISP facilitation program. Both staff bring their own professional expertise and commitment to the HD community as well as further expanding the skill base of the Client Support Services team.

Fundraising

Last year demonstrated once again the commitment of a number of community members who dedicate their efforts to raising much needed funds for the HD community. I would like to acknowledge the following community members for their contribution:

- Jess Rice
- Maurie Browne
- Simon Philpot
- Kristin Davies
- Melbourne Fire Brigade

Launch of "Our HD space"

The creation of the "Our HD space" website was the brain child of Michelle O'Brien, Naomi Van Dijk and Tony Mims. This collaborative effort of these dedicated community members went across state boundaries 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.

Given the accomplishments of 2010, Huntington's Victoria aims to maintain the momentum of success into 2011 and beyond. We hope to use this year to further develop and build on partnerships with Victoria's leading hospitals, Government departments and agencies as well as be responsive to client and community need. Through improved means of collecting data and information about our client group and gaps in service, we hope to use this year as a springboard in program development in order to achieve our goals of meeting client need.

With this in mind, we hope that more members of the community respond to our request for input into service delivery. This input will help steer the direction of our current and future service and ensure that the programs that are delivered are in fact what you- the community are asking for.

I would just like to finish by saying that I am looking forward to the year ahead and continuing to face any challenges in collaboration with the HD community.

Tammy Gardner
General Manager

Inside:

A Quarter in Review	2	HD Research Update	6
Client Support Services	3	Get Updates from HV	6
In Your Community	4	Fundraising	7
Community Profile	5	Diary Dates	8
World Congress Update	5	Community Notice Board	8
From Further Afield	5		

HD Research Update

The Academic Unit for Psychiatry of Old Age - by Dr. Anita Goh



Here at the Academic Unit in Kew, we are very active in HD research. We are still recruiting for some, so for more information, head to the AUPOA website

www.aupoa.unimelb.edu.au or contact me at goha@unimelb.edu.au

The Behavioural and Psychological Symptoms of Huntington's Disease (BPSHD)

This booklet clearly outlines the treatment, measurement, and management of the BPSHD. A public launch will be held for this booklet on 23rd of March 2011@ Huntington's Victoria. To access this booklet please contact Dr Anita Goh at goha@unimelb.edu.au or phone 9816 0513.

We are currently recruiting for the following studies:

PREDICT-HD 2.0 - This study looks at the link between the early signs of HD and brain pathology so we can target the appropriate point for treatment of the disease. We are currently in our 9th year of this study.

COHORT- The aim of the study is to collect clinical data and biological specimens to identify the natural course of illness and the nature of pathways in individual patients.

FuRST-pHD- This study aims to develop a rating scale to assess symptoms in early HD

HORIZON- The goal of this trial is to determine the safety of Dimebon 60mg versus placebo and its effect on mental abilities. Recruitment has closed for this study.

Other studies:

Motor symptoms in HD- Due to begin in 2011, this study measures motor symptoms in HD. The study will be jointly conducted by us and Professor Alison Perry at the school of Human Communication Sciences at La Trobe University. Recruitment will begin soon.

Genetic Discrimination & RESPOND-HD- Results of these studies revealed significant concerns and experiences of genetic discrimination and a concerning lack of knowledge of legal rights and avenues. Recruitment has closed for this study.

More information can be found on the website <http://www.respondgeneticdiscrimination.com>

The CAB Beta Study- Due to begin in 2011, this is an observational study of cognition in late pre-manifest and early HD in comparison to healthy controls. The study will be jointly conducted by us and Dr. Julie Stout's lab at Monash University. We have not yet begun recruitment for this study.

The Kingston Centre

The Clinical Research Centre for Movement Disorders and Gait at the Kingston Centre is investigating how the brain controls walking in people with Huntington's disease and are now looking for participants.

Participants will be required to donate 90minutes of their time to walk unassisted over a 7meter long electronic mat at 5 different speeds. The electronic mat will record each footstep with the aim to provide further insight into the pathways of the brain that are disrupted in people with HD. To participate, individuals must be able to walk independently and follow simple directions. Transport can be arranged. The Kingston Centre is located on Warrigal Road in Cheltenham. For further information or to register your interest please contact **Mary Danoudis** on **9265 1360**

Client Support Services

Information Support and Education Services

Information services, is Huntington's Victoria longest running program, and continues to be the first point of contact for new and established clients, families, friends, professionals and the broader community who want to learn more about HD.

In an effort to broaden the awareness of HD in the community, the IS&E service has been active in promoting and providing a range of educational support to the community. Over this past quarter, the IS&E team have experienced an increase in bookings for education sessions particularly from residential aged care settings as well as community/government service organisations. Frequently requested topics include:

- What is HD?
- Behaviour and Cognitive Changes
- Diet and Nutritional needs
- What services does HV provide?

The majority of requests for education sessions have been from metropolitan areas however we have received some requests from regional Victoria. Outcomes from education sessions include:

- Re-link or referral to a HD specialist
- Implementation of management strategies to minimise and cope with difficult behaviours.
- Referral for dietetic review to ascertain clients nutritional needs
- Referral to HV client support services for information or case management support.

In order to reach as many people as possible the IS&E team are currently exploring the use of technology such as Skype and teleconferencing to improve response time to those requesting support primarily in regional areas. HV are currently providing educational support to the community via phone, email, in office or on location sessions. Education sessions are able to be tailored to meet the specific needs of organisations and facilities.

The increase in requests for education sessions demonstrates that HD's profile is growing and that more people are interested in learning about the condition in order to provide better care and quality of life for those affected by the condition.

If you would like to make a referral for education or would like further information please contact either Viv Davis on 9818 6333 or by completing the referral form which will be available online by the end of April.

Case Management/Individualised Support Package Facilitation Services

Throughout this past quarter, Huntington's Victoria case management/ISP facilitation team have been actively improving and developing relationships with some of Melbourne's largest hospitals. These partnerships have been developed in order to provide a better continuity of care for our clients who are receiving support as either an inpatient or outpatient. This model of care ensures that those who require additional support have the opportunity to access HD specific support to identify and address gaps in their overall care.

Since introducing this model of care to the hospital systems, Huntington's Victoria has received an increase in referrals to our case management program and has worked collaboratively with the hospital staff, the client and their network to achieve positive outcomes. These outcomes have been in relation to maintaining independence in the community, improving social & community connectedness, and avoiding residential aged care placement by facilitating appropriate links and referrals to DHS Disability Client Services and registration on the Disability Support Register (DSR).

The hospitals who we currently have built a relationship with include:

- Royal Melbourne Hospital
- Alfred Health
- Austin Health
- Calvary Healthcare Bethlehem.

To make a referral to our case management services please complete our referral form (available online by the end of April) or contact Huntington's Victoria on 9818 6333.



