

General Manager's Report



I hope you all had a relaxing and safe Easter break and did not over-indulge in too much chocolate. During this quarter HV continued to develop our Client Support Services by engaging in program developments and initiatives which benefit our community through direct service provision.

Most noticeably, the re-development and launch of our new website enables ease of access to up to date information & research, links to other relevant websites as well as provid-

ing an opportunity to refer to our client support services. The addition of the virtual library also means that people are able to download and/or borrow information on line.

This past quarter has also seen the development of the "HD Alliance". This is a network that has been established between healthcare professionals who work with those impacted by HD in an effort to improve supports and services available in the community. Please expect feedback from these meetings in future newsletters.

Huntington's Victoria has also been involved in the following initiatives/projects :

Community Consultation

In order to enable community members to participate and provide feedback to HV we will now engage with the community via surveys posted on our website which is being well utilized since the launch. This will be advertised in the 'News' section of the website.

Younger Persons Project

Two university students approached HV to donate their services and skills. Both have agreed to complete the following project titled: "Engaging with and meeting the needs of younger people affected by Huntington's disease". In the next edition of HV Contact I will provide further information in regards to the project purpose and project objectives.

The Young People In Nursing Homes Alliance

HV was invited to attend a National roundtable on lifetime care and support for younger people which brought key individuals/ organisations together to explore major themes for the development and implementation of a lifetime care approach in Australia.

My Future My Choice Program Evaluation

I attended a service review workshop with the purpose of assisting in setting the framework for review. The workshop was attended by a select group and the outcome was a determination of agreed areas for review and suggested questions to help form the framework for review.

Building on Strategic Partnerships

Throughout this quarter, Huntington's Victoria has continued to build and develop our strategic partnerships with:

- Chronic Illness Alliance
- Social Work in Progressive Neurology Group
- Brainlink Network

World Congress

As you all are aware Melbourne is hosting the World Congress in September. As part of this World Congress there is the IHA family day for community members to attend. I am currently the chair person for the IHA organizing committee. Please continue to register your interest via our website as this years IHA day will prove to be a practical benefit to all.

Tammy Gardner
General Manager

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A Quarter in Review

The Behavioral and Psychological Symptoms of Huntington's Disease Book Launch

On Wednesday 23rd March 2011, Huntington's Victoria was host to a book launch on The Behavioural and Psychological Symptoms of Huntington's Disease – A practical guide to assist in caring for a person with HD.

This booklet clearly outlines the treatment, measurement, and management of the behavioural and psychological symptoms of Huntington's Disease. This book was written by Dr Anita Goh a Research Fellow and Clinical Neuropsychologist at the University Of Melbourne in collaboration with the Academic Unit for Psychiatry of Old Age in conjunction with NARI and was generously supported by a University of Melbourne Dreamlarge Knowledge Transfer Project Grant.



Huntington's Disease Awareness week

HD awareness week ran from Monday 21st March until Friday 25th March. In order to celebrate this week, Huntington's Victoria was host to a number of events including:

- Carer's Support Group
- Book Launch
- HV Open Day

It was great to see so many people attend these events in particular the book launch. We hope to build on numbers in the coming years, & encourage our members to take advantage of the events available to them.

Meet and Greet

Community members Eleni and Mel first met on the HD forum as they searched for support from others who understood what it meant to be impacted by HD. After catching up for dinner they identified how invaluable this support is and decided that this opportunity should be shared with others.

It was from this experience that Eleni and Mel hosted the first 'Meet and Greet' at the offices of Huntington's Victoria. It was attended by a variety of people all affected by HD in some way and allowed for those who attended to join in as they talked, listened, laughed and ate.

Due to the success of the first meeting, Eleni and Mel are excited to invite you to the second of what will hopefully be many Meet and Greets.

Date: Wednesday 22nd June 2011

Time: 7:00pm

Where: Huntington's Victoria
16 Wakefield Street
Hawthorn 3122

Huntington's Alliance Group

Huntington's' Victoria in conjunction with allied health professionals from Calvary HealthCare Bethlehem and Melbourne Health have formed a 'Huntington's Alliance Group'. The aim of this group is to

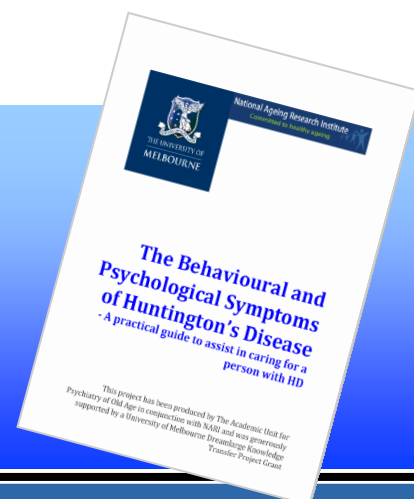
- Identify the clinical service needs of the HD community
- Identify strategies for addressing these service needs
- Identify the support needs of clinicians working with people with HD
- Identify avenues to improve the support of clinicians working with people with HD.

This group is available to all allied health professionals who are working with clients diagnosed with HD. Please refer to HV Diary Dates for information on the next meeting.

Find out more about the book....

The Behavioral and Psychological symptoms of Huntington's Disease A practical guide to assist in caring for a person with HD is now available on our website for download. Check out HV's updated website at www.huntingtonsvic.org.au

For further information please contact Huntington's Victoria at 03 9818 6333.



Client Support Services

HV New website—NOW LIVE!

The new/updated website is now live and available to the public as of Monday, 9th of May 2011.



The original Huntington's Victoria website was launched in late 2008 and since this time has served as an alternative method of information management and distribution to the community. The Huntington's Victoria website has enabled those directly affected by HD as well as the broader community to access information about the disease and the services available to them in the community.

This recent update of the Huntington's Victoria website has been pre-empted by the varying needs and representation of different groups within the HD community. Huntington's Victoria has also utilised this opportunity to further develop mechanisms via the website to continue to build awareness within the general community.

We have addressed these needs by redesigning the original Huntington's Victoria website by establishing:

- Sections in the website targeted towards particular groups in the community

•Living with HD

•Younger People

•Family Centre

- These sections also support and provide another access point to community websites such as The HD Advocacy Centre Forum and Our HD Space.
- Virtual Library to provide an additional means to access information
- Online referral links to access Huntington's Victoria Client Support Services
- Links to current research

The purpose of this revision is to provide a relevant and accessible website that will provide up-to date information about HD, studies and research as well as, list of available services in the community and links to other sources of information. Check our new website at

<http://www.huntingtonsvic.org.au>

Farewell to Julia Cafilich



After 8 years of dedicated service to the HD community, Julia has left the team at Huntington's Victoria. Throughout her time here Julia has been an asset to the organisation with her knowledge, experience and compassion she has shown towards our community.

Whilst we are saddened to see her leave, we wish her all the best in her future endeavours and hope that in her new role she will continue to advocate and raise awareness of HD.

On behalf of Huntington's Victoria and the HD community we thank Julia for all her efforts and hope that she will continue to stay in touch.

In your community...

Evaluation of life quality outcomes for My Future My Choice participants

The Summer Foundation has been engaged by Department of Human Services (DHS) to evaluate the quality of life outcomes for *my future my choice* participants.

This will involve interviewing people who are receiving *my future my choice* supports and/or their families members or significant others. The interviews will explore how *my future my choice* supports have impacted on the person's quality of life.

The evaluation aims to interview a total of 90 people to provide a broad range of experiences.

The outcomes of interviews will be analysed by the Summer Foundation, and a report on the findings will be provided to the Department of Human Services.

Who can participate?

Anyone who currently receives *my future my choice* funded supports is invited to participate in the evaluation. This may include:

- people who live in residential aged care (RAC) and receive supports through *my future my choice* to improve their quality of life
- people who have moved out of RAC into the community into either shared supported accommodation or other independent housing options
- people who have been diverted from entering RAC by receiving *my future my choice* supports.

Interviews

The interviews generally take about 1 hour and are conducted by an experienced health professional. Everyone's opinions are valued and are confidential.

The Summer Foundation will organise interviews to best suit the person's needs. The location of the interview will be arranged to suit the person and/or family member

and be scheduled for a convenient time and location.

Participants can nominate a family member to participate in all or part of the interview on their behalf, or they might like to have a support person assist them in the interview.

If a person is moving into a new *my future my choice* service, we may ask to do a before and after move interview.

Being involved

If you would like to participate in the evaluation and share your experiences since receiving *my future my choice* supports, please contact Nadine Holgate or Di Winkler at the Summer Foundation on (03) 9894 7006 or email nadine.holgate@summerfoundation.org.au.

PT Lonsdale Getaway

BrainLink is pleased to announce a 2 night holiday for carers to rest and refresh themselves.

All accommodation transfers, meals and activities will be included and full respite can also be arranged if required.

Where: Pt. Lonsdale Guest House

When: 27th to 29th of June 2011

If interested, contact Karen of BrainLink by the 20th of June on 03 9845 2956

or email clientservices@brainlink.org.au.



In your community continued...

Medical Companion Project

A free new service is available for regional travellers who are attending health appointments in Melbourne

On 8 March 2011, Travellers Aid Australia successfully launched a new pilot service to help regional Victorian travellers get to their medical appointments in Melbourne safely and confidently. The Medical Companion Project is an initiative in partnership with the Victorian Government's Transport Connections Program.

Approximately 50,000 regional Victorians travel to Melbourne each year for medical treatment. Many rely on others to drive or accompany them to Melbourne. When assistance is unavailable, patients may risk their health by delaying appointments or not going at all. Now trained volunteers are available to meet medical travellers at their train, taxi or bus platform at Flinders Street Station or Southern Cross Station.

Volunteers will accompany patients by public transport to and from their appointment in central Melbourne. The service assists people who are able to travel independently but feel anxious about using public transport or travelling in Melbourne alone. The program operates Monday to Friday 8am – 6pm. Out-of-hours service is possible depending on volunteer availability.

To use this free service, call 1300 700 399. Bookings are essential and a minimum 24 hours notice is required. You will need to purchase your own public transport tickets, but we will cover the cost of volunteer transport.

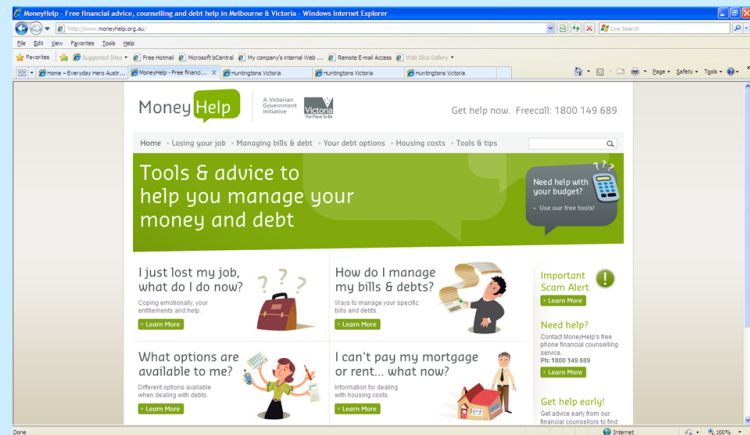


MoneyHelp

MoneyHelp is...

Free, confidential and independent financial information for Victorians experiencing difficulty paying their rent or mortgage or facing job loss.

- Contact MoneyHelp's free phone financial counselling service. **Ph: 1800 149 689**



Volunteer at a Patient Information Session—Genetic Support Network of Victoria & Genetic Health Services Victoria

The Genetic Support Network of Victoria in conjunction with Genetic Health Services Victoria are seeking volunteers who would be happy to share their individual experiences/stories with a range of professionals at a patient information session. Volunteers would be required to share their stories with 20-30 professionals with the following backgrounds:

- Clinical Genetics Services laboratory staff
- Geneticists and Genetic Counsellors
- Masters of Genetic Counselling students

If you are interested in participating please contact Huntington's Victoria for more information



HD Research Update

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



1. Neuropsychological tests are good clinical indicators of the disease process prior to reaching criteria for a motor diagnosis of HD. In a sample of 738 HD participants, and 168 control (no HD) participants, nineteen cognitive tasks were used to assess attention, working memory, psychomotor functions, episodic memory, language, recognition of facial emotion, sensory-perceptual functions, and executive functions. Overall, the cognitive battery could predict with greater accuracy the time to clinical diagnosis, when compared to motor rating scale.

Stout, J. et al.(2011). Neurocognitive signs in prodromal Huntington disease. *Neuropsychology*. Vol 25(1), 1-14

2. This London-based MRI study suggests that the cingulate area in the brain undergoes degeneration during early HD. Degeneration of this area may contribute to problems in mood, emotional processing, and visual working memory in HD.

Hobbs NZ, et al., (2011). The structural involvement of the cingulate cortex in premanifest and early Huntington's disease. *Mov Disord*. 2011 May 6. doi: 10.1002/mds.23747

3. An Italian study suggested that whole-body and brain cholesterol metabolism are impaired in participants with HD.

Leoni V, et al. (2011) Whole body cholesterol metabolism is impaired in Huntington's disease. *Neurosci Lett*. 2011 May 2;494(3):245-9. Epub 2011 Mar 22.

4. The objective of a study from the Johns Hopkins University School of Medicine, USA was to determine which factors are predictive of institutionalization in HD. In 739 participants, neurological findings, functional capacity, cognitive impairment, and CAG repeat length were all likely causes of institutionalization. In contrast with other conditions like Parkinson's and Alzheimer's, psychiatric symptoms were not shown to predict institutionalization in HD. The authors stated that this may illustrate the especially devastating nature of the movement disorder of HD in comparison with the other dementias.

Rosenblatt A, et al. (2011). Factors contributing to institutionalization in patients with Huntington's disease. *Mov Disord*. Apr 29. doi: 10.1002/mds.23716.

5. Researchers in Austria investigated whether HD-related deficits in emotion recognition and experience

are associated with specific changes in brain grey matter volume. In a small sample of 18 patients with HD and 18 controls, the patients with HD showed normal affective experience but impaired recognition of negative emotions (disgust, anger, sadness). The HD patients perceived the emotions as less intense and made more errors than non-HD participants. These deficits were related to degeneration in the emotion-relevant areas of the brain (insula, orbitofrontal cortex) and in memory-relevant areas (dorsolateral prefrontal cortex, hippocampus).

Ille R, et al. (2011). Emotion recognition and experience in Huntington disease: a voxel-based morphometry study. *J Psychiatry Neurosci*. Mar 1;36(2):100143. doi: 10.1503/jpn.100143.

6. Dr Anita Goh and Professor Edmond Chiu were asked to write a guest editorial about the journey of HD research – to be published in the August issue of the esteemed journal *International Psychogeriatrics*

Goh, A. & Chiu, E. (2011) Huntington's disease research and practice: Reflections on the journey made and lessons learnt. *International Psychogeriatrics*, in press.

IMAGE HD Project Update

Project lead by A/Prof Nellie Georgiou-Karistianis

The Project: Neuroimaging methods have gained significant momentum in Huntington's disease (HD) research in recent years with high resolution techniques, like new developments in positron emission tomography (PET) and functional magnetic resonance imaging (fMRI), providing a dynamic representation of brain function that enables insight into underlying cellular dysfunction. Although structural imaging (MRI) has been included in various large scale multi-site studies in HD (i.e., PREDICT-HD, TRACK-HD), given its sensitivity in reliably detecting progressive volumetric changes pre clinically up to 10 years prior to symptom onset, functional and other types of imaging methods may offer a more complete understanding of the complex web of interactions underlying the neuropathology of HD. IMAGE-HD is a "multi-modal" neuroimaging study based in Melbourne, incorporating a range of neuroimaging techniques in the one large-scale longitudinal study. Baseline data from 35 early symptomatic, 35 pre-symptomatic and 35 healthy controls was collected during 2008-2009 and re-scanning of subjects is currently in progress. Neuroimaging results from the baseline study (structural, microstructural, functional) will demonstrate how neuroimaging methods can sensitively

detect brain changes in pre-symptomatic HD up to 15 years prior to disease onset. Neuroimaging methods enable a more complete and comprehensive understanding of the mechanisms involved in neural breakdown that characterizes this devastating disease, and longitudinal studies will determine the sensitivity and reliability of potential imaging biomarkers in tracking disease progression, as well as to evaluate their links to clinical outcomes.

Progress to date: As of April 2011 we have completed the second stage of longitudinal data collection, 18 months from initial baseline testing. We have one further time-point remaining due to commence May 2011. Since baseline we have highlighted subtle changes in brain tissue size (grey and white matter volume) associated with Huntington's disease. We have also observed very small differences in the way this tissue is structured (via diffusion tensor microstructural analysis). Based on these results we have proposed a biomarker which describes how the brain changes during the early stages of this disease which considers both volume and microstructure. We are currently preparing a paper on this data for publication.

Further examination of how the specific circuits in the brain function during set-response shifting (numbers and letters task) have found that during this task, the function of specific parts of the brain (ie frontal cortex) also reflect general cognitive and emotional difficulties that symptomatic HD patients may experience. This suggests this brain region is important in coping effectively with HD. Finally, we are also examining how volume, microstructure and brain function change over time. These findings will be reported by A/Prof Nellie Georgiou-Karistianis as part of a key note presentation at the *World Congress on Huntington's*

World Congress Update

The 2011 International Huntington's Disease Association Family Day

The IHA Organising Committee is delighted to invite you to join the Biannual International Huntington's Disease Association Family Day (IHAFD) to occur on Sunday, the 11th of September 2011 and to be held at the Melbourne Convention and Exhibition Centre.

Since its inauguration in 2009 at the World Congress on Huntington's Disease held in Vancouver, Canada the IHAFD is now an integral part of the World Congress on Huntington's disease. The IHAFD upholds the essential principle that the HD community and lay person's participation is fundamental for community capacity building. The program for the day aims to demonstrate and enhance this proposition by:

- Providing the community with an opportunity to meet and discuss common issues with other members of the national and international community
- Enabling discussion of practical strategies and accessible community services that can assist community members to manage with HD in their everyday life

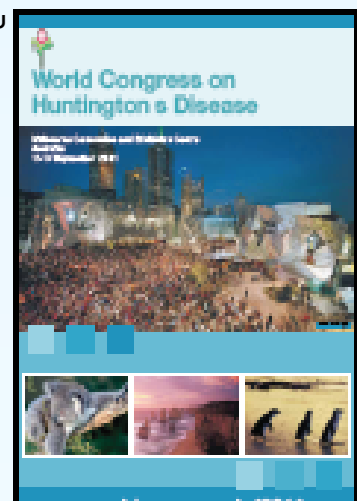
The sessions of the day will be given by recognised medical experts, researchers and community leaders from across the world in their area of expertise in relation to these topics:

- Youth living with HD
- Coping Strategies
- Starting a family - IVF
- Accessing Community Resources (Support Groups/ Information Provision)
- Relationships (e.g. managing behaviours within a relationship)
- Living with HD (Carers)

The IHA Day will provide an innovative and informed introduction to the World Congress on Huntington's disease and provide attendees an opportunity to meet other like minded people, to engage with new knowledge on core principles for future change and discuss realistic strategies that will assist you when you return home.

Please join us for the IHA Day by returning a completed **Expression of Interest** and/or **Registration Form** as included in this newsletter.

Register at:
www.huntingtonsvic.org.au



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 Everyday Heroes

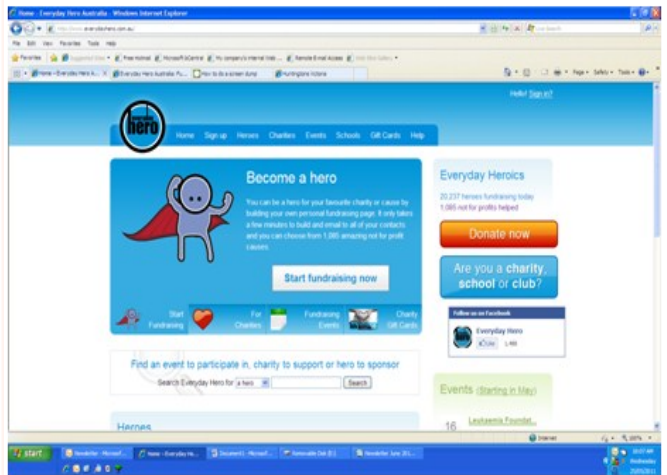
Huntington's Victoria would like to acknowledge a number of 'everyday heroes' who are undertaking their own personal challenges in an effort to raise both awareness and funds to support those affected by HD.

All of our 'everyday heroes' are in some way uniquely impacted by HD, however they all share a common goal which is to improve the quality of life of those affected by HD.

Huntington's Victoria is committed to raising the profile of HD throughout the broader community and this can only be achieved with the support of our community. Therefore we would like to recognise the contribution of the following people who have assisted in this process and are also raising much needed funds:

- Justin Morris www.everydayhero.com.au/justin_morris
- Nicola Duckett www.everydayhero.com.au/nicola_duckett
- Clint Goddard runmelbourne.everydayhero.com.au/clint_goddard
- Jade & Anita Wells www.everydayhero.com.au/run4hv

If you or someone you know would like to make a donation to any of the above individuals or learn more about them please go to the above links.



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

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

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

2011 International Huntington's Disease Association Family Day (IHA Day)

Date: 11 September 2011

At: Melbourne Convention and Exhibition Centre

For more information visit:
www.huntingtonsvic.org.au

Meet and Greet

Date: 22nd June 2011

Time: 7:00pm onwards

At: Huntington's Victoria

RSVP: Eleni 0431 084 297/ Mel 0421 799 747

HV Carers Group

Date: 29th June 2011

Time: 2:00pm - 4:00pm

At: Huntington's Victoria

RSVP: 24th June to Huntington's Victoria on 9818 6333 or email info@huntingtonsvic.org.au

HD Alliance Group

Date: 10th August 2011

Time: 4:15pm– 5:30pm

At: Huntington's Victoria

RSVP: Viv Davis (03) 9818 6333

Wills & Estate Planning Evening

Date: Tuesday 21st June 2011

Time: 7:00pm-9:00pm

At: Huntington's Victoria

RSVP: Stefanie Hansen (9871 2603) or shansen@each.com.au

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 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

Web: www.huntingtonsvic.org.au

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

Fax: 03 9818 7333

Community Notice Board



*Hope, Dignity,
Awareness*

**HUNTINGTON'S
VICTORIA**

16 Wakefield Street
Hawthorn 3122
PO Box 2112
Hawthorn 2112

Phone: 03 9818 6333
Fax: 03 9818 7333
E-mail:

info@huntingtonsvic.org.au

'Meet And Greet' Evening



on Wednesday 22nd of June
at 7.00 pm here at H.V.

This evening is dedicated to
people who are affected in
some way by H.D.—
please come along and join
Eleni and Mel.

For further information , please contact:

Eleni : 0431 084 297
Mel: 0421 799 747

Or Huntington's Victoria : 9818 6333
Toll free: 1800 063 501

Family Relationship Services
for Carers
 in partnership with
Huntington's Victoria

Invite you to a
Wills and Estate Planning Evening


Are you the parent or carer of a child or person with a disability?

- Are you concerned about their future should something happen to you?
- Do you have questions about making a will or Powers of Attorney?
- Are you seeking information about the different trusts and future planning?

Then come along and listen to our guest speakers:
 Angela Cursio (Solicitor at Fischer McCrae)
 Mirko Oklobdzija (Centrelink)


Date: Tuesday, 21st June 2011
Time: 7.00 – 9.00pm
Venue: Huntington's Victoria
 16 Wakefield Street
 Hawthorn 3122

RSVP: Stefanie Hansen (9871 2603 or shansen@each.com.au)
 by 17th June 2011



Huntington's Victoria
CARERS SUPPORT GROUP

Carer's Support Group Meeting



WEDNESDAY 29TH JUNE, 2011
at 2.00 pm.
16 Wakefield Street, HAWTHORN

This is a great opportunity to reunite and meet other carers, to discuss and share your own knowledge and experiences

If you are interested in attending, please contact Glenys or Viv : 9818 6333

or via email : info@huntingtonsvic.org.au

by Friday 24th June. Thank you.

HANK YOU TO THOSE THAT HAVE ALREADY EXPRESSED THEIR INTEREST!

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.