



May 2010

NEWSLETTER

HUNTINGTONS QUEENSLAND

CONTENTS

Making the Connection - Conference 2010	1
From the President	2
Diary Dates	2
EPAs & AHDs	2
Farewell to Julie Morrow	3
Finding a Dentist	3
Young News	4
Our HD Space	4
YPAHD - Canada	4
The Circus Comes to Town	4
RentConnect	5
Physiotherapy Guidance	5
Newsletter on CD	5
Strategies to Enhance Communication	6
Fundraising	7
Association's Contact Details	8



National Conference on Huntington's Disease

Brisbane • 9-10 September 2010

MAKING THE CONNECTION – CONFERENCE 2010

Huntingtons Queensland, in collaboration with the Queensland Brain Institute – The University of Queensland, is hosting a National Huntington's Disease Conference in Brisbane in September this year. The Conference will provide an opportunity to meet and share knowledge and experiences with family members, researchers, allied health professionals, care workers, members and supporters.

KEYNOTE SPEAKERS – BRIEF BIOGRAPHIES

Professor Gary Egan is a Senior Principal Research Fellow at the Howard Florey Institute, University of Melbourne and Associate Director and Professor in the Centre for Neuroscience, University of Melbourne, and Deputy Director of the National Imaging Facility. He has published over 140 papers and over 200 abstracts in peer reviewed journals. He leads the Neuroimaging and Neuroinformatics Laboratory undertaking neuroscience imaging research in human diseases including high resolution functional and structural brain mapping in Huntington's Disease (HD). He is also Head of the Small Animal Magnetic Resonance (MR) Imaging and Spectroscopy Laboratory where he leads a translational research programme investigating small animal models of HD.

Jimmy Pollard MA holds a Master's Degree in special education, a nursing home administrator's licence and is a popular author of books on HD. He is well known to people with Huntington's Disease and their families around the world and has been an invited speaker at national meetings in Ireland, Scotland, England, United States and Australia. A frequent speaker at meetings of the International Huntington Association, the European Huntington Association and the World Congress on HD, he has worked in Huntington's Disease specialty care programmes in nursing homes, assisted living and hospital settings for over 20 years.

Dear Friends

The National Huntington’s Disease Conference is now only four months away. The theme **“Making the Connection”** reflects the meeting and sharing of knowledge and experiences with all those involved in the Huntington’s field – family members, community services, researchers, allied health professionals, care workers and members and supporters of all HD Associations across Australia.

Professor Gary Egan will be presenting a keynote address on Multi-modal MR Imaging of Neural Pathways in Huntington’s Disease and a worldwide research update on HD. It is especially pleasing that we are also able to cover research being conducted locally in Queensland and also in other Australian States. You will see the various sessions in the Conference Programme enclosed with this Newsletter.



Jimmy Pollard, MA from the USA will be presenting two papers on aspects of caring for a person with HD. These presentations will be particularly useful for families, care workers and health professionals. Many of you will remember the article in the February 2009 Newsletter “Huntington’s Disguise”, a chapter from Jimmy Pollard’s book “Hurray Up and Wait”. I am sure his presentations at the Conference will attract as much positive feedback as did the above Newsletter article.



The Hon Bill Shorten MP the Parliamentary Secretary for Disabilities and Children’s Services is also attending the conference and will give an Update on Current Initiatives in Disability, Care and Support in Australia.

In addition to these keynote presentations, we have a varied and interesting programme – for details of these please refer to your Conference Programme. I hope you are able to join us for the two days of the Conference.

Gerry Doyle, President

DIARY DATES

May

27 Brisbane Carers’ Support Group

June

7 South Coast Family Support Group
11 Toowoomba Family Support Group

July

6 or 7 Kids’ Skating Day – to be advised
14 Brisbane Carers’ Support Group

**Enduring Power of Attorney
and Advance Health Directives**

The School of Social Work and Human Services at The University of Queensland is seeking participants who are attorneys appointed under an EPA or who have completed an EPA or an AHD in the past two years for a project that aims to investigate the issues associated with the Queensland forms and suggest improvements. For further details contact Carlie Rocco on **(07) 3346 7314** or c.rocco@uq.edu.au



Farewell to Julie Morrow

It is with regret that we advise you that Julie has tendered her resignation as Senior Welfare Officer effective 14th May 2010. Julie joined our staff in February 2005 as a part-time Welfare Officer and when Gwen Pratten retired in June 2009, Julie was appointed Senior Welfare Officer. Under Julie's guidance, the Welfare Service has continued to offer a valuable and supportive service to HD families. Growth has been dependent on staffing resources and funding; however given these restrictions, Julie has been instrumental in significantly increasing support offered to young family members, providing a benchmark from which to continue this support. We are thankful for her vision and dedication.

On behalf of the Management Committee and staff, I wish Julie well in her new appointment. Thank you Julie for your commitment to the role of Senior Welfare Officer. You have ensured that the Welfare Service has maintained its direction and focus, provided generous support and guidance to staff in the Welfare team and been a valuable and dedicated member of our whole team.

Thank you Julie, all the best.

Barbara Gray, Operations Manager

Dear Families

More than five years ago I started working at the Huntington's Disease Association. I wasn't really sure what was ahead of me at that point, but now feel very fortunate that I have had the opportunity to assist many families across the state and liaised with an ever expanding array of community, health and residential services.

It is with mixed feelings that I have resigned from my position and will be leaving the Association on May 14 to take up a new position with Ozcare as a Dementia Co-ordinator.

Although I'm looking forward to embracing a new challenge, I know I will miss the contact I have with families. The support relationships I have formed with many of you will remain very special to me.

I would like to thank Barbara and the Management Committee for their support and in particular Christine and Theresa for their dedication. I would also like to thank Iris Simpson and the specialists at the HD Clinic for the opportunity to participate in the monthly clinics.

My warmest regards

Julie Morrow



Are you looking for a special needs dentist?

The Australian Dental Association (Queensland Branch) is able to provide you with contact details of dentists who can assist with special needs patients.

Please phone them on **(07) 3252 9866** for details of your nearest dentist.



YOUNG NEWS

Our HD Space – A Website for Young People

Hi everyone!

The new website for younger people is live! It caters for eight year-olds to eighteens +. You can check it out at <http://ourhdspace.org> and feedback is welcomed.

Please pass the link onto anyone you feel may benefit from visiting the site.....spread the word!

A big thanks to the Scottish HD Association who shared a lot of content in the different age information sections from their youth site www.hdscotland.org/youth/

Congratulations to Michelle O'Brien, Namoi VanKijk and Tony Mims for their hard work and commitment in getting the Australia wide project off the ground. The site is amazing! Michelle O'Brien will be addressing our *Making the Connection Conference* in September in Brisbane.



YPAHD – Canada



YPAHD stands for Young People Affected by Huntington's Disease. They are a chapter of The Huntington Society of Canada made up of young people ranging from 16 to mid 30s. This dynamic group of young people have got together to help other sufferers of Huntington's Disease, their families and is also there for friends or carers. They want to reach out to the younger people not only in Canada but those who live in all corners of the world. They would like to assist you in any way that they can; to try and make *your* 'journey' with HD a little less bumpy. YPAHD was initiated during the 2008 National HD Conference.

If you are interested in finding out about YPAHD, please go their website www.ypahd.ca

The Circus Comes to Town

From time to time, the Lions Club of Brisbane MacGregor Inc hosts children's circus shows and movie days around Queensland. Children of Huntington families are invited to register their names with the Lions Club who will then notify you when a nearby event is coming your way.

Lions are hosting events in Maroochydore, Kawana Waters, Harbourn, Carrara, Biggera Waters, Mackay, Rockhampton, Townsville, Thuringowa, Gladstone and Nambour up till Christmas 2010.

All parents need to do is contact them with your name, postal address and phone number and they will put you on their mailing list.

Contact: Lions Club on phone (07) 5570 6775





RentConnect

RentConnect, a Queensland Government initiative, helps Queenslanders to find and secure a tenancy in the private rental market. RentConnect officers work with people to identify what type of assistance they may need. They can:

- advise how to find a rental home
- help people to understand the rental application process
- help prepare a rental application.

RentConnect officers may also put people in contact with local real estate agents and providers of community services.

RentConnect is now available at the following Housing Services offices:

<p>Brisbane North Level 3, 18 Banfield Street Chermside Qld 4032 Phone: 3896 9900</p>	<p>Brisbane South Level 1, 221 Logan Road Buranda Qld 4120 Phone: 3405 5300</p>
<p>Brisbane Central 505 St Pauls Terrace Fortitude Valley Qld 4006 Phone: 3872 0320</p>	<p>Central Queensland (Rockhampton) 229 Musgrave Street North Rockhampton Qld 4701 Phone: 4938 4089 Toll free: 1800 801 176</p>
<p>Caboolture 60-78 King Street Caboolture Qld 4510 Phone: 5431 2501</p>	<p>Gold Coast Robina Town Centre Robina Qld 4230 Phone: 5583 2200</p>
<p>Townsville Level 2, 143 Walker Street Townsville Qld 4810 Ph 4760 7378</p>	

For further information on RentConnect please contact your nearest office in the above table or phone 1300 880 882.

New Physiotherapy Guidance Document

Physiotherapy is becoming more frequently recommended for people with Huntington’s Disease (HD) but to date, there have been no specific implementation guidelines. The Physiotherapy Working Group of the European Huntington’s Disease Network (EHDN) has developed a comprehensive Guidance Document for Physiotherapists. It aims to assist therapists in implementing a plan of care that is consistent with current best practice in physiotherapy provision to people at all stages of HD. The document will be reviewed and updated as new research becomes available.

The current version (180 pages, February 2010) is available (free of charge) for download at:

<https://www.euro-hd.net/html/network/groups/physio> or <http://freedownloadbooks.net/ehdn-doc.html>

Would you like to receive our Newsletter on CD?

If you would like to receive the Huntingtons Queensland Newsletter on CD, please let us know by contacting our Administration Officer, Anne Stanfield, on (07) 3391 8833 with your postal details.



STRATEGIES TO ENHANCE COMMUNICATION

Introduction

It is important to understand that communication is a two way process, and that changes in one person mean that modifications are often required on the part of those around them to make communication successful and enjoyable.

It is therefore important to devise a system to establish an effective way of communicating needs, feelings and emotions. Both parties can use these strategies:

1. Slow rate of speech

Model this yourself. Pause between sentences. Encourage the person with HD to “slow down a bit” so that words do not run together.

2. Overemphasize key words

The main goal is to understand the basic message being conveyed. You can do this by saying, “just tell me the main words of what you want to say”.

3. Repeat or rephrase the message

Ask them to repeat or rephrase their message. “I am sorry, I am not following that; can you tell me again in other words?”

4. Simplify the message/offer cues

Ask the person to show you via gesture or pointing to clarify the message. You can achieve this by asking questions. “Tell me the two main words. Give me the key word or thought.”

5. Ask for clarification

Repeat message back. “Did you say . . .?”

6. Spell part of the message

“Could you spell that?” You can use verbal spelling, written spelling or a letter board.

7. Use Yes/No questions (be specific)

This makes responding to questions easier.

8. Refocus the person on topic

Use the person’s name or say “We are talking about . . . now”.

9. Go from general to specific

For example “Are you talking about family?” then “Are you talking about your daughter?” etc.

10. Monitor preservative (repetitious) behaviour and provide feedback

Reduce the number of times you change topics during a conversation. Allow some time to pass before introducing a new topic. Let the person know when they are stuck on a topic. “Let’s talk about now”.

11. Allow adequate time for communication

This means making time to fully understand the message and giving the person time to think of a way to respond.

12. Reduce distractions when having a conversation

13. Use communication aids if they have been found to be useful

Try letter boards, word boards and picture boards. All communication aids need to be designed individually and change, as the person’s needs change. The basic guideline in achieving effective communication is for the listener to consciously *accept the responsibility* for the conversation exchange. Because of the cognitive deficits, which occur, the person with HD often needs to rely on external cues and guidance from the listener to achieve communication. It is also important to realise that whilst you accept the responsibility for the exchange, you must not control the conversation. When interacting with a person with HD who has communication difficulties, it is recommended that you speak with a Speech Pathologist to help you implement, monitor and adjust communication strategies.

REMEMBER *It is the skill that degenerates, not the need to communicate.*



FUND RAISING

FINANCIAL ASSISTANCE

We have received and gratefully acknowledge major financial assistance from the following donors:

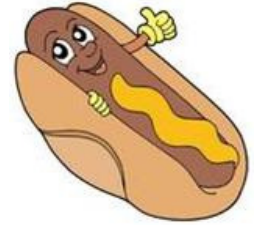
*S Gordon C Rolley M Harriman
Z Walker K Horton C Taylor
H Wilson D Hewitt*

*Ipswich Multicultural Projects Inc
JW Bell & Associates
Wagstaff Piling*

BUNNINGS SAUSAGE SIZZLES

Thanks once again to Bunnings for their ongoing support through their weekend sausage sizzles. In March we raised \$1100 at Bunnings Rocklea.

It would not have been possible without our kind volunteers Ray Bellert, Anita Smith, Kevin & Emma Cunnington, Cheryl & Bob Dowling and Anita Sundhom. Two more days are booked – North Coast Support Group 22/5/10 and Rocklea again 13/6/10.



DONATIONS ARE ALWAYS WELCOME!

If you would like to donate to Huntingtons Queensland and have internet access – just go to our website www.qahda.com and scroll down to the 'Please Make a Donation' section on the bottom left and click on the button <CLICK HERE> and follow the instructions. All donations are receipted for taxation purposes.

LORI SEDGMAN PAINTING RAFFLE

Our sincere thanks and appreciation to Lori Sedgman for her kind donation of a painting for raffle at the March



Abstractions Plus Exhibition on Bribie Island. Many thanks too, to Marg Turner for donating the frame and organising the raffle and sale of tickets, raising \$317.

A BIG THANKS TO TOOWOOMBA GOLF CLUB!

We would like to thank the members of The City Golf Club Inc of Toowoomba for their generous donation of \$500. We appreciate their support.



A GREAT GOLF DAY AT HOWESTON GOLF CLUB

Our thanks also go out to Jan Szlapak and Wendy Edwards for raising \$650 at a golf day at the Howeston Golf Club at Birkdale in Brisbane. We'd also like to thank those who donated on the day, the golfers who participated and volunteers who all helped to make it a very successful day!

OUR WEB DESIGNER – DIANE ALLAN

Some time ago Diane Allan designed our Huntingtons Queensland website and has continued to maintain it over time. It's a wonderful resource and we sincerely thank Diane for her great work.

THANKS TO WILL STANFIELD FOR HIS IT ASSISTANCE

Finally, we'd like to thank Will Stanfield for donating a PC for our Annerley office. We also appreciate his expertise and time spent in setting up our wireless network and email systems.



HUNTINGTONS QUEENSLAND

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Website: www.qahda.com

Australian Huntington's Disease Association (Qld) Inc
is a not-for-profit service organisation.
Established in 1976.

Our Mission is:

To provide professional support and advocacy for all persons affected by Huntington's Disease in Queensland.

Our Services Include:

- Providing individual and family support
- Facilitating the HD Day Respite Program
- Facilitating support group meetings
- Recreational activities for families with young children
- Organising respite holidays
- Providing information to families and health professionals
- Distributing a regular Newsletter
- Co-ordinating the annual HD Awareness activities
- Fundraising activities

Management Committee 2009/10:

President	Gerry Doyle
Vice President	Ray Bellert
Secretary	Pam Cummings
Treasurer	Darren Careless
Members	Nadia Farha
	Cliff Farmer
	Denis Kelly
	Jan Mealy
	Jan Szlapak

Staff Members:

Operations Manager	Barbara Gray
Senior Welfare Officer	Julie Morrow
Welfare Officer	Christine Parfitt
Welfare Officer	Theressa Byrne
Day Respite Assistant	Lydia Hudson
Telemarketing Officer	Helen Johnston
Administration Officer	Anne Stanfield

