NEWSLETTER

HUNTINGTONS QUEENSLAND

May 2011

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FROM THE PRESIDENT

Dear Friends

This year is fast developing and proving to be both busy and interesting. It is with pleasure that I can announce Huntingtons Queensland's success in securing a large grant from the Department of Communities – Disability Services. The opportunity to put forward our case for this grant came suddenly and we had to set to it without delay. The welfare staff and the office staff provided very useful input. Cliff Farmer, Alan McKinless and Christine Parfitt (who is currently on maternity leave) joined in a 'brainstorming session' that we hurriedly organised. Mike collated the information and wrote up our business case to show that we had both the needs for this grant, and the expertise to administer it. This allowed us to put forward a submission that we can be proud of. It was successful to the tune of $300,000 that we can use to provide aids and equipment to assist our families and their carers. We already have a good list of possible uses to which we can now put serious thought.

On the 16th and 17th of May I attended a forum on Housing and Design and Specialised Accommodation Options for People with Complex Support Needs. I addressed this forum and put forward Huntingtons Queensland's interests. It was at this forum that the Health Minister announced the above mentioned grant.

Best wishes to wish all our families and members!

Gerry Doyle, President

DIARY DATES

June 2011

6th June	Gold Coast Family Support Group
6th, 7th & 8th June	Bundaberg & Fraser Coast Regional visit by Tressa Byrne & Iris Simpson
15th June	Eastern Suburbs Satellite Respite Group
24th June	Toowoomba Family Support Group

……oOo……

Hello everyone! I would like to say a very big thank you on behalf of Murray and I, for all the kind wishes, lovely cards, letters, emails and gifts that you have sent congratulating us on the birth of our beautiful daughter, Lauren Adell. She is a beautiful, happy and healthy baby and we feel truly blessed that she is a part of our family. Lauren is three months old now, where has the time gone? She has everyone wrapped around her little finger – especially her big brother, who absolutely adores her.

I hope you are all healthy and well and look forward to catching up with everyone when I come back to work in a few months time. In the meantime and in my absence, please remember that you can call Theressa or Lesley if you have any questions or concerns or just need someone to talk to. They are only too happy to help. Take care everyone.

Christine Parfitt

FROM THE OPERATIONS MANAGER

I am settling in well here at Huntingtons Queensland. Thanks to all who have been helpful in my introduction to the organisation. It is a great team to work with. It is inspiring to see the level of effort and ability that so many put into their work here. This includes the welfare officers - our front line troops who I would particularly like to thank, our very hard working and efficient office staff, our really great volunteers and last but certainly not least our committee, led by Gerry.

I am getting to know many of the families and members. I have made a start with the support groups, travelling to Toowoomba to share lunch and discussions with a lovely group of people. As usual, I welcome your contact and thoughts on any ways that we can improve our service, or be of assistance to you.

I am developing a concept that should prove useful as a means of entertainment and as a fundraiser. Some of you may be aware of a singer called Helmut Lotti. He is known in Australia mainly through the Ovation TV channel, but is hugely popular worldwide. He sings across a wide range of musical styles including classical, swing, the crooners, and pop, as well as specialising in songs relevant to a particular country such as South Africa and Russia. I have secured approval from his management company to use his music in our fundraising events. The format that I have in mind is initially to stage an event at Annerley, where we would project two Helmut Lotti DVDs onto a large screen and play the music through a top quality sound system. While this would not be the same as a live concert, it would be significantly better than watching on TV. As well there would be the sense of occasion of the event. If you are not already familiar with Helmut Lotti you could be in for a big surprise as well as a very good evening of entertainment. The selections that I would like to present first are his DVDs on Swing and South Africa. There will be an intermission with light refreshments available. I am anticipating a ticket price of $20. I am aiming at this being a great night of entertainment and coming together, not just fundraising, so if the admission price is an obstacle, I have a limited number of free admissions that I can offer.

After the initial evening, I would like to take the event to regional areas based on our support groups. This would enable us to further both of the aims of these events, and hopefully to provide something special to our members and families in these areas.

In addition to this, I have plans to produce other theatre nights, with maybe a play that we could put on, attending an external production as a theatre group, or a concert. If you are interested in what I have outlined above could you please email me at mike@huntingtonsqld.com. I am interested in the response to the 'Helmut Lotti concert'. I am also interested to hear from anyone who would like to join in with the production of a play and whatever skills or resources they might have to bring. Likewise I am interested in hearing from anyone who can sing, dance, entertain and would like to work towards a concert or talent contest format.

Finally on a different subject, we are looking to get a list of people who would be able to volunteer to help out, particularly for our Tuesday day respite activities. Any help would be greatly appreciated and would share the load from the current willing but overworked helpers. You would be interacting with our Day Centre participants, with involvement in their ten-pin bowling and musical activities and outings and a little bit of food and drink service and clearing up afterwards. As well as being helpful, you might find such volunteering to be personally very rewarding. We'd love to hear from you if are interested in helping us out.

It's great to be a part of the team.

Mike Mclean, Operations Manager

WELFARE NEWS

Much has been happening at Huntingtons Queensland over the past couple of months. Christine is still on maternity leave, but has made herself available by telephone and email, and has called in at the office from time to time, to offer her help and support with various matters. Meanwhile Lesley and Tressa have been doing their best to maintain as consistent a service as possible to our families affected by HD and to meet needs as they arise. They have been working hard, and with great success, to cover the extra workload. Anne and Helen have been a great help at the front desk. I've also chipped in with encouragement and assistance where I can. And Iris Simpson has been a great support over the past few months. Many phone calls have gone her way and she has also accompanied the welfare officers when meeting some of the new clients.

The surrounding support groups have been well attended lately including our latest Brisbane and District School Holiday Activity Group at Settlement Cove, Redcliffe. The day started off much the same as the few days prior – overcast with rain periods. We struggled with the decision of whether or not to call it off. However we decided to go ahead, with the worst case scenario being that we would have to walk around inside a shopping centre for a number of hours. Then the sun came out, the children swam in the pools and walked along the beach collecting shells and we all admired the numerous turtles popping their heads out of the water into the beautiful sunshine. We then had the enjoyment of sharing fish and chips at a picnic table together. A lovely day was had by all.

The Day Respite Centre has continued this year, albeit in an altered format. In order to try and expand our service to those outside of the Day Centre, we have commenced a "coffee catch up morning" on the first Tuesday of the month. At present it is still early days, with a small number of participants, and only on the North side of Brisbane, but we're hoping that it will become a regular occasion for those who would like to spend a few hours with others who are in similar circumstances to themselves. Day Respite at Annerley has continued in a similar format to that offered in the past, with a mix of activities such as bowling, music as offered by our very talented music therapist, Mark Penman, cards and games, and the occasional social outing. We had morning tea and a tour of Barb's delightful garden last month. This was very much enjoyed by the entire group. This month, at the request of one of our Day Centre participants, we visited Mayes Cottage at Kingston for morning tea.

The East side group has continued with various clients and their carers attending, depending on the activity. This year we have ventured 'overseas' to Stradbroke Island for lunch at the little Ship's Club, and had a day at Macleay Island where we met one of our usual members on his own turf. These days are open to anyone on the Bayside, client or carer who is interested in attending, and are usually a lot of fun for all of us.

Report compiled by Michael McLean, Operations Manager, with valuable input from Theressa Byrne and Lesley Frazer (Huntingtons Queensland Welfare Team)

The following article is reprinted courtesy of UQ News Online (The University of Queensland)

RESEARCH OFFERS CLUE TO HALT HUNTINGTON'S DISEASE

Surprising findings from a study into the brains of transgenic mice carrying the Huntington's Disease mutation could pave the way for treatments which delay the onset and progression of this devastating genetic disease. Researchers at the Queensland Brain Institute (QBI) have found that the brains of mice with Huntington's Disease nevertheless retain populations of the precursor and stem cells which can give rise to new neurons. The potential for stimulating the production of new neurons in Huntington's Disease patients thus remained high, according to Dr Tara Walker, the postdoctoral fellow who carried out the work in the laboratory of Professor Perry Bartlett.

"Combined with previous findings which show that environmental enrichment and antidepressant treatment delayed both the onset and progression of Huntington's Disease in mice, these findings are encouraging," she says. Huntington's Disease (HD) is a neurodegenerative disorder that results in progressive motor, cognitive and psychiatric deficits which eventually lead to death.

Currently, there is no known cure. However, the research, published this week in PLoS ONE, holds out hope that retained cell populations in the brains of Huntington's Disease patients could one day be manipulated to replace degenerating neurons.

"Now we know that the capacity to generate neurons is retained in animals in even advanced stages of Huntington's Disease, further research will need to explore what stops this process from occurring," Dr Walker says.

"This may not only allow the restoration of neurogenesis, but may also allow this process to be harnessed to repair other areas of neuronal cell loss."

CAN YOU HELP US REDUCE OUR RUNNING COSTS?

At Huntingtons Queensland we are constantly seeking ways to keep our costs down so that we can put more money into providing assistance to our families. You can help us by opting to receive your Huntington's Newsletter by email rather than by post.

If you wish to help us, please send an email to admin@huntingtonsqld.com with your name and contact details. If you are a health professional, please include the name of your organisation.

Alternatively, please let us know if you DO NOT wish to receive our Newsletter, by EMAIL OR POST.

The following article has been reprinted from the AGSA Newsletter February 2011 Issue 93 with kind permission from Sydney IVF and The Association of Genetic Support of Australasia Inc.

GIVING YOU PEACE OF MIND FOR A HEALTHY BABY

Sydney IVF is pleased to announce their support of the 'PGD Assistance Program'. The Program has been created by generous donations to provide financial assistance to families in the community who would otherwise be unable to afford Preimplantation Genetic Diagnosis (PGD).

PGD is an advanced screening technique that can determine whether an embryo has a genetic condition, common examples include cystic fibrosis, Huntington Disease or muscular dystrophy. Tests for over 160 different genetic conditions have been developed to date. More tests are being developed as required. PGD is most commonly used by couples who are aware of the possibility that their children risk inheriting a serious genetic condition.

The PGD Assistance Program provides qualifying couples access to Sydney IVF's PGD services – either at no out-of-pocket cost for PGD treatment expenses, or for a co-contribution, depending on their financial circumstances. Both levels of assistance provide PGD treatment for two cycles and two additional cycles to use any tested but frozen, stored embryos within 12 months or longer, for further pregnancies if a baby has resulted.

Couples can be considered for the PGD Assistance Program by submitting a completed application form providing information about their income, expenses and medical history, along with a supporting letter from their healthcare professional familiar with their genetic condition.

A selection committee assesses each application based on a set of eligibility criteria. This committee is independent and comprised of members of the genetic field and the broader community. The selection committee meets throughout the year with closing dates available on this site.

The PGD Assistance Program helps support families in our community whose lives are affected by a genetic disease and the associated financial hardship to have the opportunity to consider PGD treatment in their quest to have a healthy baby.

For more information on how to apply, visit www.pgdassistance.com or call 02 8484 7600.

Note from the Editor: *The Sydney IVF PGD Assistance Program is available to all qualifying Australians. You do not need to reside in Sydney or NSW.*

GENETIC TESTING FOR HUNTINGTON'S DISEASE

Jennifer Berkman, Senior Genetic Counsellor, Genetic Health Queensland

A large proportion of pre-symptomatic genetic testing for Huntington Disease (HD) in Queensland is facilitated by Genetic Health Queensland (GHQ), a Queensland Health state-wide service. GHQ offers clinics in Brisbane, Gold Coast, Nambour, Toowoomba, Bundaberg, Townsville, Cairns, Ipswich, Gympie, Hervey Bay, Rockhampton and Mackay. Specialist clinical geneticists from Brisbane travel to all of these locations and in most locations there is also a resident genetic counsellor. Testing can also be facilitated by private geneticists, though there are few of these in Queensland.

Genetic testing for HD can be accessed via two different pathways:

Predictive (pre-symptomatic) testing is offered to people who either have no symptoms, or only mild symptoms of the condition. This testing provides information about an individual's future health and there are international guidelines for how this should be performed. The process involves four consultations:

1. An initial information and discussion session with a geneticist/genetic counsellor
2. A consultation with a psychiatrist or psychologist to discuss coping strategies and psychological wellbeing
3. Another consultation with the geneticist/genetic counsellor to arrange a blood sample to be taken
4. A results session with the geneticist/genetic counsellor. An optional 5th session with the geneticist/genetic counsellor is also offered to discuss family planning, coping strategies or any other issues that have arisen.

Diagnostic testing is offered to individuals who are showing signs of the condition. Testing is therefore providing a diagnosis relating to a person's current health status. There are fewer guidelines for this type of testing and this can be arranged by various specialists including geneticists, neurologists and psychiatrists. It usually only involves two sessions: an information and blood collection session and a results session.

Some individuals who are known to have, or are at risk of carrying, an HD gene mutation are concerned about passing this on to their children. For each child of a person with an HD mutation there is a 50% chance that the child will inherit it. There are several ways of preventing the mutation from occurring in the next generation.

Some couples choose to not have children, to adopt, or to use donor eggs or sperm. However some couples prefer to have their own biologically related children and there are two main options to avoid having a child who has inherited the HD gene mutation.

The first option is ***prenatal diagnosis*** which can be undertaken to determine whether an existing pregnancy carries the gene mutation. This is usually performed at 12 weeks' gestation, and involves a sample being taken from the developing placenta. This procedure carries a small risk of miscarriage. If, after testing, the mutation is found, parents can opt to terminate the pregnancy. These procedures are available through the public health system.

In some cases the affected parent does not wish to know his/her own HD status, but wants to avoid the risk of HD for their child. There is a method of performing prenatal diagnosis known as "exclusion testing" which can facilitate this. The down side of this procedure is that some couples will be faced with the decision of whether to terminate pregnancy which has a 50% chance of having the mutation and a 50% chance of being unaffected.

The second option is ***pre-implantation genetic diagnosis*** (PGD). This is performed via in vitro fertilisation (IVF). Embryos are generated in the laboratory by IVF and then tested for the presence or absence of the HD gene mutation. Only embryos without the mutation are then transferred to the mother's uterus. This procedure is only available through private IVF clinics and is very costly.

For further information about genetic testing for HD please do not hesitate to contact Genetic Health Queensland on (07) 3636 1686. Our service is available to all individuals and families concerned about the risk of HD. There is no obligation to seek testing; the role of GHQ is also to provide information and counselling.

FIND ME CARERS WATCH

What is the Carers Watch?

The Carers Watch is a Personal Emergency Alarm designed to look like an ordinary watch, weighs in at only 60 grams and is comfortable to wear. Should you not be able to wear a watch, it converts to a brooch or can be worn on a lanyard. The Lanyard has a snap lock and this means that if it becomes caught, it will unlock, a safety requirement here in Australia. All these parts come as standard with the Carers Watch.

On one side of the watch are two call buttons that can be set to call friends, relatives or neighbours in case of a minor emergency. On the other side of the watch is a panic button. You can set who it calls in an emergency; this button will alert up to five more nominated people by SMS.

Because the Carers Watch works over the mobile phone network, it will work anywhere where a 2G (ordinary) mobile phone works. This means you are no longer limited to a few rooms in the house. The Carers Watch also incorporates a medication reminder that will remind you up to ten times a day to take your medication.

It's the additional features of the Carers Watch that make it so different from everything else, as well as giving the wearer an easy way to contact you (or you to contact them), the watch contains a simple to use AGPS, a tracking system that can send their location to their nominated mobile phone as a simple street address.

It has had over two years of testing here in Australia, and latterly in other parts of the world. It has many specialised accreditations, to ensure the user's safety.

The cost is an initial setup charge of $176 (including GST) plus $2 per day ($60 per month) on a six month lease.

For more information on the Carers Watch, please contact Dave Ingerson on 07 3209 6255 or go to the website www.find-me.net.au

World Congress on Huntington's Disease

Melbourne Convention & Exhibition Centre
Australia
11-14 September 2011
To register go to www.worldcongress-hd2011.org

The Congress will include the Marjorie Guthrie Day – an IHA Family Day on Sunday 11th September (12 noon till 5pm). Attendance will be free of charge to delegates representing IHA organisations and anyone associated with an HD organisation.

Join others from around the world to share and learn more about youth needs, helping families stay strong through HD, coping strategies, starting a family, IVF, support groups, residential care facilities and caring – share the care!

You may like to organise a group of family and friends to attend the World Congress in Melbourne. Go to the official website www.worldcongress-hd2011.org for information on Speakers, Program, Accommodation, Travel Information and Bursaries, Tours and Partners Program, Satellite and Related Meetings, Exhibitors and more.

IMAGE-HD RESEARCH UPDATE

Following is an update on using neuroimaging methods to further the understanding of brain mechanisms in Huntington's Disease and working towards identifying an imaging biomarker of disease onset and progression for use in clinical drug trials. From the Image-HD Team: A/Prof Nellie Georgiou-Karistianis, Prof Gary Egan, Prof Julie Stout, Dr Andrew Churchyard, Dr Phyllis Chua, Dr Marcus Gray, Dr Juan Dominguez and Ms Rebecca Langmaid.

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 (ie 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.

Our 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. Both of these findings have been accepted for presentation at the *International Human Brain Mapping* conference in Québec City, Canada in June 2011. Analysis of neuroimaging data during a working memory task (remembering number locations) reveals differences in working memory circuits in the brain in HD. This data has been submitted for publication in the journal *Cerebral Cortex*.

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 Disease* in Melbourne 11-14th September, 2011, Convention & Exhibition Centre. We encourage as many family members to register and attend this exciting event. The IHA Family day will be held on 10 September, 2011 (for more information go to www.worldcongress-hd2011.org).

Funding Sources

We would like to acknowledge and thank all participants for their invaluable contribution to this study. We would like to also thank the Cure Huntington's Disease Initiative (CHDI) Ltd, USA, and the National Health & Medical Research Council (NH&MRC) for funding this study.

UNIVERSITY OF MICHIGAN STUDY

Analysis Shows Promise for Developing Protein Therapies for Disease Prevention

http://www.mdnews.com/news/2011_04/university-of-michigan-study-shows-promise-for-developing-protein-therapies-for-disease-prevention

MDNews.com Friday, April 29, 2011

ANN ARBOR, MI - A computer analysis by two University of Michigan researchers shows promise for helping develop therapies for some major diseases by rescuing proteins that have stopped performing normally.

Understanding the role of protein molecules is vital for health research and finding cures and medicines for diseases. The U-M findings appear as a cover story in the April 20, 2011 issue of Biophysical Journal.

"There are many diseases, including cystic fibrosis, Alzheimer's disease, Huntington's Disease, Parkinson's disease and diabetes, that are products of improperly folded, but potentially functional, proteins," says lead author Santiago Schnell, Ph.D., associate professor of molecular and integrative physiology at the U-M Medical School, and Brehm investigator at the Brehm Center for Diabetes Research. "These diseases are known as protein folding or conformational diseases."

Conformational diseases can occur when proteins fail to fold into their correct functional states. A folded protein is a complex and useful three-dimensional protein with specific functions.

However, a common hallmark of many conformational diseases is that an otherwise functional protein changes into a misfolded protein that has a higher tendency to aggregate and become harmful to cells and the patient.

The human body has about a million different protein molecules, which serve to manipulate and accommodate important cellular procedures, such as metabolism, signalling cell structures, hormone action and cell-to-cell interactions. Many common diseases may be treated or cured by designing drugs that can activate or inhibit corresponding protein molecules.

"Our model proposes a couple of remedies for recovering a patient's own misfolded proteins so they become correctly folded and functional proteins again," adds Schnell.

"The first remedy is giving the patient a higher concentration of correctly folded proteins to increase the ratio of folded over misfolded proteins. An improved ratio will prevent attack by misfolded proteins. The second remedy is administering drugs to patients to help the proteins fold correctly and to accelerate the folding of proteins, which reduces the chances of misfolding during protein synthesis."

The authors developed a theoretical model that explains a sudden shift in the concentration of misfolded proteins from a low to a high misfolded concentration inside cells. At high concentration, misfolded proteins become harmful to cells and the patients.

"If we can understand the mechanisms driving toxic misfolded protein production, this will help with the development of medical therapies to reduce misfolded protein production and recover folded proteins that are important to disease prevention," says co-author Conner I. Sandefur, Ph.D. candidate, U-M Center for Computational Medicine & Bioinformatics.

"This is a really interesting piece of work that has shed light on two critical variables that can influence the toxicity - and ultimately the clinical severity - of protein misfolding diseases like the one we study: misfolded proinsulin that triggers diabetes," says Peter Arvan, M.D., Ph.D., chief of the Division of Metabolism, Endocrinology & Diabetes, and director of the Michigan Comprehensive Diabetes Center.

"These ideas provide compelling directions for us to pursue new therapeutic options to escape the devastating consequences of a variety of protein misfolding diseases," adds Arvan.

PFIZER AND MEDIVATION ANNOUNCE TRIAL RESULTS

Phase 3 Horizon Trial of Dimebon in Huntington's Disease

Dimebon DID NOT Meet Primary Efficacy Endpoints

4th April 2011 Pfizer Inc and Medivation Inc today announced results from the Phase 3 HORIZON trial of the investigational drug dimebon (latrepirdine*) in patients with Huntington disease. Dimebon did not achieve statistical significance for either of the co-primary endpoints, the Mini-Mental State Examination (MMSE), which measures cognition (p=0.39), or the Clinician's Interview-Based Impression of Change, plus caregiver input (CIBIC-plus), which measures global function (p=0.84).

"We are disappointed with the results of the HORIZON trial given the high unmet need in this patient population. At this point, we will discontinue development of dimebon in Huntington disease, including the ongoing open-label extension study," said David Hung, M.D., president and chief executive officer of Medivation. "We will continue our ongoing 12-month Phase 3 CONCERT trial of dimebon and its open-label extension in patients with mild-to-moderate Alzheimer's disease. We expect to report top-line data from CONCERT in the first half of 2012."

Dimebon was generally well tolerated in the HORIZON trial, consistent with findings from previous trials including over 2,000 patients, the large majority of whom were Alzheimer's disease patients.

"Huntington's is a challenging disease area, and we are also disappointed with the HORIZON results," said Pfizer's Steve Romano, M.D., senior vice president, Medicines Development Group head, Primary Care Business Unit. "The results are expected to be presented at an upcoming medical meeting."

*Latrepirdine is the generic (nonproprietary) name for dimebon.

HORIZON Study Design and Results

The double-blind, placebo-controlled Phase 3 HORIZON trial enrolled 403 patients with Huntington disease at 64 sites in North America, Europe and Australia. The trial included patients who had cognitive impairment, based on investigator judgment and verified by MMSE score. Patients were randomized to receive either 20 mg of dimebon three times daily or placebo for six months.

No statistically significant improvements were achieved for the dimebon group relative to placebo on either of the co-primary endpoints. Dimebon was generally well tolerated in the study. The overall incidence of adverse events was equivalent between the treatment groups: 69 percent in the dimebon group and 68 percent in the placebo group. Adverse events occurring in at least 5 percent of dimebon treated patients and more frequently than in placebo treated patients were chorea (8 percent vs 4 percent), headache (6 percent vs 3 percent) and fatigue (5 percent vs 0 percent).

The trial was conducted in collaboration with the Huntington Study Group (HSG) and the European Huntington's Disease Network (EHDN). The HSG is a non-profit group of experienced clinical trial investigators from medical centers in the United States and abroad dedicated to clinical research of Huntington disease. The EHDN is a non-profit network of professionals providing an infrastructure for large scale Huntington disease clinical trials throughout Europe.

About Dimebon

Dimebon (latrepirdine) is an investigational oral medication being tested as a potential treatment for Alzheimer's disease. Dimebon is currently being studied in the Phase 3 CONCERT trial, a 12-month study evaluating dimebon in patients with mild-to-moderate Alzheimer's disease who are taking donepezil, a commonly prescribed Alzheimer's disease medication.

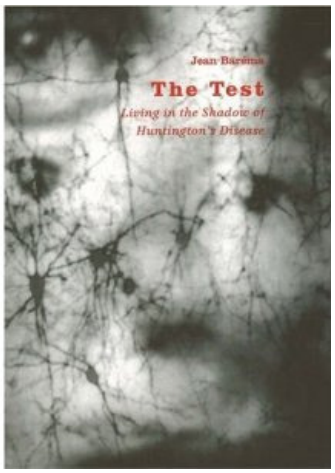
For more information on dimebon clinical trials, please visit www.dimebontrials.com or www.clinicaltrials.gov

Source: Medivation Inc

News Provided by: Acquire Media

BOOK REVIEW…..

THE TEST – Living in the Shadow of Huntington's Disease



By Jean Baréma – Published by Franklin Square Press, New York, 2005

Jean Baréma, a French journalist, watched his mother die in agony of Huntington's Disease, his brother and sister were succumbing to it in 2005 and he was about to find out if he, too, would be its victim.

The Test is a memoir of five years Baréma spent in anguish over the decision to take the test that reveals whether he is carrying the gene. Is it better to know or not to know? And if he has the disease, what should he do? Baréma recalls his long, emotionally wrought journey from decision to test to results; he tells how his daily life of work and family was plagued by questions and fear; and he movingly depicts the patience of his wife and compassion of his doctor. *The Test* is both a suspense story and a vivid portrayal of the havoc Huntington's Disease causes the families it strikes. Ultimately, it is a book about hope and love and their power to reach us even in our lowest moments.

Jean Baréma is a journalist and writer who lives in Paris with his wife and children.

The Test is available for sale from www.bookdepository.co.uk (free delivery to Australia) OR www.amazon.com

ANNUAL HUNTINGTONS QUEENSLAND GOLF DAY SUCCESS

We held our annual golf day on Sunday March the 13th at the Howeston Golf Club at Birkdale. It was a fun day for all and a fantastic success for Huntingtons Queensland, raising $2500.

Our sincere thanks go out to all the enthusiastic players, Huntington's committee members, volunteers, club members and volunteer staff who worked very hard to make the day such a success. In particular we'd like to give a very big thank you to one of our committee member's, Jan Szlapak, who organised the event beforehand and started at dawn on the day to ensure everything was in place for a very smoothly run day. We would also like to sincerely thank Lyn Weston from the Howeston Club for her generosity and kind assistance to our organisers and players.

We will be hosting another Huntingtons Queensland golf day in March 2012…so make a note in your diaries and start thinking about your teams. We'd love to see you and your friends there next year!

FINANCIAL ASSISTANCE TO HUNTINGTONS QUEENSLAND

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

Rhonda & Bob Goodair
Mrs J Bennett
Ross Craig
Barb & Don Gray
Lyn Weston (Howeston Golf Club)
Norma Robertson
Mr KJ Horton
Betty Stabler
Jenny Connell

HUNTINGTONS QUEENSLAND NOMINATED AS BENEFICIARY

Our thanks go to **Beecham Holden Caboolture** who has kindly nominated Huntingtons Queensland as the beneficiary for a charitable donation by way of CTP on first time registered vehicles sold through them.

You can contact them on:

Ph: 1300 154 876
29 Bribie Island Road
Caboolture

DONATIONS TO HUNTINGTONS QUEENSLAND

If you would like to donate to Huntingtons Queensland and have internet access, go to our website www.huntingtonsqld.com. Scroll down to the 'Please Make a Donation' section on the bottom left, click on the button <CLICK HERE> and follow the instructions. All donations over $2 are tax deductible and we will send you a receipt for taxation purposes.

POTENTIAL SUPPORT FROM MACQUARIE & THEIR STAFF

The Macquarie Group Foundation, one of Australia's oldest and largest corporate benefactors, supports Macquarie staff personal donations and fundraising activities by matching staff contributions to community organisations. Huntingtons Queensland is registered with the Foundation so if you know anyone who works for Macquarie please request and / or encourage them to nominate Huntingtons Queensland as their chosen community organisation.

ROTARY CLUB - ACACIA RIDGE

The great folk at the Rotary Club of Acacia Ridge are again raffling a 6' x 4' car trailer which includes home and gardening equipment valued at $3,600. It sounds like a great prize!

We'd like to thank all our ticket sellers who support our fund raising efforts and their kind friends who buy the tickets…let's hope one of our kind supporters wins this great prize.

If you would like to sell tickets on our behalf of just buy tickets, please contact us on 3391 8833 or admin@huntingtonsqld.com

TICKETS: $2 CLOSING DATE: 15th JUNE 2011 DRAWING DATE: 21st JUNE 2011

We sincerely thank the Acacia Ridge Rotarians for their ongoing support.

HUNTINGTONS QUEENSLAND

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Huntingtons Queensland
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 2010/11:

President	Gerry Doyle
Vice President	Position Vacant
Secretary	Pam Cummings
Treasurer	Darren Careless
Committee Members:	Jan Szlapak
	Trish Flitcroft
	Alan McKinless
	Robert Westley

Staff Members:

Operations Manager	Mike McLean
Senior Welfare Officer	On maternity leave
Welfare Officer	Lesley Frazer
Welfare Officer	Theressa Byrne
Telemarketing Officer	Helen Johnston
Administration Officer	Anne Stanfield

CONTRIBUTIONS

Please feel free to submit articles or photographs for selection for publication in this Newsletter. The deadline for the next issue is 30th June 2011. Please email or post articles, details above. Please be aware that the Newsletter is published on *www.huntingtonsqld.com* in addition to postal and email distribution.