NEWSLETTER

HUNTINGTONS QUEENSLAND

December 2010

CONTENTS

FROM THE PRESIDENT

Dear Friends

As 2010 draws to a close, I wish to advise you all that Barb Gray will be retiring at the end of February next year. Barb's involvement with HD started in 1983 as a volunteer. Barb served on the Management Committee from 1984 to 1995 and was Treasurer for the period 1987 to 1994. In 1995 she took over from Alison Hopgood as Administration Officer and in 2007 was appointed to the position of Operations Manager. In this role she has been responsible for managing the activities of the Association's staff and she has used her excellent management and organisational skills to great effect covering all aspects of the operations of the Association. We all owe her a great deal of thanks.

On behalf of all the members of the Association, I thank her for her efforts and give our best wishes to Barb and Don in their retirement.

Also in early 2011 Christine Parfitt our Senior Welfare Officer will be on maternity leave and we all wish her well. We will advise families of alternative support arrangements during this time early next year.

Lastly I would like to wish everyone a joyous Christmas festive season and a safe and prosperous 2011. We look forward with hope in making 2011 another good year for all.

Gerry Doyle, President

DIARY DATES

January 2011

19th January	Kids' School Holiday Activity

February 2011

2nd – 4th February	Townsville Regional Visit by Lesley
9th February	Professional Committee Meeting
14th February	Gold Coast Family Support Group
16th February	Eastern Suburbs Family Support Group
21st – 22nd	Gladstone / Rockhampton Regional visit by Tressa (*to be confirmed*)

March 2011

16th March	Eastern Suburbs Family Support Group
25th March	Toowoomba Family Support Group (*to be confirmed*)

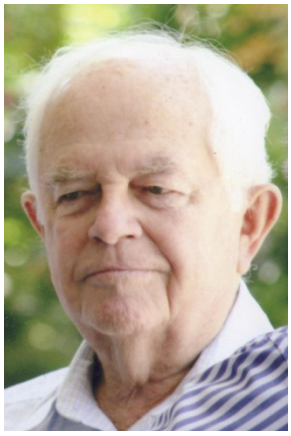
FROM THE OPERATIONS MANAGER

Volunteers

We are so very fortunate to have the service of so many volunteers across Queensland. The Association was formed on volunteer engagement and even today we simply could not provide the services we do without their willing and cheerful support. I admire them for their community spirit and so enjoy working alongside them.

Our volunteers give their time in a variety of ways – as committee members, administration support, fundraising, drivers, support group activities and assisting in the Day Respite Centre. We rely heavily on their goodwill in the delivery of these very important services.

Rob Farmer Wins Community Award



It was with much pleasure that I recently nominated Rob Farmer for the *Russell Trood Community Service Award* and was delighted to learn of the success of the nomination.

Rob was recognised for his contribution to the community by Senator Russell Trood at a ceremony held at the Tennyson Tennis Centre in Brisbane on the 8th November 2010.

Rob has volunteered for Huntingtons Queensland for over 25 years both as a driver and assistant in the kitchen at our much loved Day Respite Centre. Every week Rob would turn up and give of his time without expecting anything in return (well perhaps just a meal and a cuppa). It is impossible to measure Rob's contribution; what we do know is that his organisational skills, his friendship and concern towards those attending Day Respite is truly appreciated and meant so much to those around him. Thank you Rob.

The administration staff and I wish you all a peaceful and happy Christmas and a fulfilling New Year – here's to a good 2011!

Barb Gray, Operations Manager

SUNNYBANK COMMUNITY & SPORTS CLUB MAKES A DIFFERENCE IN THE COMMUNITY

Sunnybank Community & Sports Club President, Peter Carroll, was extremely pleased to announce a grant of $30,000 over three years to Huntingtons Queensland out of $300,000 set aside by the Club for their 2010 Community Grants Program. Peter presented the cheque to our Operations Manager, Barb Gray, and President, Gerry Doyle. These much appreciated funds will allow Huntingtons Queensland to establish a youth programme with the main focus to provide group activities that young people can attend and where they can meet others in similar situations to themselves. Huntingtons Queensland would like to take this opportunity to express their sincere appreciation of the Club's wonderful efforts in supporting the community. Why not pop in for a meal sometime? The Club is located at 470 McCullough Street**,** Sunnybank.

WELFARE NEWS

The last couple of months have been especially busy for the Welfare Team as we have been making our way around the state visiting families and facilitating family and carer support groups. Last month Barb made a trip to Townsville where she caught up with the Family Support Group, whilst Lesley made her first visit to Cairns and I (Christine) made a day trip to Mackay. On top of this, over the past two months we've had nine support group activities and are about to embark on our yearly family respite holiday. So when you are busy planning all these activities I guess you can see how Christmas can take you by surprise!

This month I thought I'd share with you some information and statistics about the work the Welfare Team does around the state. For the purpose of providing our service, Queensland is divided into sixteen regional areas which are then evenly distributed amongst the Welfare Officers. We also try to make sure that there is a Welfare Officer in the office every day, although sometimes emergencies come up and we need to go out. Here's a tip for you though...the best day of the week to catch the Welfare Staff in the office is Tuesday (between 10am and 3pm). We are all in at these times to help with transport for the day respite program and to attend our weekly Welfare Staff meeting. Here are some more facts about the welfare service and the support we have provided over the past 12 months:

- Our largest region with 29 families is the Gold Coast, covering suburbs from Yatala (just south of Beenleigh) to Kingscliff (in Northern NSW); whilst our smallest region with four families is the Scenic Rim, covering towns from just west of Ipswich, following the Cunningham Highway out to Warwick and out to Jimboomba and Beaudesert.
- 67% of our families reside within two hours of Brisbane, leaving 33% considered regional families.
- The largest attendance at a family support group was Toowoomba in November 2010 with 33 people whilst the largest attendance at an information session was at Bond University (1st year medical students) with 120 in attendance.
- 36 education sessions were delivered to universities, nursing homes, service providers, hospitals, medical and allied health professionals raising awareness and educating some 527 people
- The support provided by the Welfare Team over the past 12 months falls under one of three categories:
  1) *Information Provision* (for example: in-services, information sessions, general phone calls providing literature) of which there were 1,307 occasions helping 1,947 people
  2) *Non-clinical Support* (for example: home visits, emotional support, outings) of which there were 1,121 occasions reaching 1,487 people
  3) *Support Groups* (including family and kids groups, Brisbane day respite program, carer and family support groups and school holiday activities) of which there were 90 occasions involving 918 people
- Now...of all these occasions over the past 12 months, 610 were performed face-to-face; 1,667 were conducted over the telephone; and 291 occasions were in some other form of contact

We hope you've found this information interesting and we want all our families to know that we are committed to providing the best possible service no matter where you live. On behalf of the Welfare Team I'd like to take this opportunity to wish all our families a very merry Christmas and a safe and happy New Year. On a personal note – thank you to all my families for your very kind wishes on my wedding in October. It was everything I could have ever hoped for.

Christine Parfitt, Senior Welfare Officer, along with Theressa Byrne and Lesley Frazer
Huntingtons Queensland Welfare Team

Venezuela village holds cure for hereditary illness

By Benedict Mander in Barranquitas Published: August 17 2010

Published in the Financial Times - http://www.ft.com/cms/s/0/7a978e4a-aa2f-11df-9367-00144feabdc0.html#ixzz183N51p7v

It does not take long to realise that there is something wrong in Barranquitas. Some of the villagers wander around aimlessly, looking confused and frightened. Many are grotesquely emaciated. Their limbs jerk erratically.

A grim fate awaits many of the inhabitants of this isolated village on the south western shores of Lake Maracaibo in Venezuela, even those who appear perfectly healthy.

About half of the roughly 10,000-strong population of Barranquitas either has, or is at risk of developing, Huntington's disease (HD), a fatal hereditary illness that gradually kills brain cells and causes the body to waste away.

This remote area has the highest concentration of HD in the world, which is why Professor Nancy Wexler has come here almost every year since 1979. It was her research, far away from the cutting-edge laboratories of the developed world that was the key to a discovery that pushed back the boundaries of science.

"It was this family here that launched the Human Genome Project," says Prof Wexler, her arm affectionately around the shoulders of a young man called Siros. "Siros's family proved that we had the gene," she explains, from a dingy concrete room in Siros's home in Barranquitas.

By studying the blood samples from Siros's family, which has been afflicted with a uniquely large number of cases of HD through several generations (both of Siros's parents suffered from the disease, as did 10 of their 14 children), Prof Wexler and her collaborators isolated the gene that carries the disease.

Professor Nancy Wexler helps two locals at different stages of Huntington's Disease through the muddy streets of Barranquitas.

"They said it would be like trying to find a needle in a haystack. Actually, it's more like trying to find a particular bit of hay in a haystack," says Prof Wexler. She said that most scientists ridiculed her quest, while even the "believers" warned that the project could take anything from 50 to 100 years.

But she was determined: when Prof Wexler was in her early 20s her mother was diagnosed with HD, meaning that she herself has a one-in-two chance of developing the disease.

Prof Wexler's research, which included painstakingly piecing together family relations in Barranquitas and a nearby village called Laguneta, enabled the discovery of the gene that causes HD.

Her ground-breaking methods proved that it was possible to do the same with all genes, heralding the beginning of the Human Genome Project. "It was mind-blowing," she said. The discovery of the HD gene also meant that accurate tests could be made to determine whether or not humans, including foetuses, would develop the disease.

Prof Wexler decided not to take the test herself. "What's the point of finding out whether I have the disease if there's no cure?" she asks.

So far a cure has remained elusive. Not only would it change the lives of a huge number of people around the world – HD occurs in 5-10 people per 100,000 – but it is also believed that a cure for HD might help in finding a cure for other more complex neurodegenerative disorders such as Parkinson's and Alzheimer's.

So Prof Wexler keeps returning to Barranquitas, where she has become known as the "blonde angel". Now, wherever she goes in this rundown, forgotten place, she is greeted with smiles, hugs and cheers, and attracts large crowds that follow her around its muddy streets. "She's like the Pied Piper," remarked the former British Ambassador to Venezuela, Catherine Royle, who has closely supported Prof Wexler's work.

Although companies such as Shell and GlaxoSmith-Kline have shown support, if so far limited, for the project, perhaps the biggest barrier to progress is posed by the Venezuelan government. Permission is required to take blood samples out of the country to continue research, which is essential since no laboratory in Venezuela has the technology to do so.

The government's response has been lukewarm. There are further concerns that if the government does decide to take over the project, it will soon be forgotten and go the way of so many other poorly managed government-run ventures.

That is a prospect that dismays those who work in the field, such as María Luisa Hernández, a local who cares for children in danger of developing HD.

"Nancy Wexler has given more than just professional help but her love, her life. We also have a strong sense of community here. But we need more than that: we need support [from the state]."

RAMP UP DISABILITY. DISCUSSION. DEBATE.

On the 3rd of December 2010 the ABC launched Ramp Up, a new website dedicated to everything about disability.

It will include the latest news from the sector, drawn from across the ABC, as well as blogs, opinion articles and features that explore issues that affect people living with a disability.

You'll even have a chance to comment on what you read via our threaded message boards. The ABC wants Ramp Up to be a place for discussion and debate to thrive.

Ramp Up's core audience will be the estimated one-in-five of us who live with a disability, their family and friends, people who work in the disability sector and anyone else who wants to be informed is welcome to join the conversation.

Provocative, celebratory, challenging, supportive and a little bit funny – Ramp Up will be the place to have your say.

So log on to www.abc.net.au/rampup and join the debate.

Prevention of Alport Syndrome in the Next Generation Pre-implantation Genetic Diagnosis IVF By Dr Alison Blatt

The following story, while not specifically about Huntington's Disease, is encouraging to read as it illustrates the wonderful progress being made in Pre-implantation Genetic Diagnosis. Dr Alison Blatt has kindly granted her permission for the re-printing of this article.

I was 34 years old in 2007 when I discovered my brother had Alport Syndrome and I was a carrier. We were devastated to say the least. I had one daughter, Matilda, and was unaware of her status. But I knew I wanted more children so my husband and I consulted a geneticist at Sydney IVF and requested Pre-implantation Genetic Diagnosis (PGD).

This technology had only been available in the last 10 years and only one other person with Alport Syndrome had gone through this process in NSW. I knew Sydney IVF was one of the few places in Australia with the expertise and experience in this technology. PGD would enable us to exclude Alport-affected embryos during the in-vitro fertilisation (IVF) process and potentially have an Alport-free baby.

Finding the Genetic Defect

First the genetic defect needed to be confirmed. My brother and I had our blood sent to the UK and it took many months to get a result. It eventually confirmed that the defect was on our X chromosome. This was supported by our family tree which strongly suggested X-linked inheritance in our family.

Designing the Probe for Screening my Embryos

Rather than design a test to find the tiny defect on the chromosome, the test was designed simply to identify my faulty X as it was passed on to embryos. Blood was collected from my husband, my brother and me. My X chromosomes were identified and matched with my brother so that it was clear which the normal X was and which had the faulty gene (see Figure 1). Then my husband's X chromosome was identified. A probe was designed to mark these three Xs. This took the scientists about six months to design and create.

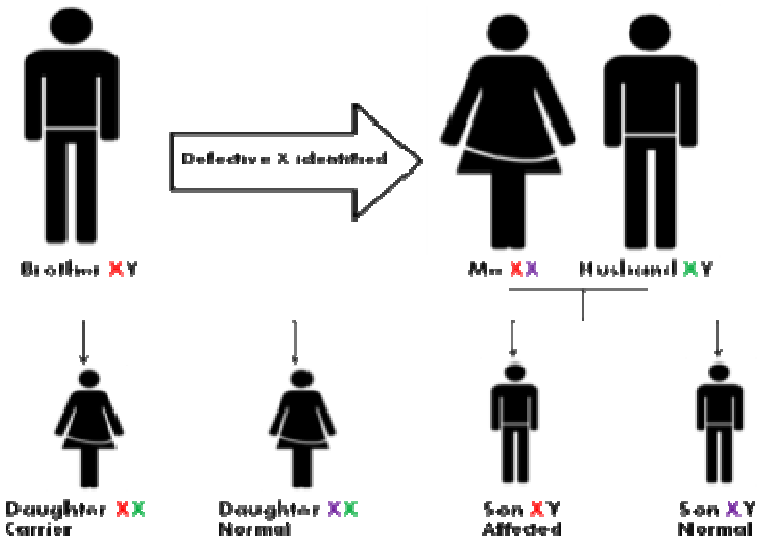


Figure 1
Designing a probe involved identifying the X chromosome containing the defective gene (in red) by matching my chromosomes with my brother's chromosomes. The embryos were each biopsied and their X chromosomes were labeled to identify Alport-affected embryos. My normal X chromosome is purple; my husband's normal X chromosome is green. There are four possible outcomes of combining our chromosomes which include (from left to right) one female carrier, one normal female, one affected male and one normal male.

The IVF-PGD Process

Once the probe had been designed my husband and I started the IVF process. I started a series of medications which manipulated my hormones and resulted in the ovaries going into overdrive. Where the ovaries would usually produce one egg per month, multiple eggs matured. I was bloated and uncomfortable and it made me feel tired and crabby (like PMS only worse!). Every second day or so I had to have my bloods taken to monitor my hormones, then as the eggs were "ripening" I was having 2nd to 3rd daily ultrasounds. When the eggs were ready I went into hospital for the "egg retrieval". This was a minor procedure done under local anaesthetic with the doctor using a long needle to collect eggs through the vaginal wall. The same day my husband had to provide a sperm sample which was used immediately to fertilise the eggs. After the procedure I had to have bedrest. We went home and waited.

Over a 5-6 day period the fertilised embryos were closely observed and I got a call every morning to give me an update on how many embryos were thriving. I had an excellent result with nine embryos eventually reaching the biopsy stage. The biopsy itself is a miracle of modern technology and involved microsurgery on the embryo. Have a look at the Sydney IVF website to see footage of a biopsy. A single cell was taken from the outer shell of the embryo (at this stage called a "blastocyst") which is a non-essential part of the blastocyst. This cell was then tested for the genetic abnormality. I had five embryos which were Alport free. This was more than I'd dreamed of! The best embryo was chosen and the rest were frozen.

The embryo transfer required no analgesia (like having a pap smear) and used ultrasound guidance to deliver the embryo to the centre of the uterus. Then it was back to waiting… After two weeks a blood test was performed. I got a phone call with the results after lunch. I was not pregnant and even though I knew my chances were poor (I'd been given a 30% chance of success with each transfer) I had still lived in hope. After many tears we picked ourselves up and tried again. Every month, with the help of medication and blood tests, I underwent an embryo transfer until all five of my precious embryos were gone. Then we started again.

By this stage you can imagine I was doing everything I could to improve my chances. I hadn't drunk any alcohol for six months and was barely drinking any caffeine. I was avoiding any food additives and a long list of potential ingredients that were vaguely rumoured to decrease one's fertility. Despite my medical background the hard scientific evidence was not necessary to scare me off even the mildest potential offenders. We had been living on a rollercoaster of emotions and it was hard to focus on outside commitments and goals. I was fortunate to have a busting two year old to keep a smile on my face and remind me of how lucky I was every day.

So, the next round of drugs and blood tests and ultrasounds started. Everything went smoothly but only two embryos made it to the end of the line. I went into the IVF hospital for my embryo transfer. For the next two weeks I did everything I could to forget about IVF and get on with things. So I ignored the tender breasts and slight constipation and told myself the bloated feeling was premenstrual tension. When my specialist called me with the good news I almost cried, "I know".

Success

My second daughter was born in April 2010. She's an absolute delight and her big sister is the proudest three year old in town. It's a great relief to me to know that although the IVF process was difficult I'm extremely fortunate to have had PGD available to me. In choosing to have a family I didn't just "roll the dice" as many people do with genetic diseases when PGD is unavailable. I highly recommend the Sydney IVF website. More information can be found on: http://www.sydneyivf.com/GeneticDisorders/tabid/57/Default.aspx

Dr Alison Blatt and her

baby daughter.

Queensland Government

Every dollar counts

Every dollar counts

Every dollar counts

The Queensland Government has launched a new website www.qld.gov.au/everydollarcounts for Queenslanders to find rebates and concessions they are eligible for. Every Dollar Counts is a comprehensive guide to concessions, retail discounts, rebates and assistance available to families, pensioners and Queenslanders who may be financially stretched, or want to save on future energy expenses.

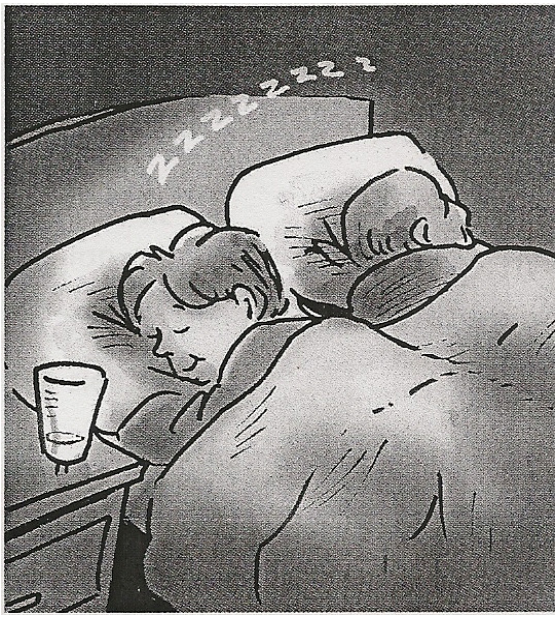
You might be pleasantly surprised at the types of assistance available - if you're wanting to buy a home, save for a rental bond, save on power, invest in solar panels, or take advantage of the many concessions offered for travel, rates and even car registration - this is the website for you.

The Every Dollar Counts website has information on a number of concessions including:

- The electricity rebate for pensioners and seniors
- The new electricity concessions for low income Queenslanders who have multiple sclerosis or other chronic medical conditions significantly affected by changes in temperature
- The natural gas rebate
- Motor vehicle registration rebate

For more information, go to the website www.qld.gov.au/everydollarcounts or phone **13 13 04**.

Sleep right, sleep tight



Our sleep patterns change as we get older. Developing good sleep habits is a more effective way of solving sleep problems than resorting to medicines. Sleeping tablets usually make sleep problems worse, not better, in the long term. They can also cause side effects, even those bought without a prescription. If you don't sleep well, some of these strategies might help.

Reset your body clock

We all have an internal 'body clock' that controls our daily cycle of becoming sleepy in the evening, sleeping through the night, and waking up in the morning. Being 'in sync' with your body clock makes it easier to sleep.

You can help to set your body clock by consistently going to bed and getting up at the same time every day, regardless of how well you slept the previous night. If you can't get to sleep within 20 minutes, get up and do something relaxing in another room until you feel sleepy again. Persist with this routine until you develop a regular sleep pattern. It will also help your body to associate going to bed with sleep rather than sleeplessness and frustration, which, in turn, will help you to sleep better.

Sunlight also helps to set your body clock, so try to get outside in the sun for a while every day. Some people can sleep well despite having a short nap in the afternoon. However, if you're having trouble sleeping at night, avoid having a nap during the day. If you do nap, keep it to only 20 minutes before 3 pm.

Have a bedtime routine

Doing the same things each night in the last half hour or so before going to bed helps to remind your body that it's time to go to sleep. Your bedtime routine might include things like having a light bedtime snack or glass of warm milk, having a warm bath, reading, or listening to music, the radio or a talking book. Avoid computers.

Be comfortable

Keep the bedroom dark while you sleep. Even dim lights, such as those from a television or computer screen, can disturb the body clock and result in poor sleep. Try to keep your bedroom and bed at a comfortable temperature. Being too warm or cold is a common reason for waking up frequently in the night.

Relax your mind

You can't sleep well if your mind is not relaxed, so try not to take your day-time stress, anger or work to bed with you. Also, avoid work and activities involving concentration, such as working on the computer, late in the evening. If you can't relax because of chronic worrying, stress or anger, consider learning some relaxation techniques to help you 'switch off', or seek help from a GP or counsellor.

Avoid stimulants

Avoid caffeine drinks, such as tea, coffee, energy drinks and cola, close to bedtime and maybe even from early afternoon. Milk contains tryptophan, which has been shown to enhance sleep, so consider a warm milk drink instead. Alcohol before bedtime may help you to dose off. However, it also disturbs the normal sleep rhythm, so you won't tend to sleep as well.

Get regular exercise

Being physically active during the day makes it easier to fall asleep and improves how well you sleep. However, the timing is important. Exercise too late in the day stimulates the body and raises body temperature, making it harder to sleep. Exercise in the morning or afternoon gives your body time to wind down and cool down.

Getting back to sleep

If you wake up during the night, relax and try not to get stressed. Try some relaxation techniques or a repetitive, non-stimulating activity like counting sheep. Remind yourself that although it's not as good as sleeping, resting in bed can still refresh your body. If you've been awake for more than 20 minutes, try getting out of bed and doing a quiet activity in dim light until you feel sleepy again.

Tackle underlying problems

Poor sleep can be a side effect of some medications and some chronic conditions, including depression, anxiety and sleep apnoea. In these situations, treating the underlying problem often alleviates the sleep problem.

If you have sleep problems, talk to your doctor or pharmacist, and tell them about any other symptoms you may be experiencing. If their suggestions don't help, consider asking for a referral to a sleep specialist or sleep clinic, so your sleep problem can be investigated.

Get NPS resources

NPS has some resources to help you get a good night's sleep. They can be ordered from the NPS website.

- The Sleep right, sleep tight fact sheet has advice about sleep, sleep problems and things you can do to improve your sleep.
- If you're having trouble sleeping, use the Sleep diary to help you work out what might be affecting your sleep. Take it to your doctor to use as basis for discussing your sleep problems.

Reproduced with permission, National Prescribing Service, Medicines Talk Winter 2010.

AND HERE'S A POEM TO READ BEFORE BED…..

Ode to Huntington's Disease *By Ronald T Roberts*

On top of all the stress and strain,
The fears, the loss, the psychic drain,
Of coping with the risk ahead
Or giving care with all its dread
Now comes the jargon of the lab
As science shares its chatty gab.

Now one more way our stomachs churn,
And one more language we must learn.
Proline endopeptidase
And other terms assault our space,
Bilateral quinolinate –
Now there's a phrase to comtemplate!

Take ganglionic eminence
And other terms that make no sense.
There's not a one of them routine.
Explain striatal dopamine!
Or tryptophan metabolites
Or malonate and other frights.

There's C-A-G and R-N-A
With dorsal caudate interplay,
And neurons that degenerate,
And aspartate and glutamate!
Excitotoxic neuron death –
There's hardly time to catch your breath.

Of all the things that cause us stress,
Much more than words can half express,
The other losses that depress
Are worse by far than this, I guess.
But still this abstract language mess
Is one more insult, I confess!

Mr Roberts is a care-giving husband. "To my unseen… friends… who give us help or struggle with us to decipher the exciting research material.' 1996

Reprinted from Huntingtons WA Newsletter

Book for Sale…

Talking to Kids About Huntington's Disease

'Talking to Kids About Huntingtons Disease' by Bonnie L Hennig MSW LCSW is a 45-page book designed for caregivers of children who have a loved one affected by HD. It is a wonderful resource for family members as a teaching tool and will enable carers to feel more comfortable and confident in dealing with this topic.

Bonnie is the Clinical Social Worker at the University of Connecticut Health Centre Huntington's Disease Program. She has been invited to speak nationally and internationally on the topic of helping children cope in an HD family.

AVAILABLE FOR SALE AT HUNTINGTONS QUEENSLAND @ $18 PER BOOK INC PACK & POST.

FUND RAISING

FINANCIAL ASSISTANCE

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

Dr Geoff Cheyne
Del Clark
Sharon Elsley
Maurice Harriman
Patricia Feeney
Mr & Mrs Hartkoph
Yellow Cabs (Qld) Pty Ltd
J Bennett
Rolina Bowhay
GR Phillips
Trish Flitcroft
N Longland
The Catering Ladies ARV

HUNTINGTONS QUEENSLAND – GOLF DAY

Here's a golf date to look forward to…..6th March 2011.
Pop it in your diary and invite your friends along!

Howeston Golf Club
Creek Road Birkdale
8am tee off
Sunday 6th March 2011
Cost $50
Carts available
Contact Barb for further details on 3878 8600

QUT STAFF COMMUNITY WELFARE FUND 2010

This wonderful organisation has been supporting Huntingtons Queensland since 1998 and they recently donated $840 for the purchase of wheel chairs and an outdoor setting.

We would like to take this opportunity to say thanks to the kind staff of the QUT for their continued support of our organisation – their ongoing commitment over the years has assisted us to meet our commitment to provide the best possible support to our family members.

HUNTINGTONS QLD 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

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.

Macquarie Group Foundation

DONATIONS TO HUNTINGTONS QUEENSLAND

If you would like to donate to Huntingtons Queensland and have internet access – just go to our website www.huntingtonsqld.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 over $2 are tax deductible and we will send you a receipt for taxation purposes.

FOR SALE – CONFERENCE MATERIALS

Conference DVDs & Hard Bound Copies of Speaker Slides & Profiles

DVDs – Full set of 5 $80 or $20/DVD
Hardcopy $15
(Packing and post inclusive)

Please contact Huntingtons Queensland for an order form

Making the Connection
National Conference on Huntington's Disease
Brisbane • 9-10 September 2010

PLEASE REMEMBER!!!

2010 / 2011
Huntingtons Queensland membership renewals are due now!

HUNTINGTONS QUEENSLAND

Florence Dannell House
385 Ipswich Road
Annerley Q 4103

All Correspondence to
PO Box 635
Annerley Q 4103

Phone: (07) 3391 8833
Fax: (07) 3391 0443

Emails:
admin@huntingtonsqld.com
christine@huntingotnsqld.com
lesley@huntingtonsqld.com
theressa@huntingtonsqld.com

Website: www.huntingtonsqld.com

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
Members	Jan Szlapak
	Trish Flitcroft
	Alan McKinless

Staff Members:

Operations Manager	Barbara Gray
Senior Welfare Officer	Christine Parfitt
Welfare Officer	Lesley Frazer
Welfare Officer	Theressa Byrne
Day Respite Assistant	Lydia Hudson
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 31st January 2011. Please email or post articles, details above left. Please be aware that the Newsletter is published on *www.huntingtonsqld.com* in addition to postal and email distribution.