NEWSLETTER

HUNTINGTONS QUEENSLAND

August 2012

CONTENTS

FROM THE PRESIDENT

Dear Friends

The 36th Annual General Meeting of the Association will be held at 7pm on Wednesday 26th September and I hope as many of you as possible are able to attend. We are also looking for any members who have the time and motivation to serve on the Management Committee. If you are interested please contact the Office. The AGM Agenda and Nomination Form are included with this Newsletter

Our guest speaker for the AGM will be Dr Trent Woodruff. He has been leading the Research Project at The University of Queensland that the Association has supported by providing funds for the last three and a half years. Special thanks must be given to The John and Wendy Thorsen Foundation for their very generous support of this research. Trent will be presenting the research thus far plus future plans and activities.

The Sunnybank Community & Sports Club has also provided funding for the third consecutive year to support our Youth Program on the Southside. We acknowledge the great work carried out by the big hearted members of this Club.

You would have all heard the recent announcements regarding the Federal National Disability Insurance Scheme (NDIS). It is disappointing that the Queensland State Government has decided not to participate in the planned State based trials, however community based forums and information sessions are planned to be held throughout Queensland to explain the NDIS. It is also very important that pressure is maintained on all politicians to push the case for an NDIS, as lack of support and the current 'broken system' remains the biggest problem in the care of people affected by Huntington's. The NDIS website gives a lot of information and is worth checking for any forums in your location http://www.ndis.gov.au/

2012 HD Awareness Week is coming up 10th – 14th September. We will be launching our youth program HYPe (**H**untingtons **Y**outh **P**rogram **e**tc) and we are endeavouring to get as much press coverage as possible.

One of our kind members, florist Merrilyn Brown, who owns 'Flowers by the Bay' will be holding a High Tea at her home at Gumdale from 2:00-4:00pm on Saturday 16th September to raise funds for HYPe. If you and your friends would like to attend or if you would like some information on holding your own HYPe High Tea, please phone or email Anne Stanfield.

On the staffing front, Anne has been appointed Administration Manager and we welcome her to this new role. She now works Tuesday to Friday. We are recruiting for a third Welfare Officer and an Executive Officer and will hopefully fill these part time positions in the very near future.

We're not including Diary Dates for carer / family support groups in this edition of our Newsletter while we are short staffed. Invitations will be emailed or posted to you prior to each event. Sorry for any inconvenience.

All the best!

Gerry Doyle, President

FROM THE WELFARE DESK…

On Monday July 30th, Gerry Doyle and I attended an NDIS forum with Senator Jan McLucas (from Cairns) and Graham Perrett MP (Federal Member for Moreton).

The NDIS is pretty exciting news and it's supported by all major government parties which is even better news! So finally, people with HD will be eligible for support and will be able to access supports as soon as they are assessed – instead of waiting on the ever growing, never-realised waiting list of Disability Services Queensland. So whilst it does not specifically mention Huntington's Disease, be assured that HD is included in this scheme. Something else worth pointing out is that whilst it is 'called' an insurance scheme, you do not have to 'buy' insurance to get this support. It is simply the best word they could find to explain the scheme and it will be funded by the federal and state governments – or at least that is the goal.

At the time this article is being written, the Qld government had still not agreed to join this initiative. That is why we are bringing this to your attention – because FINALLY there is something that YOU CAN DO to help families with HD. I've included a press release later in this article from the office of Graham Perrett MP about the forum Gerry and I attended so you can read about where things are at in Qld.

To explain a little about the scheme, the following information has been drawn from the website – www.ndis.gov.au

What is an NDIS?

An NDIS will be aimed at those who are most in need, providing long term, high quality support for around 410,000 people who have a permanent disability that significantly affects their communication, mobility, self-care or self-management. It will focus on intensive early intervention, particularly for people where there is good evidence that it will substantially improve functioning or delay or lessen a decline in functioning.

How will NDIS improve the lives of people with disability, their family and carers?

An NDIS will look beyond immediate need, and will focus on what's required across a person's lifetime. At its core will be:

- A lifetime approach – funding is long-term and sustainable. People with disability and their carers will have peace of mind that the individualised care and support they receive will change as their needs change.
- Choice and control – people choose how they get support and have control over when, where and how they receive it. For some, there may be the potential to manage their own funding.
- Social and economic participation – people with disability will be supported to live a meaningful life in their community to their full potential.
- Focus on early intervention – the system will have enough resources and will be smart enough to invest in remedial and preventative early intervention instead of just providing support when a family is in crisis.

Who will be eligible?

- An NDIS will work with people who have a permanent disability that significantly affects their communication, mobility, self-care or self-management to ensure that they get the support that is reasonable and necessary to meet their needs. This could include an individual plan and an individually funded package.
- Individual support will also be given to people for whom there is good evidence that early intervention would substantially improve functioning (for example, autism, acquired brain injury, cerebral palsy or sensory impairments), and those for whom early intervention will delay or lessen a decline in functioning (for example, multiple sclerosis and Parkinson's disease).

PTO for Press Release

Press Release…..

Queenslanders deserve better!

NDIS

Brisbane's southside have (*sic)* thrown their support behind a National Disability Insurance Scheme (NDIS) at a forum with Senator Jan McLucas on 30 July 2012.

Approximately 50 people with disability, their families and carers, local service providers and advocacy groups attended a forum at Moorooka Sports Club to discuss the importance of an NDIS in Queensland.

The strength of feeling at the forum demonstrated the support of the wider Brisbane community for fundamental reform of disability care and support.

The Gillard Government is delivering $1 billion for the first stage of an NDIS.

The NDIS will give people with disability more control and choice over their care and support, irrespective of where they live in Australia.

An NDIS has the potential to do for disability what Medicare did for health in this country, what superannuation did for retirement savings and what the HECS scheme did for education.

From the middle of next year launch sites will commence in South Australia, Tasmania and the ACT – a year ahead of the timetable set out by the Productivity Commission. NSW and Victoria have also signed on but not Queensland.

The Queensland community are (*sic*) rallying behind the NDIS and I call on Premier Newman and our local State LNP representatives to stop leaving Queensland behind when it comes to supporting people with a disability.

It is disappointing that the Queensland LNP Government have chosen to turn their back on people with disabilities.

Campbell Newman is leaving Queensland behind. I encourage you to sign this e-petition to support an NDIS in Queensland visit:

www.everyaustraliancounts.com.au to show that Every Australian Counts.

End of Press Release

So I would encourage our families to tell other families, friends, work colleagues, church congregation and neighbours…and ask everyone to sign the online petition. HD families need this scheme and everybody's' support will help. This is not about political persuasion; it's about what is right, fair and justly deserved.
As always, please feel free to call our office anytime if you have any questions or concerns, or you'd just like a chat. If you'd like to know more about the NDIS you can sign up on the website www.ndis.gov.au for regular updates. Take care.

Christine Fox (Senior Welfare Officer) along with Theressa Byrne (Welfare Officer & Day Centre Facilitator)

STUDENT REPORT

Greetings from The University of Queensland, School of Public Health!

My name is André McDuling. I'm a final year Health Science student and I'll be working along with the wonderful people here at Huntington's Queensland for the next few months. I've been at university for a long time now, having qualifications in Computer Science as well as a degree in Pyschology. Although it would seem that I love studying, I am endeavouring to complete Medical School after this degree to finally become the doctor I have always wanted to be.

My contributions around the office will be helping Christine and Anne out with any tasks they need me to work on as well as conducting a literature research in Huntington's Disease for the purposes of updating the Association's factsheets and sourcing new information, websites, articles etc especially in relation to Juvenile Huntington's Disease.

So if you are at Huntington's Queensland and you see a tall, blonde South African wandering around, don't forget to say, "howzit"!

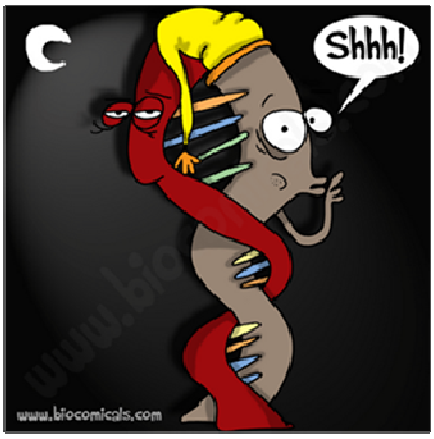
André McDuling, Health Science Student

ASO gene silencing reaches further, lasts longer

Silencing the Huntingtin gene using ASO drugs reaches further, lasts longer and is safe. Human trial soon?

By Dr Nayana Lahiri on June 21, 2012. Edited by Dr Ed Wild.

Drugs called anti-sense oligonucleotides, or ASOs, are one way of silencing the gene that causes Huntington's disease. A new publication in the journal Neuron suggests that ASO gene silencing reaches further in the brain than other methods, lasts longer and is safe.



Gene silencing - 'switching off' the gene responsible for Huntington's disease - is one of the most promising approaches researchers are working on. Image credit: www.biocomicals.com by Alper Uzun, PhD

We have been waiting eagerly for developments in the field of gene silencing, and so we were super excited to read a major new piece of research published today in top journal Neuron. A group of researchers, led by Dr Don Cleveland at the University of California San Diego, in conjunction with the drug companies Isis pharmaceuticals, Genzyme and Novartis, have been developing **anti-sense oligonucleotides** (**ASOs**) for Huntington's disease. So what have they been up to and what have they found?

Genetics recap

The Huntington's disease gene is just one of around 25,000 pairs of genes, made up of DNA, which carry the code for making proteins; the building blocks for the cells, which make up our bodies. There are a couple of steps between the DNA 'code' and the finished protein. One of those steps involves **messenger RNA**, or **mRNA**.

The HD gene is the code, which when translated makes HD mRNA. It's the mRNA that tells a cell how to make the huntingtin protein. People who have Huntington's disease have one normal copy and one expanded copy of the gene, so they make two different types of mRNAtoo.

Since the HD gene was identified, nearly 20 years ago, scientists have been trying to understand what it does, how it causes the symptoms of HD and how to effectively switch it off.

Switching off the gene

There are a number of possible methods for switching off the HD gene. Perhaps the most widely known is **RNA interference**, also known as RNAi or sometimes siRNA.

Another approach uses a slightly different molecule called **anti-sense oligonucleotides**, or **ASOs**.

ASOs are a bit like a cross between DNA and mRNA. They are chemically similar to DNA, but are made of a single strand like mRNA. Just like other gene silencing drugs, they are designed to stick to the HD mRNA and tell the cell to destroy it, so preventing the abnormal huntingtin protein from ever being made.

The theory behind this is that if you prevent the abnormal huntingtin protein from being made, you prevent its damaging effects on cells, and therefore reduce or delay symptoms.

In the past few months, we've heard good news from several groups working on RNAi drugs, but until recently the ASO researchers haven't published as much. That just changed with this latest publication, which brings us up to date with several years' hard work.

ASOs treat parts of the brain that other gene silencing techniques have been unable to reach

Human clinical trials of ASOs in other neurological diseases have already started, but the situation in HD has been slowed down by some unanswered questions.

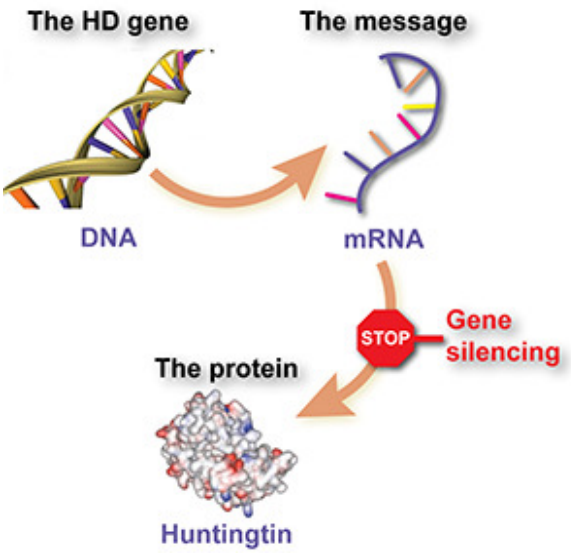
The effect of ASOs

In this brand new work, a clever bunch of researchers have have looked at the effects of using theASOs in 3 different mouse models of HD, and also in a monkey model (the next best thing to humans in terms of animal models), to try to figure out the answers to a number of different questions.

In the monkeys, the drug was injected into the spinal fluid — a much less invasive procedure than injecting it into the brain, and one that would be preferable for human patients.

1. What happens when you infuse an ASO, and how long does it last?

Well, they infused the ASOs into the brain ventricles (fluid filled spaces in the brain) for two to three weeks. This led to decreased levels of the abnormal huntingtin protein throughout many areas known to be important in the brain, including the striatum, which is affected most prominently in Huntington's disease. ASOs were able to spread much further in the brain than we've seen with RNAi drugs.



What's more, the levels remained low for a long time — up to three months after stopping the infusion.

2. What happened to symptoms?

Researchers are able to monitor the symptoms of animal models using tests that measure movements and behavior. The animals treated with ASOs improved compared with their untreated counterparts. Even better, improvement was sustained for a long time — and not just while the protein levels remained low. Symptoms were still better some months after the levels of abnormal huntingtin protein had returned to pre-treatment levels.

This supports the idea that the brain may only need a little assistance, to help it survive the effects of the HD gene. One prominent HD researcher, Carl Johnson, coined the term **'huntingtin holiday'** to suggest that a short break from the harmful protein may be all that's needed to tip the balance in favor of recovery.

In this work, ASO drugs were used to silence the HD gene. The drugs stick to the mRNA message molecule. That makes the cell delete the message and the protein doesn't get made.

3. When is the best time to give treatment?

This study suggests that early treatment is probably better.

Motor symptoms in one particular mouse model improved within a month of treatment, and continued to improve until the HD mice looked no different from normal mice. Behavioral symptoms were restored to normal within 2 months of treatment.

When older mice with more symptoms were treated, their motor and behavioral symptoms did improve, but it took much longer for improvements to be noticeable, and they didn't gain as much back as the younger, healthier mice.

4. What happens if you block the 'normal' HD mRNA?

This is one of the main questions holding us back from starting trials in Huntington's disease. We know huntingtin protein is essential for early development, as mouse embryosengineered to produce no huntingtin die before they're born. Is it safe to switch off production of both the normal and the abnormal huntingtin protein in adults?

Thanks to this work, and the work of other gene silencing researchers, we are getting closer to an answer. Switching off normal HD mRNAfor up to 3 months in healthy monkeys was well tolerated. In the animal models of HD, switching off both the normal and the abnormalmRNA didn't change the amount of recovery and didn't have any bad effects.

The only possible sticking point now, is that humans may be more sensitive to having less huntingtin than any animal we could test the drugs in. Only a trial with patients will tell us for sure.

This is all good news

We now have proof that ASOs treat parts of the brain that other gene silencing techniques have been unable to reach. Not only that, but a short-term infusion with ASOs was enough to delay the progression of symptoms in Huntington's disease animal models. And the reversal of symptoms lasts much longer than expected, even after levels of the abnormal huntingtin protein return to normal.

Reach2HD TRIAL

This trial is a randomised, double-blind, placebo controlled study to assess the safety and tolerability and efficacy of PBT2 in patients with early to mid-stage Huntington Disease.

What is the Reach2HD Trial?

The Huntington Study Group (HSG) is conducting a trial of an investigational drug called PBT2 in persons who have clinical features of Huntington Disease (HD). Reach2HD is designed to determine how safe and tolerable PBT2 is at a dose of 100 mg and 250 mg per day versus placebo and to determine whether or not there is an effect on cognitive (thinking) abilities. The study will also look at whether PBT2 will affect other HD symptoms including motor (movement) and overall functioning of people with HD when taken over a period of 6 months. PBT2 has shown, in animal models and a small group of individuals with Alzheimer disease, signs of improvement in cognition. There is some indication in animal models of Huntington Disease that PBT2 improved motor function and control.

Who Can Participate in Reach2HD?

The main eligibility criteria to participate in the Reach2HD trial require you to:

- Have early to mid-stage HD
- Be at least 25 years old
- Be able to provide written informed consent
- If taking the drug tetrabenzine be on a stable dose for at least three months prior to your first visit
- Have a study partner who assists/spends at least two hours a day for at least four days a week with you and is able to attend certain study visits with you
- Be able to take oral medication and be willing to comply with study-specific procedures
- Not be pregnant, lactating, or intending on becoming pregnant or impregnating someone
- Be fluent in English

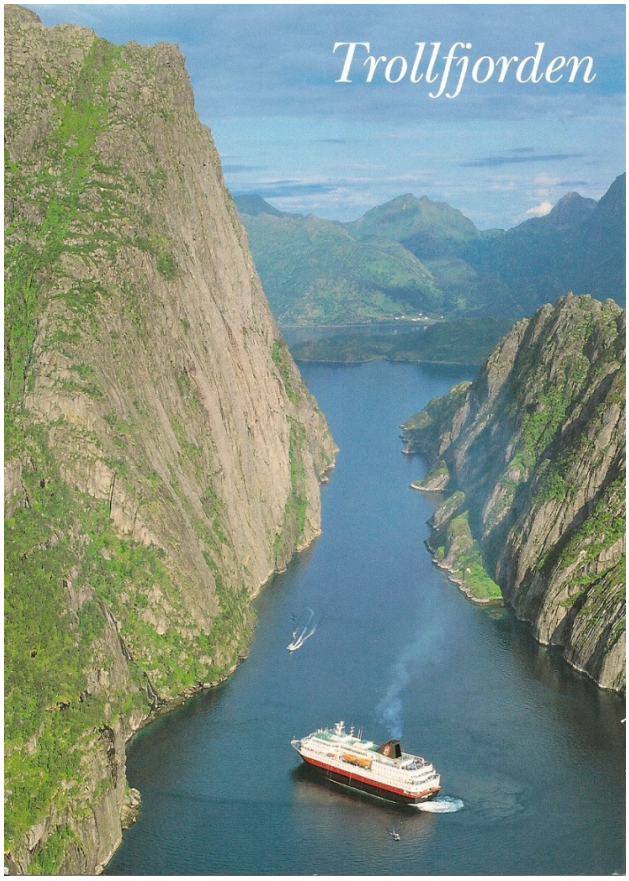
Approximately 17 research centres across the United States and Australia will enroll about 100 individuals. Our site at The University of Melbourne / St Vincent's Hospital has had interest from eight potential participants and we screened our first participant last week.

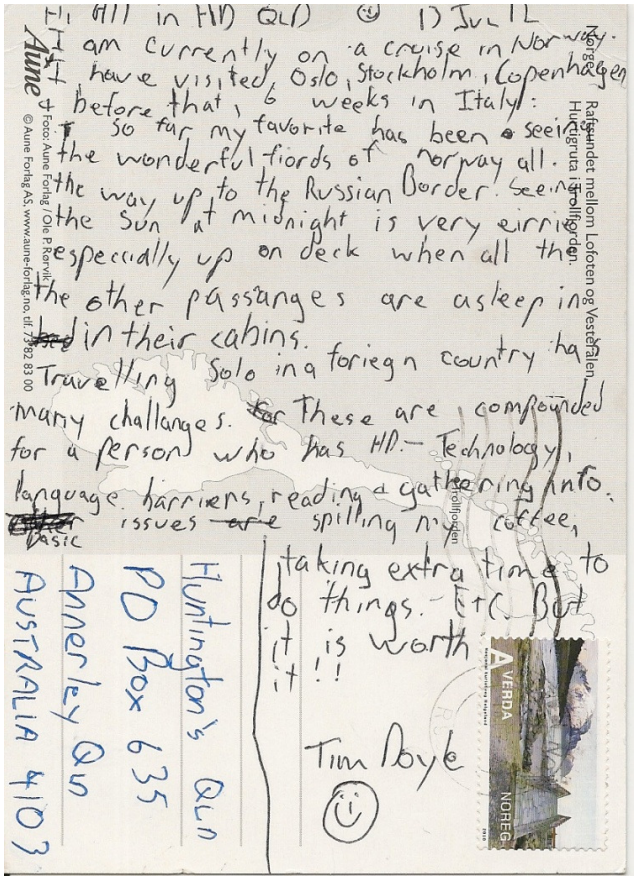
How Can I Learn More?

If you want to know more about participating in HD research you can contact:

Dr Anita Goh on goha@unimelb.edu.au

POSTCARD FROM NORWAY – *An inspiring account from an adventurous, solo traveler…..*





Tim Doyle from Mt Sheridan in North Queensland wrote…..

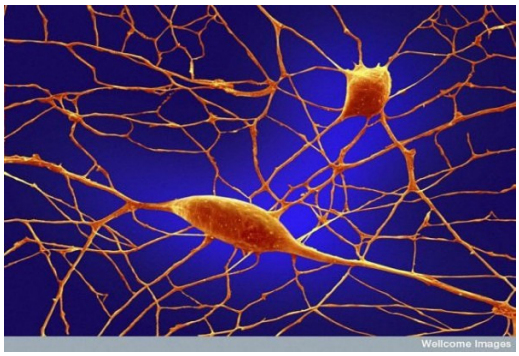
Hi all in HD Qld. I am currently on a cruise in Norway. I have visited Oslo, Stockholm, Copenhagen and before that, 6 weeks in Italy.

So far my favourite has been seeing the wonderful fiords of Norway all the way up to the Russian border. Seeing the sun at midnight is very eerie especially up on deck when all the other passengers are asleep in their cabins.

Travelling solo in a foreign country has many challenges. These are compounded for a person who has HD – technology, language barriers, reading and gathering info, basic issues, spilling my coffee, taking extra time to do things etc. But, it is worth it!!

Tim Doyle

Rebooted Neurons Halt Brain Degeneration in Mice



Mice with a form of dementia have had the condition reversed by a process that involves 'rebooting' brain cells otherwise destined to die.

The process that kills the cells could be common to all dementias, so blocking it in the same way might hold promise for Alzheimer's disease and Parkinson's disease – although more research is needed to explore this further.

"This is potentially a common pathway in all these diseases," says Giovanna Mallucci at the University of Leicester, UK. "The key thing is that we've moved away from a disease-specific mechanism to a more generic cause of cell death," she says.

Mallucci and colleagues treated mice that were bred to develop a form of prion disease similar to mad cow disease and Creutzfeldt-Jakob disease. Misfolded prion proteins accumulate in cells, forming dense plaques that clog up the brain and kill brain cells in the process.

Protein shutdown

Instead of trying to tackle the prions or plaques – an approach that has so far proved unsuccessful in Alzheimer's disease – Mallucci's team tackled another process that goes wrong in the affected brain cells: a complete shutdown of protein production.

Such shutdowns are routine in healthy cells if they produce too many misfolded or unfolded proteins, but normal protein production resumes again once the mess is sorted out.

In prion diseases, and possibly in other dementias blighted by the accumulation of plaques, normal protein production is shut down permanently. This kills neurons and destroys their connections to neighbouring cells.

In the mice with prion disease, Mallucci disrupted this process by neutralising the gene – called eukaryotic translation initiation factor, or *eIF2alpha-P* – that halts protein production. Called eukaryotic translation initiation factor, or *eIF2alpha-P*, the gene generates a protein that needs to have a chemical grouping called a phosphate group attached to it to halt the protein production line.

Mallucci's team restarted protein production with a treatment that stripped off the phosphate group. They did this by using a virus to load into the mice's brains extra amounts of another protein, called GADD34, which snips off the crucial phosphate from the eIF2alpha-P protein.

Protein reboot

By rebooting protein production, the treatment halted any further degeneration in the mice. Post mortems showed that brain connections lost in the untreated mice remained healthy, and completely normal protein production had resumed in the treated animals, even though the prions continued to accumulate. The treatment slightly extended the lifespan of the treated mice too. On average they died after 90 days. Untreated mice died after 83 days on average.

"We think it worked because we hit the executioner of the cells," says Mallucci. One challenge now, she says, is to find drugs that reboot normal protein production in the same way. A second challenge is to see if the same "production line closures" are what kill cells in patients with Alzheimer's and other dementias. If they are, then finding a drug to halt them might work in several diseases.

Mallucci says that there is hope, because *the eIF2alpha-P* protein is already known to be produced in abnormally high amounts in Alzheimer's, which suggests that it is potentially blocking protein production in the same way as in prion diseases.

"The burning question posed by this work is whether similar mechanisms operate in more common neurodegenerative diseases characterised by pathological protein deposits, including Alzheimer's, Parkinson's and Huntington's disease," says Andy Randall at the University of Bristol, UK.

Source: http://www.newscientist.com/

newshd.net By AICH – Roma Onlus Italy - www.aichroma.com

DONATIONS TO HUNTINGTONS QUEENSLAND

If you would like to donate to Huntingtons Queensland, please cut off the slip below and return it to our office with your payment. Alternatively you can donate online – directions on page 13 of this Newsletter. All donations over $2 are tax deductible and we will send you a receipt for taxation purposes.

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Life Extension Update – *Courtesy* http://www.lef.org/

CoQ10 shows promise for Huntington's Disease

Friday, June 22, 2012. Research conducted by Kevin M. Biglan, MD, MPH of the University of Rochester and his colleagues, described in the inaugural issue of the Journal of Huntington's Disease, provides more evidence for the use of coenzyme Q10 (CoQ10) to retard Huntington Disease's progression. Huntington's Disease is a neurodegenerative disorder caused by a genetic error that produces abnormal proteins in the brain's cells. Scientists believe that these protein deposits result in oxidative stress that ultimately kills the cells that contain them.

CoQ10, due to its support of the cells' mitochondria and its antioxidant effect, has been investigated as a possible agent to treat Huntington's Disease. The current research evaluated 14 Huntington's Disease patients and 6 healthy controls that had been given CoQ10 in a clinical trial known as Pre-2Care. Participants in Pre-2Care received 1200 milligrams CoQ10 daily for eight weeks and 3600 milligrams per day for the remaining 12 weeks of the study.

Stored blood samples obtained at the beginning and end of the treatment period were analyzed for serum 8-hydroxy-2'-deoxyguanosine (8OHdG), which has been correlated with the presence of oxidative stress in the brain's cells and has been found to be elevated in those with Huntington's Disease and other neurologic disorders. While the Pre-2Care study had found a reduction in Huntington's Disease symptoms after treatment with CoQ10, the current research uncovered a 20 percent reduction in 8OHdG levels in CoQ10-treated Huntington's Disease patients as well as a nonsignificant reduction in subjects who did not have the Disease. "Identifying treatments that slow the progression or delay the onset of Huntington's Disease is a major focus of the medical community," observed Dr Biglan, who is a neurologist at the University of Rochester Medical Center. "This study demonstrates that 8OHdG could be an ideal marker to identify the presence oxidative injury and whether or not treatment is having an impact."

He noted that "While the current data can't address the use of 8OHdG as a surrogate marker for the clinical effectiveness of antioxidants in Huntington's Disease, we've established that 8OHdG can serve as a marker of the pharmacological activity of an intervention."

"This study supports the hypothesis that CoQ10 exerts antioxidant effects in patients with Huntington's Disease and therefore is a treatment that warrants further study," he concluded. "As importantly, it has provided us with a new method to evaluate the efficacy of potential new treatments."

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community connect keeps you connected with programs and services supported by the Department of Communities.

The Department is moving to a dynamic online format – meaning you will be able to receive more timely news and information.

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community connect online will let you receive regular, timely updates and interact with the Department through Facebook and Twitter.

Making the move to online is easy:

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2) **Or visit www.communities.qld.gov.au and follow them on Facebook and Twitter.**

community connect online is about connecting you to convenient and timely information, while lessening the environmental footprint by reducing paper and energy consumption associated with printing and distribution.

POEM

Here's a rather sentimental poem that's doing the rounds on the internet at moment. It was sent to us by one of our members, Randell Summerville. It's an anonymous poem attributed to an old man from a country town somewhere, who knows where. If you happen to know the author, please let us know. Here's the story…

When an old man died in the geriatric ward of a nursing home in an Australian or American or English (your country of choice) country town, it was believed that he had nothing left of any value. Later, when the nurses were going through his meagre possessions, they found this poem. Its quality and content so impressed the staff that copies were made and distributed to every nurse in the hospital.

One nurse took her copy to (Brisbane, New York, London). The old man's sole bequest to posterity has since appeared in magazines and on the internet around the world. Here's the poem…

CRANKY OLD MAN

What do you see nurses…what do you see?
What are you thinking…when you're looking at me?
A cranky old man…not very wise,
Uncertain of habit…with faraway eyes?

Who dribbles his food…and makes no reply.
When you say in a loud voice…"I do wish you'd try!"
Who seems not to notice…the things that you do.
And forever is losing…a sock or shoe?

Who, resisting or not…lets you do as you will,
With bathing and feeding…the long day to fill?
Is that what you're thinking…is that what you see?
Then open your eyes, nurse…you're not looking at me.

I'll tell you who I am…as I sit here so still,
As I do at your bidding…as I eat at your will.
I'm a small child of ten…with a father and mother,
Brothers and sisters…who love one another.

A young boy of sixteen…with wings on his feet
Dreaming that soon now…a lover he'll meet.
A groom soon at twenty…my heart gives a leap.
Remembering the vows…that I promised to keep.

At twenty-five, now…I have young of my own.
Who need me to guide…and a secure happy home.
A man of thirty…young now grown fast,
Bound to each other…with ties that should last.

At forty, my young sons...have grown and are gone,
But my woman is beside me…to see I don't mourn.
At fifty, once more…babies play 'round my knee,
Again, we know children…my loved one and me.

Dark days are upon me…my wife is now dead.
I look at the future…I shudder with dread.
For my young are all rearing…young of their own.
And I think of the years…and the love that I've known.

I'm now an old man…and nature is cruel.
It's jest to make old age…look like a fool.
The body, it crumbles…grace and vigour, depart.
There is now a stone…where I once had a heart.

But inside this old carcass…A young man still dwells,
And now and again…my battered heart swells
I remember the joys…I remember
the pain.
And I'm loving and living…life
over again.

I think of the years, all too
few…gone too fast.
And accept the stark fact…that
nothing can last.
So open your eyes, people…open and see.
Not a cranky old man.
Look closer…see…ME!!

Remember this poem when you next meet an older person who you might brush aside, without looking at the young soul within. We will after all, one day, be there, too!

FUND RAISING

FINANCIAL ASSISTANCE TO HUNTINGTONS QUEENSLAND

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

William Abraham
Margaret Buchanan
Dr Geoffrey Cheyne
Jan Hall
Alan McKinless
HG Wilson
Lions Club of Brisbane Bunya
Janet Wallace
Forde & Jenny Williams
The John & Wendy Thorsen Foundation
Dorothy Smyth
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Tim Doyle

HUNTINGTONS QUEENSLAND NOMINATED AS BENEFICIARY

Our sincere thanks continue 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 661 958
29 Bribie Island Road Caboolture

ERGON ENERGY

The Association would like to acknowledge the Ergon Energy Corporation for their kind donation. Participants in their Health & Safety Program nominated charities and Huntingtons Queensland was nominated by the winning team. It's great to know that organisations such as Ergon Energy factor community support into their training activities.

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.

Alternately you can cut off the slip on page 9 of this Newsletter and return to us with your donation – cheque, money order or credit card.

All donations over $2 are tax deductible and we will send you a receipt for taxation purposes.

UPCOMING RAFFLE

We are now raffling an LG 50" Plasma TV worth $1500, kindly donated by an anonymous supporter. Second prize is a beautiful queen sized quilt, hand stitched and donated by the Little Mountain Quilters. If you would like to sell tickets on our behalf, please phone or email. Tickets are $2 each. To be drawn at the AGM on 26th September 2012.

IOOF

Thanks to the generous support of the IOOF, the Association's new Coffee Catch Up (CCU) Group has seen its first successful year.

The CCU Group is a great social outlet to catch up with others with HD in similar circumstances who know and understand, possibly better than any others, exactly what everyone is going through. The CCU Group provides a great opportunity to discuss common issues and share real experiences. Call us for information if you'd like to attend.

SUNNYBANK COMMUNITY & SPORTS CLUB

For the third consecutive year the kind members of the Sunnybank Community & Sports Club have donated funds to support Huntingtons Queensland's Youth Program (Southside).

In all there are nine separate families with twenty-one children among them in the Southside catchment area who have benefited from their generosity during this past year.

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 2011/2012:

President	Gerry Doyle
Vice President	Robert Westley
Secretary	Pam Cummings
Treasurer	Heather Whye
Committee Members:	Jan Szlapak
	Alan McKinless
	Keryn Stewart
	Esther Elliott
	Marty Harmsworth
	Shirley Ross

Staff Members:

Senior Welfare Officer	Christine Fox
Welfare Officer	Theressa Byrne
Telemarketing Officer	Helen Johnston
Administration Officer	Anne Stanfield

CONTRIBUTIONS & DISTRIBUTION

Please feel free to submit articles or photographs for selection for publication in this Newsletter. The deadline for the next issue is 1st October 2012. 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.

This Newsletter has been printed free of charge by the office of Graham Perrett, Federal Member for Moreton. Our kind thanks to Graham & Staff.