



December 2011

NEWSLETTER

HUNTINGTONS QUEENSLAND

CONTENTS

Christmas Greetings From the President	1
From the Operations Manager	2
Welfare Report	2
Carer Business Discount Card Qld	3
Qld Companion Card	3
Disability Parking Permit	3
Taxi Subsidy Scheme	4
Patient Travel Subsidy Scheme	5
Black Dog Institute	5
Respite Holiday	6
Enroll-HD	7
Newsletter Contributions	10
Poem 'The Calf Path'	10
iPhone & Android app for HD	11
Do you know about HDBuzz?	12
Fund Raising	13
Association & Contact Details	14

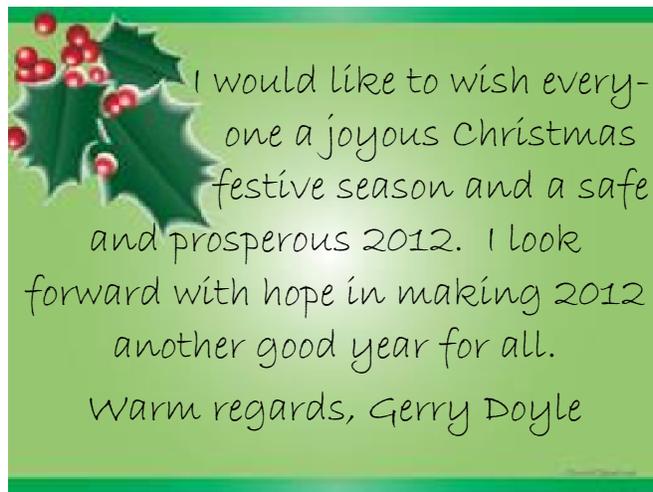
FROM THE PRESIDENT

Dear Friends

Looking back over the past year there have been many achievements but I want to mention two in particular. Firstly, the introduction of HQAssist which followed the Association receiving a \$300,000 grant from the Department of Communities, Disability Services. It is still early days and over the next year you should see a lot more activity with this program. The second has been our youth program. Christine and her team have done a great job fostering this program which is now supported by our Rotary Grants. I look forward to next year and hopefully we will have more improvements in the support and services we offer.

Once again it is my pleasure to thank the tireless efforts of our long-standing and new volunteers who help out in the day centre and in the office. Five times a year, around 450 Newsletters are folded and packed for posting by some of our original volunteers. Again, I'd like to ask anyone who currently receives our Newsletters from the postman to swap to email if possible. If you can help, please email your details to the office on admin@huntingtonsqld.com

Thank you once again to our small team of staff members – your efforts and enthusiasm on behalf of our families, carers and supporters are always appreciated.



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

FROM THE OPERATIONS MANAGER

Here we are in December with Christmas and the end of the year almost upon us. This presents us with the opportunity to reflect on how the past year has gone. For Huntingtons Queensland and for the Huntingtons community at large, I would like to say that progress is occurring. The World Congress in September provided updates on research and clinical trials. It also highlighted the accelerating growth in momentum for our cause. The 'hunt' is not over but many great people and significant resources are hammering away at the problem. In the mean time we 'hunters' band together for support and encouragement. I wish you all strength.

There is not a lot of new information since our October Newsletter, although we continue to be very busy continuing and expanding the services provided by Huntingtons Queensland. Huntingtons Awareness Week has had to be postponed and is still slipping from my grip, but it will be rescheduled in the near future. Other than that I will spare you reading my words just for the sake of it, and will have more to say as and when it occurs. Later in this Newsletter you will find a poem 'The Calf Path'. It is a favourite of mine and I would like to share it with you. It is good sometimes to have a break from such a serious issue as ours. I am not trying to send a message and there is no moral to the poem other than to highlight the need for a sense of our own identity and originality. People dealing with the severity of issues such as ours, develop their own strength and individuality in any case. I offer it to you for enjoyment.

In my last column I invited suggestions for a word to best describe Huntingtons people. Cliff Farmer is the winner of the cup of coffee and a chat with me – what a prize. He hasn't claimed it yet. On a serious note, I am using this as a way to remind you all that a cuppa and a chat is on permanent offer, should I be able to be of assistance, or if you have any suggestions.

Have a great and safe Christmas and holiday period.

Michael McLean, Operations Manager



WELFARE REPORT

Hello Friends and Families!

In early November we ran a respite holiday for two groups to a wonderful house in glorious Runaway Bay on the Gold Coast. McKinnon House is owned and operated by MS Aust and is available for weeklong holidays to anyone with a disability at a very affordable rate. Lesley and Tressa took turns to take two different groups of people along to relax and refresh and you can read their accounts a little later on in this Newsletter. If anyone would like more information about McKinnon House as a possible holiday location, feel free to give us a call at the office and we would be more than happy to send you some information and contact details.

In this Welfare Report, we thought we'd revisit some of the incentives and schemes that some of our families may find they are eligible for. We have made every effort to collect the most current and correct information on each of these initiatives and in most cases have taken the definitions directly from the websites so as to not cause any confusion. If you have any questions about what you read, would like a little more information (in particular if you do not have internet access) please feel free to call our office and we will be only too happy to help. Likewise, if you would like us to print of any of these applications out for you, please feel free to ask.

Details of some of these incentives and schemes follow.....



Carer Business Discount Card Queensland

What is it? To recognise the valuable role carers play in the community, the Qld Government has introduced the Carer Business Discount Card scheme. With the support of the business community, carers can use their Carer Business Discount Card to obtain discounts and incentives from participating businesses.

Who is eligible? To be eligible for a Carer Business Discount Card you must be a resident of Queensland with a Queensland residential address registered with Centrelink, and receive the Centrelink Carer Payment or Carer Allowance.

Who completes the form? Carer can complete the form. Huntingtons QLD staff can assist.

Is there a cost? There is no cost involved in lodging the application.

How to apply: You can lodge the form online; or download the cardholder application form to complete your details and post; or you can make your application over the phone by calling Smart Service Queensland on 13 QGOV (13 7468) (Monday to Friday, 8.00 am - 6.00 pm).

Queensland Companion Card

What is it? The Companion Card program was introduced to support people with a disability who have a lifelong need for a carer / escort in order to be able to participate in community activities and attend venues, promoting fair ticketing in order for the person with a disability to be able to attend these activities and venues in the community.

Who is eligible? To be eligible for a Companion Card you must demonstrate that you:

1. are a lawful Australian resident living in Queensland; and
2. have a disability; and
3. because of the impact of the disability, you are unable to participate at most community venues or activities without attendant care support and
4. need, or have a likely need, for lifelong attendant care support.

Who completes the form? Most of the form can be completed by the applicant (or a helper) however there is one section of the form that needs to be completed a medical professional or service provider. Huntingtons Qld may be able to help some people with this application.

Is there a cost? There is no cost involved in lodging the application, however you will need to supply passport sized photos with the application.

How to apply: Call Smart Service Queensland on 13 QGOV (13 74 68) and they can mail you a cardholder application form and handbook. The form can also be downloaded.

Disability Parking Permit

What is it? A disability parking permit is granted to applicants when their ability to walk is severely restricted by a medical condition or disability. The Department of Transport and Main Roads is responsible for the administration the Queensland Disability Parking Permit. Along with being able to park in car parks allocated for wheelchair spaces, parking holders are entitled to parking concessions that allow access to on-street and off-street parking bays. On-street parking in local government metered and regulated parking areas are free of charge with the following conditions:

- where the time limit specified by a sign is less than 30 minutes, parking will be allowed for 30 minutes;



- where the time limit specified by a sign is 30 minutes or more, parking will be allowed for an unlimited amount of time.

Who is eligible? To apply for a permit, the applicant must be a Queensland resident and meet **one** of the following eligibility criteria:

- must be unable to walk and always require the use of a wheelchair
- their ability to walk is severely restricted by a permanent medical condition or disability
- their ability to walk is severely restricted by a temporary medical condition or disability.

Who completes the form? The applicant completes some parts of the form, however there is a section that can only be completed by a GP or Occupational therapist. Huntingtons Qld cannot help with this part of the form.

Is there a cost? Yes, there is a small fee to be paid when lodging the application.

How to apply: Collect a form from any Department of Transport and Main Roads customer service centre, you can call to have the form mailed out to you or you can download the form.

Taxi Subsidy Scheme

What is it? The taxi subsidy scheme is a Qld Government initiative which aims to improve the mobility of persons with severe disabilities. The scheme is funded and administered by the Department of Transport and Main Roads.

Who is eligible? To be eligible for membership of the taxi subsidy scheme you must:

- be a permanent resident of Queensland
- fully meet at least one of the eligibility criteria listed below:
 1. Physical disability requiring dependence on a wheelchair for all mobility outside the home.
 2. Severe ambulatory problem that cannot functionally be improved and restricts walking to an extremely limited distance.
 3. Total loss of vision or severe visual impairment (both eyes).
 4. Severe and uncontrollable epilepsy with seizures involving loss of consciousness.
 5. Intellectual impairment or dementia resulting in the need to be accompanied by another person at all times for travel on public transport.
 6. Severe emotional and/or behaviour disorders with a level of disorganisation resulting in the need to be accompanied by another person at all times for travel on public transport.

Who completes the form? The applicant completes Part A of the Form – and a doctor, specialist or other recognised health professional completes Part B and C of the application. Unfortunately, this is *not* a form that Huntingtons Queensland staff are qualified to assist you to complete.

Is there a cost? There is no cost involved in lodging the application, however you will need to supply passport sized photos with the application.

How to apply: If you think you may be eligible you must:

- complete Part A of the Taxi Subsidy Application Form
- provide two passport size photographs
- visit your doctor or specialist and have them complete Part B and Part C of the application (and sign the back of your photograph)



- mail the completed Taxi Subsidy Application Form with the photographs to the Taxi Subsidy Unit, Department of Transport and Main Roads.

A Little Note: Unfortunately, a diagnosis of Huntington's Disease does not mean that someone is automatically eligible for this scheme, however if someone is experiencing significant impairments due to the symptoms of HD, it is worth asking your doctor.

Patient Travel Subsidy Scheme

What is it? The Patient Travel Subsidy Scheme has been put in place to help Queenslanders access specialist medical services, which are not available in their local area. When these specialist services are not available within 50 kilometres of the nearest public hospital, the Scheme offers assistance by providing a contribution towards the cost of transport and accommodation. When a patient requires assistance with either the demands of treatment, or the demands of living away from home, the Scheme can sometimes also provide a contribution towards the cost of transport and accommodation for an escort.

Who is eligible? To be eligible you need to meet the following criteria:

- You need a current Medicare Card (or be eligible to hold a Medicare Card).
- You need to be a resident of Queensland.
- The service for which you are seeking travel subsidy must be classified as 'essential' (attending a specialist's appointment for symptoms of Huntington's Disease is considered 'essential' but you should always refer to your doctor)
- The service you are seeking is not within 50 kilometres of your nearest public hospital.
- A medical practitioner must refer you to the service.

Who completes the form? There are several forms involved in this subsidy, some are completed by the patient, some are completed by your doctor, and some by the specialist. Talk to your Doctor for more information.

Is there a cost? There is no fee to lodge the application.

How to apply: If at anytime you are required to travel (by car, public transport, plane, etc) to attend a medical appointment for Huntington's Disease then you may be eligible for this subsidy. Ask your GP next time you are referred to see a specialist and they will be able to assist you with the paperwork. It is important that the paperwork is submitted prior to the appointment to ensure you will receive a subsidy. For more information, including subsidy entitlements, look online at <http://www.health.qld.gov.au/iptu/html/ptss.asp>

We hope you find this information helpful. Remember, email or call us if you need more information or assistance.

On behalf of the Welfare Team, I'd like to wish you all a very Merry Christmas and a safe and happy New Year.

**Christine Fox, along with Theresa Byrne and Lesley Frazer
Huntingtons Queensland Welfare Team.**



Depression is a common experience that can affect anyone from time to time. For information go to this great website <http://www.blackdoginstitute.org.au>



RESPIRE HOLIDAY AT MCKINNON HOUSE RUNAWAY BAY GOLD COAST



Tressa's reminiscences of the respite holiday...

Good weather, beautiful surroundings and terrific company were all on the menu when six of our clients stayed at McKinnon House at Runaway Bay on the Gold Coast. The house is in a stunning location right on the Broadwater where we spent a relaxing but endlessly fascinating time looking out for dolphins, yachts and other sailing craft.

Day one found us relaxing on the deck of the house, and those of us who were more active and didn't mind the brisk sea breeze, put the pool to good use. After we'd explored our very pleasant surroundings most of us were content to eat, talk and enjoy the constantly changing view right at our feet.

Day two saw us at Main Beach for a very long walk and some paddling in the waves, followed by more swimming and some very dedicated eating. On our final day, with great difficulty, we decided to leave the comfort of the house and take a drive up to Mount Tamborine, where we picnicked in the very pretty surroundings of the Botanical Gardens. For one of our regional members, a quick tour of the Mount Tamborine township was a must do.

It was with some regret that we packed our bags on the final day to return to Brisbane. The early mornings waking up to the spectacular view were certainly something that I for one missed on coming home. Now we can start counting down to next year's escape!

Tressa

And Lesley's recollections...

On Sunday the 6th of November, a group of seven ladies arrived at McKinnon House for a few days of relaxation and time out. While we were able to fit a few occasions in to just sit on the verandah and enjoy the sights, a few of us felt like we were taking part in 'laughter therapy'. This therapy was compounded even more when we went to the cinema and watched the movie titled 'Crazy Stupid Love'.



One of the many highlights of our time there, was watching ten or more dolphins frolicking only a few metres from us. On the Tuesday it was hard to say our goodbyes to both each other and Runaway Bay.

Along with the extra insights of each other we also took many lovely memories away with us.

Thank you ladies, for an absolutely great few days – I can't wait to do it again.

Lesley





The following three pages of information are extracted from Enroll-HD News - July 2011 (Issue 1) and October 2011 (Issue 2) of Enroll-HD News. This information was emailed to our Huntingtons Queensland members who have email on November 10th 2011. If others of you would like to receive this information via email, please email your request to admin@huntingtonsqld.com

Source: Enroll-HD News July 2011 (Issue 1)

A WORD FROM THE PI: Bernhard Landwehrmeyer

Dear Enroll-HD Working Group Members, Investigators, Research Staff, Participants and Family Members

As you are aware, a lot of efforts have focused on the development of a study protocol for the Enroll-HD Study as a global observational study that allows for full participation of new study sites (e.g. within the rapidly-expanding network of colleagues in Latin America) as well as for a continuation and extension of the established observational studies REGISTRY (Europe) and COHORT (North America/Australia), building on their many strengths and successes.

Over the past few months, these efforts have been supported by colleagues from across the HD community - clinicians, patients, families, researchers, advocates - and across the globe - from North and South America to Europe and the Asia Pacific region.

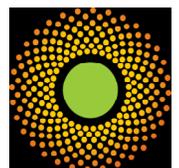
It is my pleasure to announce that the Enroll-HD Study Protocol has been drafted and can now be viewed on the Enroll-HD WebPortal - <http://www.enroll-hd.org/html/wg/protocol/review> I would like to personally welcome all of you to review this version of the protocol and provide your feedback. We kindly request that you submit your comments via the WebPortal directly, by no later than July 15, 2011. We plan to finalize and publish a final version of the core protocol in the course of July 2011. If you need technical assistance in uploading your comments to the WebPortal, please contact Katrin Barth on email katrin.barth@uni-ulm.de

We will continue to provide you with study updates on a regular basis using this e-Newsletter format. E.g., we will invite you to send in proposals for sub-studies and for ancillary studies for integration into the protocol as amendments; further details on the application and submission process will be provided in one of the next issues of the Enroll-HD e-Newsletter. If you have any questions or comments, please do not hesitate to contact the Enroll-HD Study Team at Outcome (the CRO supporting Enroll-HD) via email EnrollHD@Outcome.com or phone (+1-866-316-6947) or our colleague Joe Giuliano at CHDI joseph.giuliano@chdifoundation.org

Please accept my sincere gratitude for your support of and contributions to the HD community. I am looking forward to continuing to build on this work with the upcoming Enroll-HD study.

Kind regards

G. Bernhard Landwehrmeyer MD
Professor of Neurology, University of Ulm





Source: *Enroll-HD News October 2011 (Issue 2)*

NEWSFLASH: Enroll-HD Study Protocol Finalized

The Enroll-HD Study Protocol has been finalized!

Congratulations to everyone who contributed to the development, review, and finalization of the Enroll-HD Study Protocol. The Enroll-HD Study Team would like to thank members from the Enroll-HD Working Groups and all those in the HD community who provided valuable review and feedback on the draft protocol.

The final protocol can now be found on the Enroll-HD WebPortal: <https://www.enroll-hd.org/html/wg/protocol/docs> Please note that this document is intended for reference purposes only and should not be used for regulatory submissions. If you need technical assistance in accessing the document, please contact Katrin Barth on email katrin.barth@uni-ulm.de



Drs Bernhard Landwehrmeyer (University of Ulm, Germany) and **Cristina Sampaio** (Chief Clinical Officer, CHDI Foundation) sign the Enroll-HD study protocol.

Enroll-HD Highlighted at the WCHD in Melbourne, Australia

Joe Giuliano, Director of Clinical Operations, CHDI Foundation

The Enroll-HD Team took Enroll-HD “Down-Under” to the World Congress on Huntington’s Disease in Melbourne, Australia in September. The World Congress is held every two years and brings together scientists, family members, and healthcare professionals involved in the global effort to improve the quality of life for HD patients and find effective treatments. This year’s Congress provided a great opportunity to showcase Enroll-HD, explain the rationale behind the new unified global observational study, and underline the opportunities for future re-search.

Enroll-HD was highlighted during a lunch time session where principal investigator Dr. Bernhard Landwehrmeyer of the University of Ulm presented details of the new study protocol and the overall goals of the study. In addition, Joe Giuliano from CHDI Foundation gave a brief update during a town hall session on the progress of Enroll-HD to date and the team presented an informative poster during one of the poster sessions.

Throughout the Congress many investigators, coordinators, and family members in attendance expressed a lot of interest and enthusiasm about Enroll-HD, and there were investigators and family members from Australia, New Zealand, Taiwan, Sri Lanka, Mexico, and Israel who communicated their interest in participating. The Enroll-HD Study Team was also invited to a meeting of investigators from Australia and New Zealand who are deliberating on their next steps to bring together their own network of HD research centers. This was a great opportunity to explore how the groups could find new and better ways to work together in the future.

Timelines: Site Start-up Strategy

The current goal is to have all clinical sites in North America and Australia that had formerly participated in COHORT, as well as new Latin American sites, up and running under the Enroll-HD protocol by Q1 2012. This will be a challenge to achieve given some of the IRB and contract review times, but we will strive to have as many sites as possible engaged by that time. New clinical sites in North America and Australia that were not previously involved in COHORT will follow soon after.



Starting in October 2011, the Enroll-HD Study Team will be conducting site assessment visits at Latin American sites recommended by the RLAH, the Latin American HD network, in order to evaluate the resources currently available to the sites and, where needed, offer support to enable successful conduct of the study. REGISTRY sites will begin to be transitioned to Enroll-HD in the middle of 2012, followed by sites in Asia and Australasia in 2013.



Local HD Network Profile: Focus on Latin America

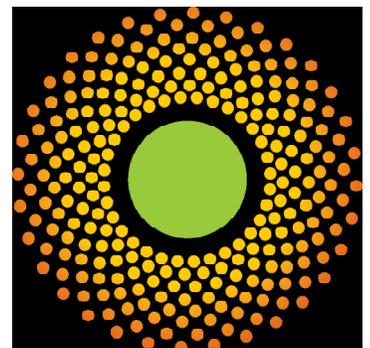
The Red Latinoamericana de Huntington (RLAH) is a burgeoning HD clinical network in Latin America and a valuable and exciting addition that exemplifies the global nature of Enroll-HD.

The RLAH was launched in February 2010 when a group of clinicians and family members, with the support of CHDI Foundation and the encouragement of EHDN, formed a committee in order to create a network that would promote and facilitate HD research in Latin America.

During 2010 the RLAH worked to set up the necessary mechanisms to contact and connect with investigators and sites in the region. A preliminary survey identified the countries where there were interested and motivated professionals, and so far 13 clinical sites in Argentina, Brazil, Chile, Ecuador, Peru and Venezuela have joined the network.

One of the initial priorities of the RLAH was to establish a collective observational study to serve as a platform for clinical trials, so the development of the global Enroll-HD has been an invaluable foundation for the set-up of the network.

RLAH members have been an integral part of the Enroll-HD Working Groups and have been fully involved in the decision-making process. The RLAH sites are now in the process of preparing for Enroll-HD, which for many of them will be the kick-off study for the HD network.



Newsletter Contributions

If you'd like to submit an article for consideration in our Newsletter, please feel free to email, fax or post your article to:

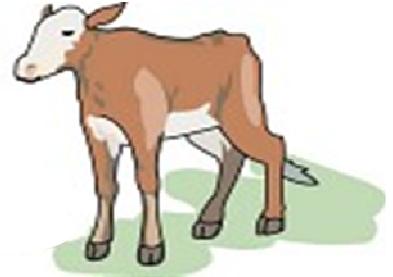
The Editor

admin@huntingtonsqld.com

Fax 3391 0443

PO Box 635 Annerley Qld 4103

Here's the poem selected by our Ops Manager, Mike McLean.



The Calf Path

By Sam Walter Foss (1858 - 1911)

One day through the primeval wood,
A calf walked as good calves should;
But made a trail all bent askew,
A crooked trail, as all calves do.

Since then three hundred years have fled,
And, I infer, the calf is dead.
But still he left behind his trail,
And thereby hangs my moral tale.

The trail was taken up next day
By a lone dog that passed that way;
And then a wise bellwether sheep
Pursued the trail o'er vale and steep,
And drew the flock behind him, too,
As good bellwethers always do.

And from that day, o'er hill and glade,
Through those old woods a path was made,
And many men wound in and out,
And dodged and turned and bent about,
And uttered words of righteous wrath
Because 'twas such a crooked path;
But still they followed – do not laugh –
The first migrations of the calf,
And through this winding wood-way stalked
Because he wobbled when walked.

The forest path became a lane,
That bent, and turned, and turned again.
This crooked lane became a road,
Where many a poor horse with his load
Toiled on beneath the burning sun,
And traveled some three miles in one.
And thus a century and a half
They trod the footsteps of that calf.

The years passed on in swiftness, fleet.
The road became a village street,
And this, before men were aware,
A city's crowded thoroughfare,
And soon the central street was this
Of a renowned metropolis;
And men two centuries and a half
Trod in the footsteps of that calf.

Each day a one hundred thousand rout
Followed that zigzag calf about,
And o'er his crooked journey went
The traffic of a continent.
A hundred thousand men were led
By one calf near three centuries dead.
They follow still his crooked way,
And lose one hundred years a day,
For thus such reverence is lent
To well-established precedent.

A moral lesson this might teach
Were I ordained and called to preach;
For men are prone to go it blind
Along the calf-paths of the mind,
And work away from sun to sun
To do what other men have done.
They follow the well beaten track,
And out and in and forth and back,
And still their devious course pursue,
To keep the paths that others do.

They keep the path a sacred groove,
Along which all their lives they move;
But how the wise old wood-gods laugh,
Who saw the first primeval calf!
Ah, many things this tale might teach –
But I am not ordained to preach.



We Have a Face.org

'We Have a Face' announces iPhone & Android app called Help 4 HD

James Valvano, Director of Operations, www.WeHaveAFace.org, has announced that their team has just released the first HD application for Apple and Android devices. The app is called Help 4 HD and contains all manner of interesting information. They are pleased that the international community has taken an active role in the project to bring about awareness of Juvenile HD and HD.

If you are interested in apps...you may like to take a look:

<http://wehaveface.org/application.html> (The application)

<http://wehaveface.org/Help4HD.html> (New website component)

Contact details are:

Email: James@WeHaveAFace.org

Help 4 HD on iTunes: [Help 4 HD](#)

Help 4 HD on Android: [Help4HD](#)

Facebook: [JamesValvano](#)

Skype: JamesValvano

Twitter: WeHaveAFace

Vimeo: Vimeo.com/WeHaveAFace

YouTube: WeHaveAFace

Scientists claim to have developed a new way to treat Parkinson's, using stem cells to replace cells damaged in the disease...

Source:

[http://115.124.104.76/images/stories/2011/Health_Fitness/September/parkinsons-disease.gif]http://www.dailypioneer.com/images/stories/2011/Health_Fitness/September/parkinsons-disease.gif

"The broader significance is that this novel approach will likely be applicable to the development of stem cell- based treatments for other neurological conditions such as stroke, motor neuron disease and Huntington's Disease," Lachlan Thompson, a team member, said.

An international team, led by the Florey Neuroscience Institutes and the University of Melbourne, says that the new technique could be developed even for application in other degenerative conditions.

In regards to Parkinson's disease, there is a progressive and permanent loss of a group of dopamine-producing brain cells that form an essential pathway in the brain circuitry controlling movement.



The first step of the technique involves generating the dopamine brain cells that are missing in Parkinson's disease, say the scientists.

"By following what we know about brain development we have been able to re-create an environment in the culture dish that allows us to generate specific cell types that may be therapeutic," Clare Parish, who led the team, said.

"A limitation of the procedure, however, is that it is inefficient. This means that only around 30 per cent of the cells become dopamine brain cells while the others may remain as stem cells.

"This poses significant risks in a transplantation setting because the stem cells may continue to grow and form tumours," she said.

The team is also working on an innovative approach using a state-of-the-art cell-sorting technology to solve the problem, say the scientists.

"Overall we have identified some interesting findings that help us to isolate the dopamine brain cells and discard the stem cells prior to transplantation. It's a strategy that we hope will bring us a step closer to clinical trials for a stem cell based treatment for Parkinson's.

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Do you know about the HDBuzz website?

Source: The following is an extract from Wikipedia, the free encyclopedia on <http://en.wikipedia.org/wiki/HDBuzz#>

HDBuzz was launched in January 2011 by Huntington's Disease researchers Dr Ed Wild (UCL, London) and Dr Jeff Carroll (Western Washington University). Its stated aim is to supply "the latest news about Huntington's disease research in plain language, written by scientists who work on HD".

As well as being accessible at www.hdbuzz.net, news is syndicated to a number of Huntington's Disease community web sites, as well as via social media routes including FaceBook, Twitter and email. HDBuzz articles are published in English and translated by volunteers into nine other languages.

Support

HDBuzz is financially supported by national and regional Huntington's Disease patient and family organizations. Among the eleven supporting organizations are the Huntington's Disease Society of America (HDA), Huntington Society of Canada (HSC) and the Huntington's Disease Association of England & Wales. *(Note from Huntingtons Queensland Newsletter Editor: The Australia HD Associations are now also contributing financially to HDBuzz.)*

A policy on neutrality of funding sources precludes HDBuzz from receiving "funding or support from drug companies or anyone else with a vested interest in a particular therapy for HD", while funding organizations "do not receive special access to" or "editorial control over [its] content". HDBuzz is a registered charity in the UK.

Oversight

An oversight committee of "independent clinicians, scientists and lay community members" scrutinizes HDBuzz content "to ensure ... content is impartial, scientifically accurate and understandable". Emmy award-winning journalist and Huntington's disease advocate Charles Sabine is a Consulting Publisher to HDBuzz.

For 'easy to understand' scientific articles on HD research and developments go to <http://hdbuzz.net/>



FUND RAISING

FINANCIAL ASSISTANCE TO HUNTINGTONS QUEENSLAND

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

*Despa Sendra
Gwen Philp
Miss Harding Smith*

*Anne Bruce
WB Kentish*

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 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.



The IOOF Foundation has very kindly made a donation of \$3,960 to Huntingtons Queensland this year with a further payment of the same amount promised for next year.

The IOOF Foundation is the IOOF Group's philanthropic vehicle and is dedicated to making an ongoing commitment to the community in which we live. The foundation achieves this by providing grants in support of Australian not-for-profit organisations working in the areas of disadvantaged aged care; and disadvantaged families, youth and children.

We thank the IOOF sincerely for their support.

CAN YOU HELP 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.

We also look forward to our members renewing their annual memberships for 2011-2012 and we welcome new members.



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 2011/12:

- | | |
|----------------------|------------------|
| ➤ 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 |
| | Katherine Parr |

Staff Members:

- | | |
|--------------------------|----------------|
| ➤ Operations Manager | Mike McLean |
| ➤ Senior Welfare Officer | Christine Fox |
| ➤ 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 1st February 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.

