



NZBRI- Huntington's Newsletter

Spring 2014

Over the last few years, some of our work at the NZ Brain Research Institute has focused on Huntington's Disease (HD), whether through some academic projects lead by some of our PhD students, or via our participation in HD clinical research programs. We also run the HD combined clinic every two months where HD patients and their families can be reviewed by a multidisciplinary team.

This newsletter aims to share some research projects and results; we also welcome written contributions from members of the larger HD community, such as the inspiring fund raising story from Cath and Gary below. –this newsletter has been compiled by Laura, Research Coordinator at the NZBRI.

A splendid fundraising effort by Cath and Gary.

Hi there,

On a sunny day in November we heard that our beloved son had inherited the HD gene and quickly learnt that there was no band-aid for it; he had been great at scraped knees and so on as a boy.

Enquiring about the needs of the researchers – an incredible team under the leadership of Professor Richard Faull – our hope for the future – discovered that they needed a freezer. Immediate thoughts of putting a Fisher and Paykell freezer on HP came to mind, until the figure of \$18,000 was mentioned along with a number of other pieces of equipment.



Putting on our thinking caps we determined to raise funds which could then be passed on to the department. Starting with creating a Foundation approved by the Justice Department, not as daunting as it sounds, we became a Charitable Society making donations tax deductible for the givers.

We talked to everyone, approaching service clubs, Rotary, Lions and so on, until we were asked to do a presentation to the Masons, which changed our lives. Incredibly one of the members took our fundraising higher up which turned into an incredible donation of \$250,000 for the Brain Researchers at the University of Auckland Medical Centre. Holding talks in small towns, talking to business owners on a one-to-one basis resulted in

a further \$30,000 in donations. Now permanently back in New Zealand we will again be turning our efforts towards more fundraising to continue our need to find that elusive "band-aid" for our beautiful son and others affected by this dreadful disease.

A few months ago, Shavanthi delighted us when she turned up in the clinic with a few of her paintings. She explained that art and music is an important part of the school curriculum in Shri Lanka, her native country.

After a long gap, she decided to enroll in a local painting class. Shavanthi's paintings are showing us that despite some involuntary movements, or problems with fine motricity, it is still possible to make the most of our talents. Well done Shavanthi!





On Tuesday 21st of August, some members of the HD community came along to an informal meeting at Christchurch South library. Connecting with each other and learning how every individual deals with his/her HD was the very first key idea that we felt we should try to implement.

For those of you who would like to get in touch with other persons affected by HD, Mandy has set up a Facebook group: **HD Members & Support Group Christchurch NZ**. Thank you Mandy! The purpose of this group is to support people affected by Huntington's Disease and to have a place to share the trials and tribulations of those in the group. We will hold another meeting in the next few months and we hope that you can join us.

Are you interested in special topic presentations, casual get togethers over a cup of coffee, caregiver support, or simply some fun activities? Tell us what you would like for the HD community!



Maggie Jury, Anita and Mandy.



Jeroen De Schepper

At a recent meeting, Laura (from the NZ Brain Research Institute) met with Belgian compatriote **Jeroen De Schepper**, from a HD family.

Jeroen cycled more than 10,000 kms around Europe in 2014 to raise money and awareness for HD.

His 4 months long trip took him to many countries where he stopped at dedicated HD clinics, nursing homes and research centres. He met many HD families and health professionals. This gave him a good insight at the way each country addresses HD, especially in nursing places where some ingenious people had come up with ideas to help with daily activities, such as veggie gardens raised to shoulder level, diverse mobility scooter prototypes, and music and relaxation rooms to name a few.

Closer to home, NZ made film **The Inheritance** was recently screened in Wellington and Auckland. This movie, made by Wellington film editor Bridget Lyon and her husband movie director Jeff McDonalds, takes us into the heart of Bridget's family. It follows the progression of Bridget's mother and confronts us with the common issues faced by a HD family. This very inspiring movie also features short interviews of HD researchers on the most recent advances. We are hoping to bring it to Christchurch soon.

Funded by CHDI (Cure Huntington Disease Inc.), **Enroll HD** is a worldwide long term observational study of HD families. It is truly a global effort: 10 countries are currently recruiting for this study, while 38 more European sites will join later this year. More than 3500 subjects have been enrolled so far in this study that promises to become the corner stone of HD research.



Who can participate?

Enroll-HD is a family study!

- Gene + (symptomatic, pre-symptomatic)
- Gene status not known (at-risk)
- Gene negative
- Spouses/Partners

What do we do?

One visit per year!

- motor assessments
- cognition testing
- mood questionnaires
- blood collection for research

ENROLL HD IS MORE THAN YOUR AVERAGE STUDY. WE BELIEVE THAT IT WILL HAVE A TANGIBLE EFFECT ON THE LIFE OF HD PEOPLE IN THIS LIFETIME THANKS TO THE LARGE NUMBER OF DATA COLLECTED, AND WE ENCOURAGE EACH FAMILY TO PARTICIPATE.

Your suggestions and questions are welcome, please contact Laura at 03 378 662 or laurap@cdhb.health.nz If you are looking for more information on HD or if you are interested in joining one of our trials, please let us know. We are also interested in hearing from HD subjects who would like to take part to some academic research with Prof. Anderson from time to time.