

### ENROLL HD Study Update.

80 participants have now been enrolled in the ENROLL HD study in Christchurch. For a small site like ours, this is fantastic and we thank our participants for their ongoing support.

The study principal investigator, Dr Bernhard Landwehrmeyer, a German neurologist, visited our site in September. He was pleased with our retention level, and indeed most of you come back for the annual follow up visits, which is important for an observational study like ENROLL HD. A regional meeting was held in Melbourne a week later to consolidate training and other aspects of the study.

The data collected in the clinic goes through a rigorous checking process before being released to the international database. It is then that researchers are able to access the data to test new hypotheses and new ideas. The philosophy of open access to anonymous data is explained in the ENROLL HD newsletter that I have enclosed for your information.

Here is the map of all the countries involved in the ENROLL HD study. More than 8000 participants are currently enrolled but ideally, 20 000 participants are needed to ensure large volume of data and blood samples.



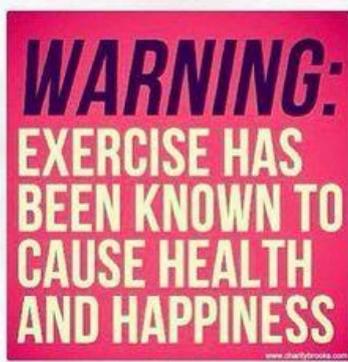
**“We are not going to stop until we find a useful treatment for HD”**

(Joe Guiliano, Cure Huntington's Disease Initiative, Director, Clinical Operations)

**“We need a few successes and we will get there. The promise is quite real”**

Dr. Michael Hayden, TEVA, President of Global R&D and Chief Scientific Officer, commenting on the current advances in gene therapy for HD.

### Staying Active and HD



We are always interested to hear how our participants keep active. Because lack of motivation can be a problem in Huntington's, it is important to find an activity that is achievable.

If we were to do a poll in our clinic, the top activity would probably be walking, with some of you walking a few hours every day! Other common forms of exercise are biking, playing lawn bowls, snooker and swimming. The impression that we have is that overall, people who regularly engage in physical activity feel better –but we haven't tried to measure this in our clinic.

Recent results from a randomised controlled trial on exercise and HD in Europe (**EXERT HD trial**, Prof. Monica Busse, Cardiff) showed an increase in fitness and an improvement of motor skills after a 12 weeks structured exercise program (three times per week, 50 minutes of aerobic and strengthening exercises with professional support). Other outcome measures did not show any statistically significant change, and some participants lost some weight –which we need to be vigilant about. This was a small scale study (32 participants) and it is hoped that it will be replicated in a larger group.

On a similar theme, a Norwegian Group (Dr. J Frich) followed a group of ten patients with early to mid-stage of Huntington’s during a two year intensive multidisciplinary program (6 admissions of 3 weeks in a centre where they did daily exercise, social activity and new skills learning). Those patients reported an improved quality of life and better motor skills for some. Again, this was a very small group of participants.

The **ENGAGE HD trial** (Cardiff, Prof. Monica Busse) is currently looking at how much support people with Huntington’s need to stay engaged. The study will look at the benefits of a home based program where participants will be allocated to either a social interaction group or a physical activity group.

A recent publication in a Gerontology journal (Experimental Gerontology, vol 69, 2015) showed that a 6 months aerobic exercise program in older people without Huntington’s changed the expression of 81 genes, which in turn made cells better at growing and healing and learning. This publication got a lot of interest from HD researchers who are keen to explore it further.

If you are struggling to find support and an appropriate activity, consider joining the Green Prescription Program. You will need a referral from either your GP, practice nurse or neurologist. The referral will give you access to personalised physical activity advice and support and will allow you to join the “Have a Go” sessions at a very low cost. Activities are varied, fun, and take place all over Christchurch and Canterbury. Contact 0800 22 84 83 for more information.

**JOIN GREEN  
PRESCRIPTION**

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The article published in the “North and South” magazine edition July 2015 on Auckland researcher Dr Melanie Cheung and her project of cognitive enrichment for Huntington’s patients attracted some interest. Although no proper studies have been done on the benefit of brain learning in people with Huntington’s, it seems that it can’t do any harm. Neuroplasticity is the ability of the brain to create new neural connections in order to adapt. This seems to happen when the brain is challenged by new activities.

Some websites dedicated to “brain training” have designed games that do just that. There is the option of a free trial, with three ten minutes sessions per week. Have a look and see if you like it. We do not encourage you to subscribe to the paying options.

[www.luminosity.com](http://www.luminosity.com)

[www.brainhq.com](http://www.brainhq.com)



#### **Shavanti’s Art Corner.**

Despite some involuntary movements, Shavanti keeps on producing quality paintings that are very realistic. At her Monday night painting class, she has been working on different projects for her family and friends. Here are two lovely examples. She might surprise us with a painting of the HD health team soon, watch this space!

