

(this newsletter was compiled by Laura, research coordinator at the NZBRI)

The National Huntington's Disease Association 2016 Conference was held on 14 – 15/ May/ 2016 at the Waipuna Hotel & Conference Centre in Auckland.

This two days conference shed light on many interesting research projects currently taking place in the country, confirming the position of NZ and the Brain Bank in Auckland as important players in the global effort towards a better understanding and a cure for HD.

More practical issues were also presented, such as Advanced Care Plan, Family planning, Personality Changes and Family updates.

The creation of the HD Youth NZ group as a support group for youth from HD families was celebrated, see below for more information.

Finally, the conference was an excellent socializing opportunity which reached its pinnacle with a very lively samba show at dinner.

One person who attending the conference is sharing her impressions. Please read below.

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My father, who is 92, turning 93 in July, joined me for the HD Conference in Auckland last month.

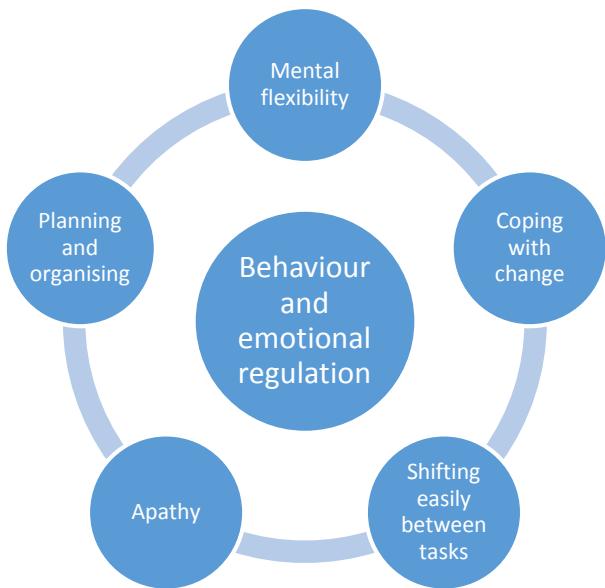
We nursed my mother at home, with lifters, feeding peg and supported by amazing carers. We thought we were all done with the disease, having a break of 10 years. Sadly my sister was tested positive. It was important for us to attend the Conference, to learn and connect.

From the welcome to the closing, there was not one dull moment. The speakers were excellent, interesting, passionate and knowledgeable. We came home with such confidence that everything is being done possible to find a cure for this disease.



Highlighting just one presentation is very difficult. Due to my own mother's awful moods from the time I was about 13 years, I was very interested in how some sufferers are affected more with movements and others with moods.

Associate Professor Lynette Tippett, Clinical Psychologist from the University of Auckland, gave a summary of some of her findings. She talked about the search for cognitive and neural biomarkers in pre-symptomatic HD patients (people who carry the gene but who are not yet showing motor signs). She found that pre-symptomatic people might have thinking problems that may be early signs of HD.



**People are more than this disease; they are the sum of who they are as a person, where and what they have experienced and that gene!**

(Ass.Prof. Lynette Tippett)

Some thinking problems found in pre-symptomatic people

Ass. Prof Tippett combines neuro imaging, clinical assessments and neurocognitive assessments to learn more about the very early stages of HD. We often wonder if we will have the same symptoms that our mother/father? There is a lot of variability within a family.

She concluded that people are more than this disease.

Our artist in residence, Shavanti, continues to delight us with her painting. She recently rose to the challenge of painting the HD combined clinic team. Here is the proof that she managed to capture our imperfections perfectly !



Katie Collins is the contact person for the Christchurch HD Association. She is part of the HD South Island Youth group that aims at supporting young people affected or at risk for HD in the South Island. Katie will organise regular meetings and fun events for this group. You can contact her on 021 025 67505 or at [katie.collins1988@gmail.com](mailto:katie.collins1988@gmail.com).



Christchurch HD association AGM on Sunday 03/07 at 2pm, Hornby Day Care Centre, 93 Carmen Road.  
Enquiry to Enquires to Dianne Collins 960 5913

HD South Island Youth Group meeting on 31/07, support and education day for all our young people.  
Enquiry to Katie Collins 021 025 67505.