

Project update: Genetics of Anorexia Nervosa research – New Zealand

The Anorexia Nervosa Genetics Initiative (ANGI) is an international research study aiming to discover genetic factors contributing to the development of anorexia nervosa. This project has brought together researchers, clinicians and those with a history of anorexia nervosa in the most extensive international initiative conducted so far in the field of anorexia nervosa. The project involved completing an online survey about eating disorder symptoms, providing informed consent and then providing blood samples for genetic analyses.

In 2014, Martin Kennedy was asked by Professor Cynthia Bulik if there would be interest in recruiting New Zealand participants as part of the Australia ANGI site. He recruited Jenny Jordan and we collected a small research team and set up the New Zealand project. Over 2015-16, we had several major publicity events focused around visits to New Zealand by Professor Cynthia Bulik, who heads the international ANGI consortium and these events generated a huge amount of interest. In fact the number of contacts we had within a few days of each publicity event overwhelmed our very small team and because of the complex process of needing to explain the study and obtain informed consent, it took us some months to follow up the initial interest on each occasion. On the plus side, it did mean that we got to meet our participants and engage with this community in a more meaningful way than is often possible in this kind of research.

Outcomes:

People came forward to participate from across New Zealand to participate in this public good research. There were very many steps involved in this project including setting up a system of shipping samples from blood testing laboratory networks across the regions to bring samples back to us in Christchurch. By mid-September 2016, we had sent away samples and de-identified surveys from 555 people with a history of anorexia nervosa to join other samples from around the world. To the best of our knowledge, this has been the biggest study of people with anorexia nervosa in New Zealand. Many hundreds more participated in the online survey. We will be coming back to those participants early next year to ask if they are willing for us to use those data.

In terms of other outcomes, apart from recruitment presentation and publicity, we presented a poster at the 2015 ANZAED conference in the Gold Coast on recruitment. There is a manuscript (currently under review with a peer reviewed journal) reporting on recruitment from the Australian site (which includes New Zealand numbers). The New Zealand project was also presented at the University of Otago, Christchurch public Open Day in September 2016.

We are still finishing behind the scenes work on the project but we hope to make Professor Bulik's 2016 talks available next year online once we get back to checking the editing.

The next stage of the project now occurs overseas as the analyses of samples gets underway. This is another very exciting stage but we will have to wait for the first results until about the end of 2017. We will inform participants and publicise the results as soon as they come available as we know how keen people are to see the results.

Acknowledgements and thanks

The international ANGI project and our local New Zealand research team want to express our grateful thanks to everyone involved in the study so far, either through participating in the study or spreading the word. This research would be impossible without your interest and participation.

A very special vote of thanks goes to EDANZ for the continuing generous support for this project and we would like to thank Nicki Wilson in particular who helped us in so many ways. We owe a great debt of gratitude to those people who came forward to help by providing profiles for the publicity campaign -thanks to Nicki and Emma, Lucy and Fin, Samantha, Claire, Amanda, Hayley and Isabella. We are aware that this was a very big ask of people and we cannot thank you enough- that personal approach touched a chord with the public and generated a tremendous amount of interest. We can tell you that very many people came forward to

participate on the basis of those stories and it is likely that there were positive ongoing impacts for people in the community struggling with eating disorders who read the stories.

Clinicians came forward in support of the study and did profiles for the publicity campaign- thanks to Rachel Lawson, Marion Roberts, and Roger Mysliwiec. Thanks also to the other clinicians; GPs, dieticians, psychologists, other clinicians from eating disorders services or other health settings who were not part of the official research team but who supported the research- as example of someone who was incredibly helpful was Michelle Meiklejohn from REDS. Thanks also to the parents, grandparents and other family members who spread the word after hearing or seeing something about this project.

Most of all, we would like to send a big THANK YOU to all participants in the various stages of the study. We are aware though that it was not all smooth sailing and we have learned a great deal from our first attempt at this kind of research. We realise that the delays and other glitches at times were testing and we greatly appreciate the forbearance that people showed while we were on this steep learning curve. We are also aware that not everyone was able to participate in all stages of the genetics of anorexia nervosa study this time and if you missed out, there will be other opportunities to participate in future studies related to the genetics (or other aspects of) anorexia nervosa or different studies on eating disorders.

If you have any further queries about the genetics of anorexia nervosa study, please feel free to contact me at jenny.jordan@otago.ac.nz

New study:

We have a new study about the costs of eating disorders in New Zealand. EDANZ are co-investigators on the new project which aims to collect information about the range of impacts that eating disorders have on those with the condition and their families. We also wanted to obtain people's views about causes, treatments and recovery, as our sense from our genetics of anorexia nervosa project was that many people wanted to tell us about their experiences to help others. Both consumers and carers can participate in this new project.

To find out more about the new study, go to <http://www.otago.ac.nz/christchurch/cost-of-eating-disorders>

Jenny Jordan

On behalf of the Genetics of Anorexia Nervosa- New Zealand study team