minds for minds
Unlocking Autism Together

the WERRY CENTRE
for infant, child & adolescent mental health

Newsletter November 2022

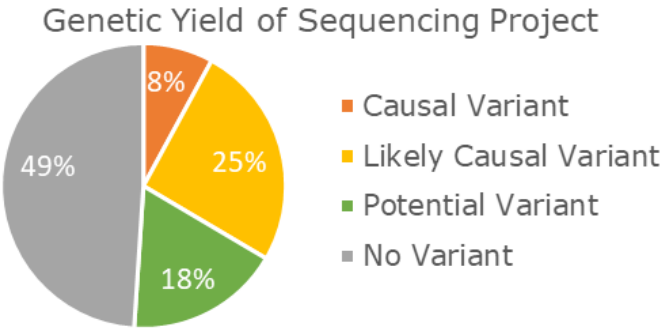
Kia ora from Minds for Minds and the Werry Centre!

Kia ora! As we near the end of the year, Minds for Minds and the Werry Centre would like to wish you and your whānau an enjoyable and relaxing summer break. A special thank you to all the families who have participated in the Minds for Minds genetics project. We are finalising results and hope to contact all remaining families with a summary of research results by early next year. This last newsletter for 2022 provides a summary of local and international research updates from the past 6 months. We look forward to more exciting research advances in 2023!

Update On the New Zealand Genetics Project

Thank you to everyone that has participated in our research. We are coming to the end of our genetic sequencing project funded by Cure Kids and A Better Start National Science Challenge. Participants in this project had their exomes (the protein coding region of the DNA) sequenced and analysed to identify candidate DNA variations.

We are still reviewing a few final variants with our clinical genetics collaborators, but have finished our analysis for most participants. We identified a causative or likely causative genetic variant for 33% of the study group (78 families). We identified many potential genetic variants in families, however, these are in very newly discovered autism-related genes, and therefore they currently don't have enough evidence to be clinically relevant. However, there is still a huge drive internationally to understand the genetic diversity in autism, so many of these genes will become clinically relevant in the near future.



We have also been looking into regions of the DNA that have previously been overlooked (the non-coding regions), as recent research suggests that these regions can affect the way other genes interact and are expressed, and therefore can indirectly contribute to autism. We have successfully been using custom Artificial Intelligence programmes to identify these variants.

For example, we identified a genetic variation that is located near, but not in, the DEPDC5 gene. DEPDC5 encodes a protein that is important for the cell-to-cell communication that regulates cell growth in the brain. This genetic variant is predicted to alter how the gene is expressed. This is important as variants that affect DEPDC5 function are known to cause a hereditary epilepsy syndrome that often features intellectual disability and autism.

A Minds for Minds Family kindly shares their story with the IHC

One family involved in our genetic research shared their story with the IHC - featured in the IHC Strong Voices magazine.

Luke's family was told he had a chromosomal rearrangement when he was born, but doctors didn't know what effect it would have on his health and well-being.

After facing many health challenges in his first few weeks of life, Luke's family found help at Starship Hospital, but the doctors still couldn't say what specific condition Luke had or how it would affect his future.

Luke was recruited into a Minds for Minds study investigating genetic variants that cause rare neurological conditions funded by the IHC foundation. In 2018 researchers discovered that Luke's chromosomal rearrangement affects the DYRK1A gene.

DYRK1A is an important gene involved in the cell cycle and brain development. Changes to this gene have been associated with intellectual disabilities, microcephaly, speech and language impairment, and autism.

This genetic diagnosis has meant a lot to Luke's family, providing certainty about Luke's condition after 21 years. His brother says that "there is a lot of power in knowing something, even if you can't do anything about it."

Read the full story in the Strong Voices Autumn issue here.

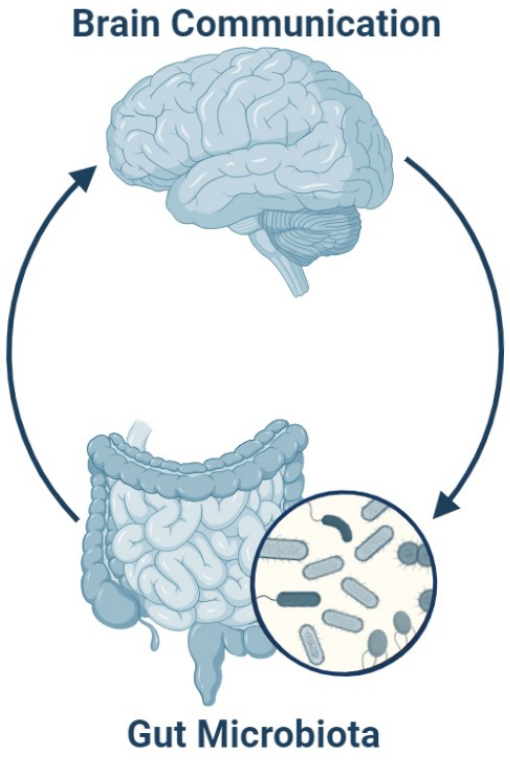
New Textbook Chapter by Minds for Minds Researchers

The Gut-Microbiota-Brain Axis in Autism.

Gastrointestinal disorders, such as severe constipation and diarrhoea, are common among autistic people and have been proposed to result from disruption to microbial communities in the gut. These gastrointestinal microbes, or microbiota, and the brain communicate and influence each other. This communication is referred to as the gut-microbiota-brain axis.

In this chapter, authors Giselle Wong, Johanna Montgomery, and Michael Taylor discuss the role of gut microbiota in autism and how potential therapies, such as probiotics and zinc supplementation, that target the gut microbiota can help alleviate autism-related gastrointestinal challenges.

Read the chapter here.



Minds for Minds Publication Highlight

The use of language in autism research.

Language has power, and how we talk about autism has a lot of far-reaching influences. It can impact how autistics view themselves as well as attitudes in the broader community. In this paper, researchers review the use of language in autism research and make recommendations for what kind of language researchers should use to reflect and incorporate the autistic community's perspectives.

This article advises researchers to move away from medical and deficit-focused language and instead use autistic-preferred terms that are more detailed and specific, and are also empowering.

Importantly, this article discusses how autism research should reflect these shifts in language by focusing on exploring ways to support autistic people and improve their quality of life instead of looking for ways to try to 'normalise' autistic people or 'intervene' in their ways of being.

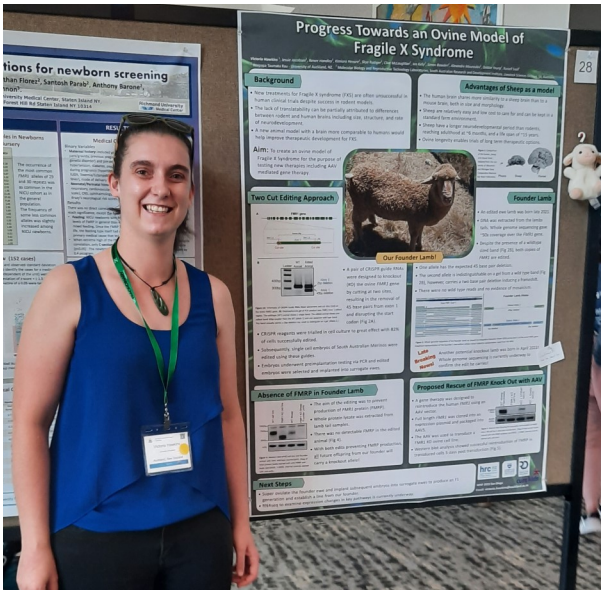
Read the full article here.

Minds for Minds researcher at an international conference

PhD Student Victoria Hawkins recently travelled to San Diego to present the latest progress of the Fragile X Syndrome (FXS) ovine model.

FXS is the most common single-gene cause of autism, accounting for 2-4% of autism. Like many neurological conditions, FXS lacks effective treatment options for those that need or would like them; Victoria's PhD project aims to create a sheep model of FXS to help trial new treatments for FXS.

Victoria travelled to the very warm and sunny San Diego in July to present at the 18th National Fragile X Foundations (NFXF) International Fragile X conference. The NFXF conference is the world's largest dedicated conference for FXS and occurs every two years. The conference is unique as it brings together researchers, clinicians, and families of those with Fragile X.



PhD student Victoria Hawkins presents her research at an international conference.

Victoria presented the latest developments on the project, including the birth of a second founder animal, a male born in April 2022. Victoria described the conference as "a fantastic opportunity to meet other FXS researchers but also to meet the people we are doing this work for, the individuals with FXS and their families". Work on the sheep model continues, including breeding from the new founder, planned for later this year. The founder's offspring will be used to characterise FXS in sheep and, in the long term, be used to trial new treatment options for FXS.

International Autism Research Update

Researchers in Australia and the United States have recently published a new study: Increased rate of listening difficulties in autistic children.

This study summarised the results of a series of clinical tests designed to assess listening/auditory processing skills in a large group of autistic school-aged children with reported auditory concerns.

All the children in this study had normal hearing sensitivity, meaning that their detection of soft sounds across the pitches important for speech and language use was within normal limits.

However, the majority (86%) failed at least one auditory processing test, demonstrating that autistic children commonly experience auditory difficulties, such as processing speech amongst background noise, that cannot be detected by a standard hearing test.

This study highlights the importance of hearing professionals assessing listening skills in autistics, not just hearing acuity, in order to provide appropriate auditory supports.

Article details: James et al. *Increased rate of listening difficulties in autistic children.* Journal of Communication Disorders 99 (2022): 106252.

Read the full article here.

Updates to the District Health Boards System

Te Whatu Ora - Health New Zealand is a new organisation that is merging the roles of the 20 District Health Boards to create a centralised healthcare system.

The government announced in April 2021 that they are abolishing the DHB system to remove bureaucracy and disparities between regions. By centralising New Zealand's public health care system, they hope to address some of the concerns raised by the Health and Disability System Review around the stress the public health system is under and inequalities between regions.

Te Whatu Ora will be taking over the roles of DHBs as well as the operational functions of the Ministry of Health. These roles will include managing hospitals, specialist services, and national contracts. Te Whatu Ora has four new regional divisions that will look after primary healthcare and community-based services. Te Whatu Ora will also work with Te Aka Whai Ora - Māori Health Authority to improve services and outcomes across the health system.

This is a big change which will take time. Therefore, you may not see any changes for a while yet as it is being rolled out slowly. Te Whatu Ora is currently working on an interim Health Plan that will set out the first two years of action for these new organisations.

Read more on their website.

Study opportunities, workshops, and new developments from the wider Minds for Minds team and their community partners

Gut Bugs in Autism

Ever wondered how the tiny microbes that live in your gut affect your health? We are looking for young autistic people aged 16 - 30 years who suffer from gut issues to take part in an important study evaluating a new therapy for gut health in autism.

The gut microbiome refers to the collection of microbes that naturally live within our gastrointestinal tract. These microbes help us to digest food, they produce vitamins, and they can even help regulate our eating behaviours and mood. Recent research has shown that autistic individuals have an unbalanced gut microbiome which may contribute to gut issues. Restoring the microbial balance may help to improve gut function and well being.

The study involves receiving either capsules containing microbes from the gut of healthy donors (the treatment) - or dilute salt water (the placebo). The capsules you receive will be randomly assigned and you will take them over two consecutive days. Follow up appointments will be scheduled 6 weeks, 3 months, and 6 months after taking the capsules.

The study will take place at the Clinical Research Unit within the Liggins Institute, located in Grafton, Auckland. You can contact the Gut Bugs Team by emailing gutbugsautism@auckland.ac.nz.

This study has been approved by the Central Health and Disabilities Ethics Committee (21/CEN/211).

Starship study to improve the hospital experience of autistic children and those with neurodevelopmental conditions

Emily Hamed is a Starship Foundation -funded Paediatric Developmental fellow. Together with Jin Russell and Elizabeth Keeling (Developmental Paediatricians), and Hiran Thabrew (Child Psychiatrist and Paediatrician), she will be conducting a research project to improve the hospital experience for children with neurodevelopmental conditions.

'My Support Plan' was co-designed in 2021 with families, Māori and Pacific Island disability support advocates, and a range of Starship staff. The support plan is designed to be completed by the child's caregiver to improve staff

understanding and awareness of the child's developmental, communication and behavioural needs, to enable staff to meet those needs compassionately and effectively during a hospital admission.

'My Support Plan' will be piloted on inpatient wards at Starship Children's Hospital in 2023. Keep an eye out for invitations to join the study or contact Emily at EmilySmi@adhb.govt.nz to let her know you might be keen to take part.

Enhancing the social communication of autistic children and caregiver wellbeing

The Waiora Tamariki programme at the University of Canterbury is currently recruiting for a study that is investigating the effectiveness of two online support programmes called Play to Learn and ACTion in Caregiving. These programmes were developed for this project by a team of psychologists.

Play to Learn is based on Naturalistic Developmental Behavioural Interventions (NDBIs) and aims to enhance the social communication of young autistic children through play and routine-based learning. Action in Caregiving is based on Acceptance and Commitment Therapy (ACT) and aims to enhance caregiver wellbeing by providing caregivers with tools to effectively respond to challenging thoughts and feelings so they can take action to be the person they want to be. These programmes will be delivered through online modules and group coaching sessions via Zoom.

Children and their caregivers will be eligible for this study if the child is 2-5 years of age and has a diagnosis or features of autism, and the family is living anywhere in Aotearoa New Zealand.

You can find out more information about the programmes in this video youtube.com/watch?v=cXrfw0GHlEI and on their website waioratamariki.org.nz. The study's flyer can be found at the end of the newsletter.

Caregivers can self-refer using the contact form on their website (waioratamariki.org.nz/act/contact/#referral) or by emailing the lead researcher, Associate Professor Laurie McLay (laurie.mclay@canterbury.ac.nz; 03 369 3522). They also welcome referrals from professionals through these avenues as well. Please feel free to contact Laurie or Jenna (jenna.vandeurs@canterbury.ac.nz; 03 369 0754) if you would like any further information.

Waiora Tamariki

Like us on Facebook

www.facebook.com/mindsforminds

Follow us on Twitter

www.twitter.com/mindsforminds

Help us continue our research

www.mindsforminds.org.nz/donate

Enhancing the social communication of autistic children and caregiver wellbeing

A national Aotearoa New Zealand study is looking for participants!

- Our research is investigating the effectiveness of telehealth-delivered supports for the social communication of autistic children and their caregivers' wellbeing
- Telehealth delivery means that assessment and support will be provided through website content, Zoom, telephone, and email
- You may be eligible to participate in this study if you are the caregiver of a child aged between 2-5 years, who is autistic or has features of autism, and is not yet attending primary school
- In this study you will be randomly assigned to receive 13 weeks of support either for your child's social communication, your own wellbeing, or both

If you or someone you know is interested in participating in this study, please contact Associate Professor Laurie McLay for more information:

A/Prof. Laurie McLay
Te Kaupeka Oranga – Faculty of Health
University of Canterbury
Phone: (03) 369 3522
Email: laurie.mclay@canterbury.ac.nz

This study has been approved by the Health and Disability Ethics Committee
(reference: 2022 FULL 12058)