

## Newsletter July 2025

### Welcome from Minds for Minds, Te Ara Hāro and the Autism Research Clinic

It is our pleasure to share with you our first newsletter for 2025, providing exciting national and international research updates from our leading clinical and research collaborators.

### Autism Research Clinic Launched

The Autism Research Clinic launched in November 2024. The aim of the clinic is to provide a world-leading genetic approach to identify the underlying reasons for an individual's autism. This is expanding on our decade-long research to support early and accurate diagnosis for autistic New Zealanders. The first year is being generously supported by the Freemasons Foundation. If you would like more information about the clinic and our launch, please read [here](#) or email [arnnz@auckland.ac.nz](mailto:arnnz@auckland.ac.nz).

For those of you who have been involved in our genetic research titled '[The molecular basis of genetic conditions](#)', we are extending our research for another five years. This has been prompted by the success of our research enabling us to launch the autism research clinic to provide more of the community the opportunity to receive a genetic diagnosis. For those of you who have already consented for our research, we will retain samples and data for this extended research period (at least 5 additional years). If we did not find an obvious genetic answer for your family, we will continue to reanalyse results as part of the research clinic. If you have any questions please do not hesitate to get in touch. You can withdraw from the study at any time.

### Other updates

The CDC has released their latest prevalence data for autism. Autism prevalence is estimated to be 3.2%, or around 1 in 31 children. Autism is still reported as being more common in boys than girls, with three times more boys being autistic. Interesting, when considering children with any developmental condition, approximately 1 in 6 (17%) of children were diagnosed. It is important to note, these overall estimates do not necessarily capture the full picture of variability across our New Zealand communities.

You can find more information [here](#).



### New Zealand Publications

Our genetics team at the Centre for Brain Research have recently published an article about the role of **germline mosaicism** in the development of **TCF20-associated neurodevelopmental disorder**, a condition characterised by developmental delays, intellectual disability and autistic features. Germline mosaicism is when a genetic change occurs in just some, but not all of the sperm or egg cells during development, and is often not present in other cells in the body. This means the variant can be passed on to children to cause a particular condition even if the parents don't have it. This suggests that germline mosaicism may contribute to the development of neurodevelopmental conditions more often than we realise. You can read the full article [here](#).

## New Zealand Publications (continued)

**Paula Araya** and colleagues have published findings from the Growing Up in New Zealand longitudinal cohort study

The study investigated long-term trajectories for gross motor development (GMD), or large muscle movement, in children with Autism. The study found that girls, preterm children and those with European mothers were more likely to experience GMD delays at 24 months, regardless of diagnosis.

Researchers also found that those with autism displayed different gross motor skills than those without autism, with a significantly larger delay in motor development found in those with an Autism diagnosis.

You can read find more information about the Growing up study [here](#) and read the full article [here](#).

## U21 Autism Research Network

Postdoctoral research fellows, **Ruth Monk** and **Joan Leung** are part of the Universitas 21 Autism Research Network. The wider team comprises 20+ universities across 12 countries (Austria, Australia, Belgium, Brazil, Hong Kong, Japan, New Zealand, Norway, Turkey, United Arab Emirates, United Kingdom, and United States), and involves autism researchers from around the world who are dedicated to making research more inclusive and representative of the full diversity of the autism community.

The team has published two notable articles in the last couple of years, one about language preferences of the autistic community, and the other on experiences of acceptance, camouflaging and mental health difficulties in autism.

### Language & Stigma

Autistic people in New Zealand have similar preferences compared to other English-speaking countries regarding the terms used to talk about them and their community. These terms include: 'Autism', 'Autistic person', 'Is autistic', 'Neurological/ Brain Difference', 'Differences', 'Challenges', 'Difficulties', 'Neurotypical people', and 'Neurotypicals'. Autistic people in New Zealand also fare relatively well on measures of external and personal acceptance, camouflaging, depression, and anxiety. However, our autistic community, along with those in Australia, Belgium, and South Africa, report significantly higher levels of stress compared to the US.

Volunteers from New Zealand make up a significant proportion of participants in these cross-country research projects, given our relatively small population.

It is an important contribution and ensures our views are incorporated and acknowledged on the world stage.

You can read Dr. Ruth Monk and Dr. Joan Leung's recent publications [here](#) and [here](#).



## In the news

*Dr. Hiran Thabrew from the team at Te Ara Hāro (Centre for Infant, Child and Adolescent Mental Health) recently published a piece in The Conversation discussing medications commonly prescribed in Autism.*



Autistic individuals often experience co-occurring physical and mental health conditions, leading to the use of various medications to manage them. Use of medication is not aimed at altering autistic traits, but to treat related challenges, including anxiety, depression, ADHD or sleep issues.

Commonly prescribed medications for mental health include SSRIs, low-dose antipsychotics and stimulants, while for physical health painkillers, antibiotics and allergy medicines are commonly prescribed.

Polypharmacy is therefore a growing concern in the healthcare of autistic people.

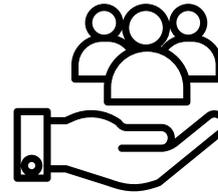
Recommendations include to use the lowest effective dose, regularly review medication use, and provide early, non-medication based support.

You can read the full article [here](#).



## Outreach Activities

The Centre for Brain Research has lots of active outreach activities including the “**Being Brainy**” Programme – a science programme to enable science and technology engagement in primary and intermediate schools. More information can be found [here](#).



---

## New Team Members

Julia Adams will be supporting Dr Jessie Jacobsen with the operations of the Autism Research Clinic.



Julia will be assisting with communications, participant engagement and data coordination. Julia is currently completing her Master’s in Psychology. She brings experience from coordinating Alzheimer’s disease clinical trials at the University of California San Diego and contributing to psychosis research at Orygen in Melbourne.



Up to 80% of autistic children and young people experience sleep difficulties. This can have wide-ranging, negative effects for children and families.

Professor **Laurie McLay** and **Dr Jolene Hunter** (Child and Family Psychologist) are providing private support for families of autistic children and young people experiencing sleep difficulties.

Referrals can be made through their website here:

[Sleep Insight – Specialist sleep support for autistic children & young people.](#)

They offer telehealth-delivered assessment and support, so can accept referrals nationwide and in-person appointments in Christchurch.

## Other Community Resources

**NZ Angelman Network:**

[NZ Angelman Network](#)

Contact Ursula at

[angelmannetwork@gmail.com](mailto:angelmannetwork@gmail.com)

**Autism NZ:**

[Autism NZ](#)

**Pasifika Autism Support Group**

[ASD Pasifika](#)

---

**Like us on Facebook**

[www.facebook.com/mindsforminds](http://www.facebook.com/mindsforminds)

**Follow us on Twitter**

[www.twitter.com/mindsforminds](http://www.twitter.com/mindsforminds)

**Help us continue our research**

[www.mindsforminds.org.nz/donate](http://www.mindsforminds.org.nz/donate)