

Newsletter May 2022



Kia ora from Minds for Minds and the Werry Centre!

We hope you enjoy our latest newsletter – we have some updates from our community partners, and as always, some exciting research developments, both locally and internationally. We acknowledge autism acceptance month was in April, there were some wonderful events sharing autistic voices in a positive and respectful way. Autism NZ also has an excellent education day coming up on May 31st, more details can be found within the newsletter. Registration for this event is full but go to Autism NZ's website for more information about recordings for the event. Noho ora mai!

Update On Student Projects

PhD Student Chris Samson is approaching the end of his doctoral studies looking at rare (and some never seen before) complex DNA changes in children with neurodevelopmental conditions.



During his studies he has provided genetic answers for all families he studied, and has identified a new gene which may be important in neurodevelopment. Chris' research focus is on balanced structural variants, a type of genetic variation where large sections of DNA are rearranged. Using the bioinformatic pipeline he developed, he was able to demonstrate that these structural variants can result in changes of the expression of genes, not due to alterations of the genes themselves, but by affecting how the genome regulates itself.

This work contributed to a big international study led by the Talkowski lab at Harvard Medical School and Massachusetts General Hospital (discussed on page 3) which indicates that long range genomic interactions are an important form of genetic variation for neurodevelopmental conditions, and may be identified in those who have not received a genetic diagnosis from other methods.



Minds for Minds Publication Highlight

Investigating Zinc Supplementation in an Autism Mouse Model

Synapse disruption is when communication between brain cells is changed, and this is thought to contribute to some of the mechanisms underlying different behaviours in autism.

For those behaviours which significantly impact the individual's quality of life, it may be beneficial to restore synapse function. Zinc is one of the most prevalent metal ions in the brain and plays an important role in maintaining brain function, including communication between brain cells.

Our work has shown that supplementing zinc in the diet helped re-establish synapse function and subsequently had beneficial outcomes on social behaviours and specific types of learning in a mouse model of autism.

Although promising, further studies are required to test the efficacy and optimal concentration of zinc, which is what we are currently working on.

<u>Authors:</u> Kevin Lee, Yewon Jung, Yukti Vyas, Imogen Skelton, Wickliffe C. Abraham, Yi-Ping Hsueh & Johanna M. Montgomery

Read the abstract <u>here</u>.



Research Community Editorial

Genomic discrimination in New Zealand health and life insurance. AGenDA: Against Genomic Discrimination in Aotearoa

Genetic testing can be incredibly helpful for all kinds of New Zealanders, from learning about and reducing cancer risk, to aiding with family planning. However, many New Zealanders aren't getting tested for fear that health and life insurance companies will use their results to increase premiums or deny cover.

Right now it is legal for these insurance companies to ask for genetic testing results and use them in making decisions about a person's cover. Keeping genetic results private from insurance companies could lead to the rejection of any claims made.

Clinicians have noticed patients who would benefit from genetic testing are declining after being told that they would have to share the results with their insurance companies. Internationally, researchers are also seeing participants leave genetic studies for the same reasons, with 28% of participants declining involvement in a US-based study for fears of insurance discrimination.

Internationally, countries are introducing legislation to protect people from genetic discrimination in insurance and the workplace, but New Zealand is falling behind. Researchers from AGenDA are calling for laws to protect New Zealanders from genetic discrimination.

Read the full editorial piece here.



International Research Collaboration

Balanced chromosomal rearrangements offer insights into coding and noncoding genomic features associated with developmental conditions

Some of our researchers have been involved in large international research collaboration. This project aimed to investigate how chromosomal rearrangements (changes to the arrangement of large sections of DNA) can contribute to developmental conditions. This study compared the DNA of 406 cases with developmental conditions to 304 controls.

The researchers found that while chromosomal rearrangements in their cases group were much more likely to disrupt genes in neurodevelopment compared to the controls, 80% of cases still couldn't be explained by a direct disruption to one of these genes. They found that chromosomal rearrangements often affected these genes by changing the 3D structure of DNA and influencing which sections of DNA interact with each other. These interactions can have a huge influence on which genes are switched on or off.

This research shows for the first time that chromosomal rearrangements don't just contribute to developmental conditions through the direct disruption of genes, but also by changing how different sections of DNA interact with each other.

One of the primary authors, Chelsea Lowther, has written a summary on <u>twitter</u>. Read the preprint article <u>here</u>.

World leading researcher Peet Dorwick will be missed

It is with sadness that we note the passing of psychologist Peet Dowrick, who was part of the original network of Minds for Minds researchers. He was a world leader in video "self-modelling", a tool that helps all sorts of people, including disabled children, achieve things that seemed beyond their current abilities. The University of Auckland has written a full obituary <u>here</u>.



Researchers Attending an International Conference

The next annual International Society of Autism Research meeting is coming up on May 11th to 14th. This year it is being hosted in Texas, USA. PhD candidate Paula Araya Herrera, who collaborates with Lisa Underwood, Karen Waldie and Katrina Phillips, will be presenting two posters at the conference. Her work explores what kind of gross motor skills Autistic children aged 9 months to 8 years develop compared to their nonautistic peers in New Zealand. She is also investigating how these gross motor skills relate to expressions of distress and expressive language in these children.



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

Autism New Zealand and the Werry Centre are hosting an interactive information morning for Autistic individuals and their support networks, professionals, and researchers on the 31st of May. More details are on the flyers at the end of the newsletter.

We have just learnt that registration for this event has been filled! Please contact Autism NZ about accessing talk recordings or being added to a waiting list.



U21 Autism Research Network

The U21 Autism Research Network was set up with funds from the Universitas 21 Researcher Resilience Fund, bringing together 6 autism research groups from U21 universities. Researchers from the School of Psychology at the University of Auckland are part of this team. The Network aims to make a starting point in addressing challenges to collaboration across borders as well as the lack of diversity and inclusion in autism research. If you would like to sign up to take part in autism research with us, please do email us at u21autismresearchnetwork@contacts.bham.ac.uk.







AUTISM EDUCATION ONLINE EVENT 2022

Tuesday, May 31st 9am - 12pm

Autism NZ is proud to partner with the Werry Centre to host an interactive information morning for Autistic individuals and their support networks, professionals, and researchers.

The programme will include:

An opening talk from Reframing Autism:

• Working to a Common Goal: Building bridges to foster Autistic wellbeing

Breakout rooms for targeted discussion about:



- Learnings from Covid
- Employment for Autistic individuals
- Inclusive education
- Support for the Autistic and autism community

Research updates from across Aotearoa New Zealand

You can find the full Education Day programme here.

This free online event via Zoom meetings is limited to 100 participants, so please register without delay.

If you would like to make a donation to Autism NZ to support this event please click <u>here</u>.

For more information contact: <u>communications@autismnz.org.nz</u>





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Full Programme:

Part 1: Opening address (9am-9.45am)

- Welcome and opening
- Working to a Common Goal: Building bridges to foster Autistic wellbeing
 -Melanie Heyworth from Reframing Autism

Part 2: Concurrent breakout sessions and discussion (9.45am - 10.30am)

Each breakout session will be led by a panel of speakers who will give updates on work they are doing in the area and facilitate Q&A and discussion. Breakout sessions will run concurrently so attendees can select which session they would like to attend.

- Learnings from Covid
 - -Includes Autism NZ vaccination clinics and Explore experiences and learnings associated with working remotely
- Employment for Autistic individuals
 - -Includes Autism NZ employment support and Robert Walters work to support Autistic individuals in the workplace
- Inclusive education

-Includes Autism NZ Tilting the Seesaw for Teams contracts for educators and perspectives on inclusive education policies

- Support for the Autistic and autism community
 - -Includes Autism NZ Autism Connect app, updates from support groups, and Q&A with an Autistic adult

Part 3: Research Updates from across Aotearoa New Zealand and closing (10.30am-12pm).

- Autistic co-led research priorities for Aotearoa New Zealand: A partnership with Autistic people, families and whānau, service and support providers and researchers
 Isa Emerson, Buth Monk, Laurie McLay and Larah yan der Meer
 - -Lisa Emerson, Ruth Monk, Laurie McLay and Larah van der Meer
- Autistic adult, parent, and professional perceptions of early learning goals for preschool aged children on the autism spectrum
 Hannah Waddington, Lee Patrick and Hannah Minnell
- Improving the paediatric inpatient care of children with neurodevelopmental conditions -Hiran Thabrew and Elizabeth Keeling
- Improving our understanding of autism using the IDI -Nick Bowden
- Raising Autistic children: Parental stress and wellbeing -Jake Meads
- Understanding the genetic landscape underlying autism and related developmental conditions latest research
 Jessie Jacobsen
- Tertiary supports
 Altogether Autism

<u>Closing</u>

This free online event via Zoom meetings is limited to 100 participants, so please <u>register</u> without delay If you would like to make a donation to Autism NZ to support this event click <u>here</u> For more information contact: <u>communications@autismnz.org.nz</u>