

Newsletter Issue #6



minds for minds
Unlocking Autism Together

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Contact Us

www.mindsforminds.org.nz

Research inquiries: inquiries@ARNNZ.org

Charitable Trust inquiries: info@mindsforminds.org.nz

Also find us on [Facebook](#) and [twitter](#) (@mindsforminds)

Updates from our Minds for Minds Researchers

Registrations for participation in the genetics and microbiome project now exceed 1,700 individuals and family members. The majority of registered individuals are registered together with affected or unaffected family members, which helps greatly in the search for the genetic variations and mutations causing or contributing to their condition. We have enlisted assistance to keep up with consenting and follow-up to increase the rate of sequencing, and preparation of DNA from 33 additional families has kept us busy throughout winter and spring. Their samples were sent away for genome and exome sequencing. The majority of data has arrived over the last fortnight, and we expect to receive the final sequences just before Christmas. This means a total of 5 terabytes of genetic information! We are very excited to unleash the full power of our combined whole-genome-plus-exome analysis tools. This is a major improvement as it will allow us to not only analyse the entire genome of each individual, but also discover all types of genetic mutations contributing to the neurodevelopmental conditions – including the large and small variants that copy, delete, or re-locate entire segments of chromosomes. We expect that this in-depth approach will allow us to return more genetic diagnoses to the families throughout 2017.

Since our last update, we have found promising candidate mutations for 6 families from the previous sequencing rounds. These are at various stages of experimental and clinical confirmation, and we're well underway with the scientific publications. Of course we will keep you informed about these discoveries once they have been fully reviewed by independent researchers.

We are extremely grateful to all the families that are contributing to our research. With this partnership we will make a major contribution to the understanding of the genetic and microbial causes of ASD. If you would like to participate in this research, please register your interest at www.mindsforminds.org.nz

Research Participation Opportunities

Vidoma study investigating nutrition supplementation

Massey University are currently enrolling families with children aged between 2.5 and less than 8 years old to take part in a nutrition intervention aimed at reducing the symptoms of ASD. They offer a free psychological assessment report worth \$400. To find more information visit www.massey.ac.nz/vidoma or call Owen on 09 213 6650. You can also "Like" their Facebook page - <https://www.facebook.com/groups/vidoma>

News from our Charitable Trust

It has been a busy and successful year for the Minds for Minds Trust. We have been developing our submission template for applications for grants and now have this completed so going into the New Year we hope to be able to use this to secure funds from grants and other sponsorship.

The scientists have been busy working with families and children who have been diagnosed on the spectrum and helping them gain a better understanding of their child's needs and ways in which they can be supported in the community.

This year members of the trust have worked with the scientists to present to our politicians. Professor Snell and Josephine Wallis (a trust board member) presented to Minister Steven Joyce about the pioneering work the scientists were performing and the work of the trust which resulted in us gaining a meeting with Professor Gluckman at the University of Auckland. Work continues in trying to attract funding from government research funds such as these and we remain hopeful that we will be able to secure some funds next year.

Last month the Fundraising Committee organized an incredibly successful cocktail party in Ponsonby. Friends of Minds for Minds attended and heard about the work done by the science team this year. The trust also launched the Celosia Plant which had been specially grown for the Minds for Minds Trust. The plant has been grown to resemble a brain and it has currently sold out!! The trust are in negotiations with a large chain of stores who will potentially sell the plant on behalf of the Trust and some of the margin will go to the trust.

2017 is set to be a fruitful year for Minds for Minds with submissions for grants, the sale of our Celosia plant and other exciting initiatives.

Josephine Wallis
Acting Chairperson

A Flowering Affair!

On Tuesday evening 22 November, researchers, supporters and those with an interest in autism came together at Ponsonby Central for the launch of a new fundraising initiative for Minds for Minds research.

The partnership between the Trust and Zealandia Horticulture, saw the launch of the first blooms of a crested Celosia specially grown for the occasion. The limited edition plants sold out on the night and the next round will be ready for sale in March next year.

The flower seeds, imported from the United States earlier this year, grow extremely well in the New Zealand climate and come in a range of bold colours from orange to red to yellow.

Plants will be available in large numbers from March next year through retail outlets. When purchased, a percentage of the sale price will be donated to autism research. In the meantime orders will be able to be made via the Minds for Minds website shortly,

www.mindsforminds.org.nz



Left: The flower, Right: Graham Windrows Zealandia Director & Russell Snell at Zealandia Nurseries, Clevedon

New Website!

We recently launched our new website. We think the new site will allow users to navigate through the different parts of the website more easily, thus being able to access the information they want much faster. The new format also allows us to communicate the latest news and events for Minds for Minds to our community.

This new website is accompanied by an increased focus on social media, including highlighting interesting news and research in the field of ASD.

Check out the new site at www.mindsforminds.org.nz and follow us on Facebook at www.facebook.com/mindsforminds and twitter at www.twitter.com/mindsforminds

International genetics + microbiology research news

Launch of MSSNG – a 5,000 strong database of genome sequences

A collaboration between Autism Speaks and Toronto's Hospital for Sick Children, with partnership from Google, saw the release of MSSNG in April. MSSNG currently hosts 5,211 genomes, with the goal of 10,000 genomes to complete their database. They wish to provide resources to investigate autism and identify subtypes of autism. This is a move contrary to the trend seen in the Diagnostic and Statistics Manual, where recent revisions have included a decrease from multiple categories encompassing what now is classified under a single umbrella of ASD. However, this partitioning will be performed using a genetic basis rather than clinical presentation. They claim this may lead to better diagnostics, as well as personalized and more accurate treatments.

There was a platform presentation on some of the initial findings from this collaboration at the American Society of Human Genetics meeting 2016 (see page 7 for our summary of the meeting).

MSSNG maintains a philosophy to promote and enable 'open science' research, allowing researchers to apply to access the data through an online portal. For more information about the database and project, including applying for access visit www.mss.ng

A new microbial link in autism

Increasing evidence suggests that the 100 trillion (100,000,000,000,000) bacterial cells in our guts have a profound influence on human health. These microorganisms, known collectively as our gut microbiome, are associated with conditions as diverse as obesity, diabetes, cancers and various neurological disorders (including autism spectrum disorder, ASD). The wording of the previous sentence was chosen carefully, in that "associated with" rather than "causes" is a more accurate description of our current understanding of microbiome-human health interactions. In most cases, it has proven extremely difficult to definitively say whether a given condition is "caused" by the microbiome; at best, we can often correlate microbiome changes with the development of a condition or disorder, but it is a chicken-or-egg situation in that we can't prove whether microbiome changes are a cause or merely a consequence of a human health condition.

Animal models of ASD, usually involving mice, are providing insights into the role of the microbiome that would be difficult or impossible to obtain from studies of humans. One recent study (Buffington et al. 2016) linked the development of ASD-like symptoms to maternal obesity during pregnancy. The offspring of the obese mice – which were fed a high-fat diet – exhibited social deficits as well as an imbalance, or dysbiosis, of their gut microbiome. They also had measurable deficiencies in certain brain characteristics compared with mice born to a mother on a regular diet. Among the most notable of these deficiencies was a reduced ability

to produce oxytocin, an important hormone. Remarkably, adding a single bacterial member of the gut microbiome was sufficient to reverse many of these deficits, including restoration of oxytocin levels and some of the social issues.

So, how did the researchers know which bug to add? Using sophisticated DNA sequencing approaches, which not only identify which bacteria are present but also what they might be doing, they compared the gut microbiomes of mice whose mother was on a high-fat diet with those mice whose mother was on a regular diet. They identified a number of bacterial types that were depleted in the ASD-like (maternal high-fat) offspring mice, most notably the bacterial species *Lactobacillus reuteri*. When they re-added *L. reuteri* (which is also a common human probiotic) to the mice with ASD symptoms, many of the normal behaviours and neurological characteristics were returned back to where they should be. These results echoed those from a 2013 mouse study in which addition of another bacterium, *Bacteroides fragilis*, led to dramatic reversal of autism-like behaviours plus restoration of the dysbiotic gut microbiome. Whether any of these findings from mouse studies can be translated to humans with ASD remains to be seen, but they provide exciting evidence for a role of the gut microbiome in ASD and point the way to potential new therapies for those who may desire or require it.

Reference: Buffington et al. (2016) Microbial reconstitution reverses maternal diet-induced social and synaptic deficits in offspring. *Cell* 165: 1762-1775.

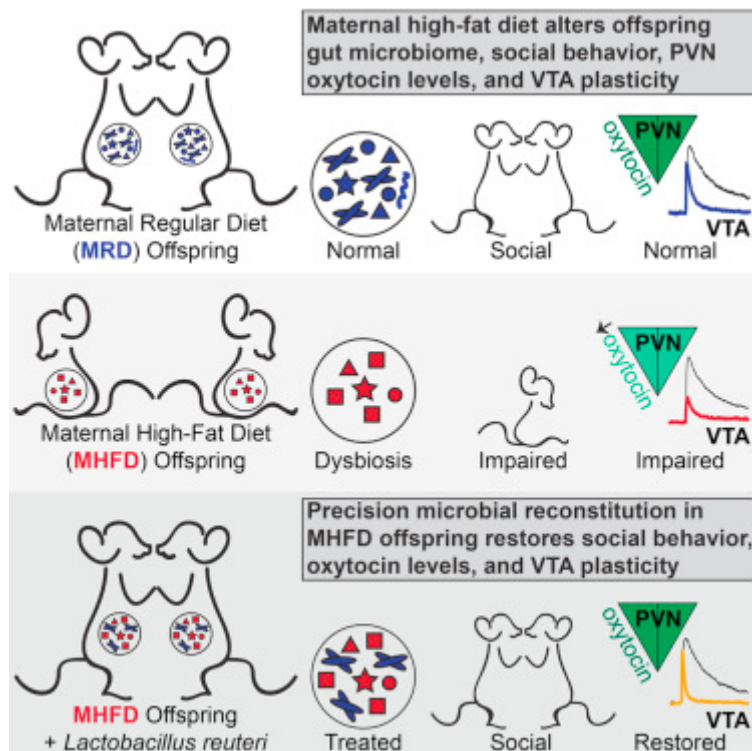


Image taken from [http://www.cell.com/fulltext/S0092-8674\(16\)30730-9](http://www.cell.com/fulltext/S0092-8674(16)30730-9)

Updates from conferences and meetings

Autism New Zealand Conference 19-20 August 2016

The Autism New Zealand 2016 Conference provided a unique opportunity for networking within the New Zealand autism community, along with experts and international speakers. The conference theme was 'Empowering People Living with Autism', embodying the work those in the field do every day in our communities. The programme encouraged current and emerging research, clinical and educational practice and the everyday life experiences and achievements of people on the autism spectrum, families/whanau and others in the autism community.

Professor Russell Snell offers some highlights of his experience:

"The major highlight for me is meeting families and hearing about living with autism. This reinforces the importance of research into autism and reinvigorates us to ramp up our efforts. The feedback we get is a wonderful affirmation of what we are doing and appreciation for the efforts of our Minds for Minds collective program.

Jessie and I were constantly approached between the formal sessions to discuss our results, answer questions or whether individuals or families would fit our ongoing genetics study. We came away a bit humbled by the enthusiasm and optimism expressed by families living with autism and the wider autism care community."



” Applied Behavioural Analysis Week 10-12 October 2016

This year, the Applied Behavioural Analysis (ABA) Programme hosted the inaugural ABA week. The week included a series of workshops and lectures, including a public lecture by Dr Gregory P Hanley, Professor of Psychology and Director of the Behavior Analysis doctoral programme at Western New England University.

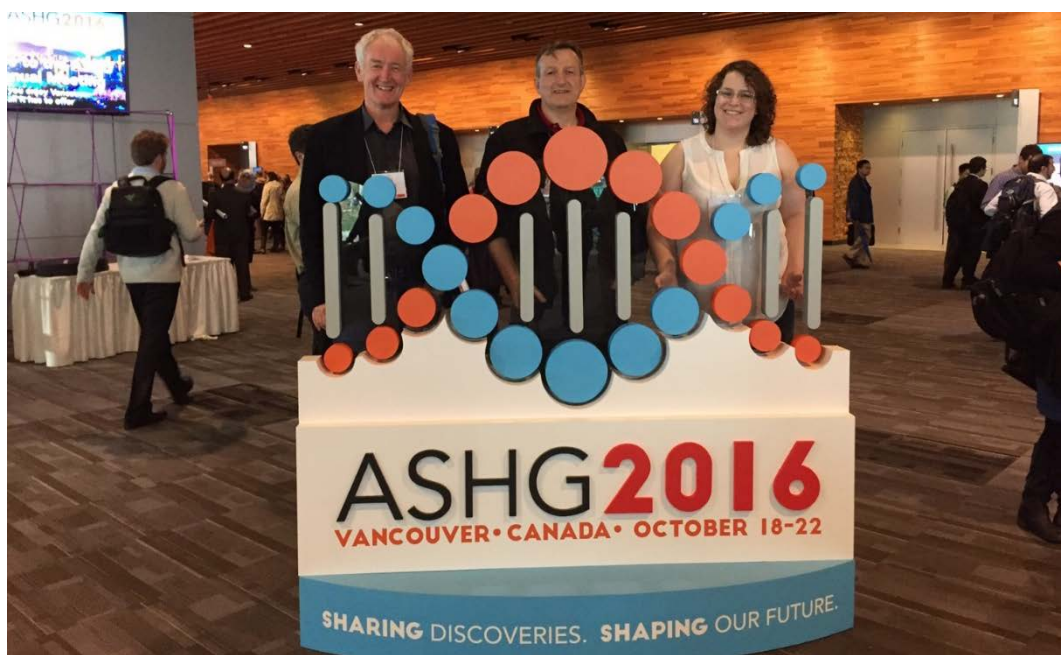
The events that comprised the awareness week were attended by over 800 people. The awareness week got national media attention from the NZ Herald. Other practical outcomes include Dr Hanley becoming an active participant in two of our PhD thesis projects. Events received direct support from Autism NZ, ABA Spain, NZ Society of Diversional Therapists, Minds for Minds, and NZABA.

American Society of Human Genetics Meeting 2016

The American Society of Human Genetics (ASHG) held their annual meeting 18-25 November 2016 in Vancouver. This is one of the leading human genetics meetings in the world and was attended by over 6,000 researchers and clinicians. This included our researchers Professor Russell Snell, Associate Professor Klaus Lehnert, and PhD Student Whitney Whitford.

The meeting provides an opportunity to network with our international collaborators along with others in the human genetics field, as well as learning the newest techniques, technologies and applications for genetics from around the globe. There was an entire session titled ‘Advances in Characterizing the Genetic Basis of Autism’ which was extremely interesting and enlightening, seeing how other research groups are investigating this complex realm of genetics with their different datasets.

We all gathered different perspectives from the meeting and will continue to implement the new thoughts and ideas we had whilst in Vancouver.



Focus On: Rosamund Hill



Doctor Hill is a Clinical Neurologist with Auckland Hospital, along with private neurology consulting with Auckland Medical Specialists. She started her academic career at the University of Auckland with a Bachelor of Human Biology, followed by a Bachelor of Medicine and Bachelor of Surgery. Rosamund spent the first part of her practicing career as a resident for Auckland District Health Board, before relocating to Boston, USA to work as a Clinical and Research Fellow in the Department of Neurology, Massachusetts General Hospital. She then repatriated to New Zealand as a Wellcome Epilepsy Fellow, Department of Neurology, Auckland City Hospital, followed by completion of a Doctor of Medicine (MD), focussing on Epilepsy with The University of Auckland.

Within neurology Rosamund is a specialist in Traumatic Brain Injury and Epilepsy. As part of her research work she has investigated the treatment and structural/electrical changes associated with Epilepsy. This is a condition which co-occurs in up to 30% of individuals with Autism Spectrum Disorder (ASD), thus linking her two research interests. Rosamund's interest in ASD, however, is not purely academic. She has a son, Claude, with Autism which inspires her to work towards a greater understanding of ASD.

The Minds for Minds research network was established in 2013 by Dr Hill, along with Dr Jessie Jacobsen and Professor Russell Snell. This collection of researchers and clinicians has grown from humble beginnings to over 50 talented individuals.

The Attitude Live video with Rosamund about life with Claude and Minds for Minds, along with another family, can be viewed here:

<http://attitudelive.com/watch/unlocking-autism>

News from some of our Community Groups

Autism New Zealand (www.autismnz.org.nz)

Autism New Zealand celebrates people with autism, and the unique and special things they bring to New Zealand society. Autism New Zealand focuses on creating supportive environments and paving ways forward for people affected by autism.

Children's Autism Foundation (www.autism.org.nz)

The Children's Autism Foundation provide direct support to families of children affected by autism. Our programmes are best practice, multi-cultural and evidence based.

Free community day workshops for families and caregivers

The Children's Autism Foundation has received funding to provide free community day workshops for families and caregivers. This is an amazing opportunity for families and those who work with them and is valued at \$140/person. For more information about this **FREE** workshop, see the following flyer.

Altogether Autism (www.altogetherautism.org.nz)

Altogether Autism is an information, advisory and support service for people with ASD, their families, professionals and service providers. A team of trained information officers put together credible evidence based information tailored to specific needs. They also have access to a consultant clinical psychologist and a team of professionals with experience and expertise in ASD.

Tuberous Sclerosis Complex New Zealand (www.tsc.org.nz)

Tuberous Sclerosis Complex (TSC or TS) is a genetic disorder that affects people in many different ways and is associated with a range of behavioural, cognitive and physical difficulties including autism spectrum disorder, intellectual disability and epilepsy. TSCNZ is a registered charity and the only organization dedicated to TSC in New Zealand.



'HANDS ON AUTISM' WORKSHOP



For Practical 'Hands On' Strategies

Are you living or working with a child with autism?

Our goal is for you to leave at the end of the day with tools & strategies that you can easily implement in the home, at school and community

Topics include:

Guide to Autism & Strategies for behaviour

Dealing with Anxiety & Sensory Issues

Where and When:

Saturday 11 February, 2017, 9am-4pm, Hub West, 27 Corban Ave, Henderson

Saturday 25 March, 2017, New Life Church, Manurewa

Speakers & Facilitators:

Arletta van den Bosch, (Family & Child Counselling)

Elisa Slaat (CAF Services Manager & Behaviour Therapist)

Christine Farquharson (Occupational Therapist)

Lisa Martin (Disability Connect)

Cost (including lunch)

Sponsored for family and caregivers who register
or \$140 for professionals /organisations

**disability
connect.**

REGISTER AT WWW.AUTISM.ORG.NZ
ENQUIRY@[AUTISM.ORG.NZ](mailto:ENQUIRY@AUTISM.ORG.NZ)

Te Pou
o Te Whakaaro Nui