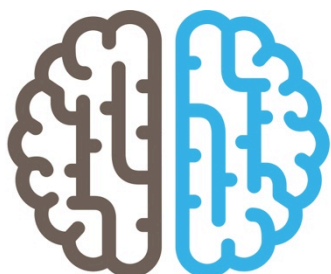


# MINDS FOR MINDS



**minds for minds**

Unlocking Autism Together

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

## Issue #2, August 2014

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Contact us: [inquiries@arnnz.org](mailto:inquiries@arnnz.org)

## Meet our charitable trust!

We have been incredibly fortunate to have a group of volunteers from the community who have offered their time to help advance our research. This group have formed the Minds for Minds Charitable Trust to help raise awareness of the research being done within the network, and to help raise funds to support further research into ASD. The group is currently made up of 9 dedicated individuals, including three mums with children on the spectrum.

The mission of the trust is to raise funds and awareness for research. They have been working incredibly hard and have secured pro bono work from one of New Zealand's top advertising agencies, Whybin/TBWA, to support the network. The company has put together an advertising campaign for Minds for Minds (in close consultation with the charitable trust), which has picked up several awards, including being shortlisted for the internationally acclaimed Cannes 2014 awards in the press category. You can see one of their award-winning advertisements on the last page of this newsletter.

If you would like to assist on the fundraising committee based in Auckland, or begin a group in your area, please let Liz Kirschberg or Ann Hill know. They are also looking for an Auckland-based person with some spare time who might be able to head/lead this committee of 9.

One of their first fundraising events is just around the corner – a fun fundraising cocktail party. You will find more details on page 6 of this newsletter. Please contact Liz if you are interested in joining us for what we're sure will be a very enjoyable evening.

Liz Kirschberg: [vinorosso@slingshot.co.nz](mailto:vinorosso@slingshot.co.nz)

Ann Hill: [emerge1@vodafone.co.nz](mailto:emerge1@vodafone.co.nz)



Jo Wallis, Rosie Lang, Rosamund Hill, Karin Cammolet-Allan, Deborah Hill Cone, Georgia Kirschberg, Ann Hill, Liz Kirschberg, Angela Griffen

## Introducing some of our researchers

Our current group of researchers at The University of Auckland is rapidly growing. We hope this will expand to include many more researchers from other universities and institutions, but in the meantime we would like to introduce you to some of our scientific team.

### Genetics

#### **Professor Russell Snell**

Russell was involved in isolating the genes behind Huntington's disease & other gene blockbusters such as Myotonic Dystrophy and Tuberous Sclerosis. He has a long-term interest in finding human disease genes and variations, with particular focus on neurodegenerative diseases like Parkinson's, Huntington's & Alzheimers.

#### **Dr Jessie Jacobsen**

Jessie is a Rutherford Discovery Fellow with an interest in the genetics underlying human conditions and their biological interpretation. She has been repatriated from the Centre for Human Genetic Research at Massachusetts General Hospital & Harvard Medical School in the USA to help establish a genetic research programme for autism spectrum disorder (ASD) in New Zealand.

#### **Associate Professor Klaus Lehnert**

A functional biologist with an interest in understanding the molecular mechanisms through which genetic variations cause disease. He is applying the computational analysis of large and complex data to identify candidate genetic variations. His ultimate aim is to unravel the pathological processes leading to autism spectrum disorder at molecular level and to identify therapeutics that can modulate these processes.

#### **Dr Rosamund Hill**

A consultant clinical neurologist working at Auckland City Hospital and in private practice with a passion for understanding the ASD condition. She has a son with severe autism. She has previously completed a research degree (M.D.) at the University of Auckland Medical School.

Genetics PhD student: Brendan Swan



Russell, Jessie, Klaus, Rosamund, Brendan

## Microbiology

### Dr Mike Taylor

A microbiologist interested in the ecology of complex microbial communities. Having worked in the past on microbes associated with various marine and terrestrial animals, he is now applying the same techniques to study the microbial communities within humans. Bacteria and other microorganisms in the human gut have a profound impact on health and there is evidence for a link between gut bacteria and the occurrence of autism.

Microbiology PhD student: Corinne Sellers; Masters students: Elahe Kia and Brett Wagner

## Psychology

### Professor Ian Kirk

A cognitive neuroscientist in the School of Psychology, he is also an Associate Director of the Centre for Brain Research at the University of Auckland. His interest is in the connectivity and plasticity in the human brain and in how these support cognitive processes. He is also interested in differences in cognitive processes in people with ASD.

### Associate Professor Karen Waldie

A developmental neuropsychologist in the School of Psychology at the University of Auckland. Her autism research focuses on the neural bases and long-term outcomes of neurodevelopmental disorders like ASD. Her experimental work combines techniques from cognitive neuroscience (fMRI and EEG) and clinical neuropsychology. She is also involved with 3 national longitudinal studies: Dunedin Multidisciplinary Health and Development Study (DMHDS); Growing Up in NZ; and Auckland Birthweight Collaborative (ABC) Study.

### Dr Angela Arnold-Saritepe

Angela is a Board Certified Behaviour Analyst and Psychologist in the Applied Behaviour Analysis Programme, School of Psychology at the University of Auckland. Her research and interests lie in the development of evidence based, socially valid interventions that improve quality of life of people with autism. Angela is particularly interested in managing challenging behaviour.

Psychology PhD student: Ashleigh Saunders



Mike, Corinne, Ian, Karen, Ashleigh, Angela

### Attitude Pictures episode features Minds for Minds

For neurologist, Dr Rosamund Hill, it is more than a field of research - her own son, Claude, is profoundly autistic. Rosamund invites us into Claude's world as she explains the motivation behind Minds for Minds.

You can watch the episode here: <http://attitudelive.com/blog/robbie-francis/full-episode-unlocking-autism>

## Speech Science

### Professor Suzanne Purdy

Suzanne Purdy is Professor and Head of Speech Science in the School of Psychology at the University of Auckland. Her academic background is in psychology, speech science and audiology. She has worked clinically as an audiologist and is an academic and researcher with broad-ranging research interests. Suzanne is particularly interested in communication disorders and auditory and speech processing in children, including perception and production of affective (emotional) prosody in autism.

Speech Science PhD student: Joan Leung

## Physiology

### Associate Professor Johanna Montgomery

Johanna Montgomery is the Principal Investigator of the Synaptic Function Research Group at the Centre for Brain Research. Her research focuses on understanding how synapses in the brain function and how alterations in synapse function manifest into neuronal disorders. She collaborates closely with Stanford neuroscientists and together they have undertaken ground-breaking research examining how synapse dysfunction relates to autism.

Physiology Postdoctoral fellow: Dr Chantelle Fourie, PhD student: Kevin Lee, Masters student: Yukti Vyas

## Pharmacology

### Associate Professor Debbie Young

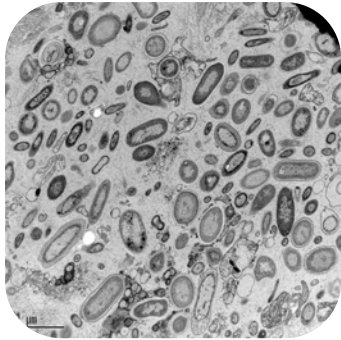
Debbie Young is an Associate Professor in Pharmacology & Clinical Pharmacology at the University of Auckland where she heads the Molecular Neurotherapeutics group in the Centre for Brain Research. Her research interests are in the development of gene therapy and antibody-based strategies for neurological diseases. She has developed an antibody that enhances learning and memory function in rodents and is interested in determining whether this treatment could have therapeutic potential in ASD. She is also interested in determining whether autoantibodies to brain proteins found in some humans with ASD could contribute to specific behavioural phenotypes.

Pharmacology PhD student: Angela Wu



Suzanne, Johanna, Kevin, Yukti, Debbie

## Minds for Minds researcher Dr Mike Taylor



*The human gut contains high numbers of bacterial cells, such as those seen in this close-up (electron microscopy) image*

The precise cause(s) of autism remain unknown, so there are busy times ahead for the Minds for Minds researchers and their colleagues around the world. Recent evidence suggests that, in addition to genetic predisposition, autism is influenced by environmental factors such as the composition of bacteria in the gut during early life. This may seem unusual to many people, but there are now firm links established between gut bacteria and neurological function. The 1-2 kg of bacterial cells in our guts have a massive impact on human health, affecting everything from digestion and resistance to disease through to immune function and even the way we behave!

Understanding the potential role of bacteria in autism is a major research focus for Mike Taylor, a Senior Lecturer in Microbiology at the University of Auckland. Mike's team investigates the ecology of microorganisms associated with various "hosts", ranging over the years from marine sponges, to scale insects and weta, to kakapo and, most recently, the bacteria living within humans. Determining which bacteria are associated with which hosts – and why – is central to this research. A number of studies have indicated that differences exist between bacteria in the guts of children with and without autism, and a high rate of gastrointestinal disturbances (ranging from severe constipation to severe diarrhea) among those with autism does tend to suggest an imbalance within their "community" of gut bacteria.

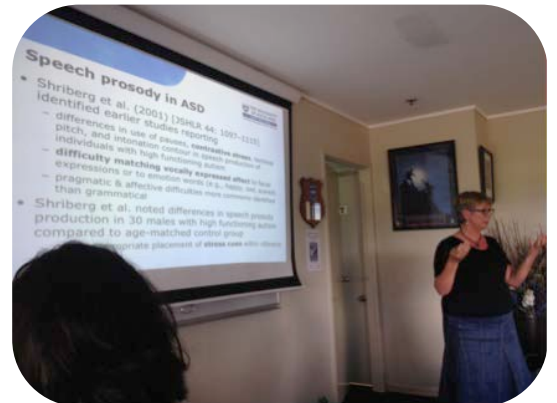
International research using mouse models of autism also supports the case for bacterial involvement in this enigmatic disorder, though overall a clear picture is yet to emerge of the relationship between autism and bacteria. Mike's research group is contributing to the international research effort by starting to apply modern molecular biology techniques to investigate the role of gut bacteria in causing autism. While the overall goal of this research is to develop a microbial therapy for autism, the initial aims are to determine: (1) whether bacterial community composition varies between people with/without autism; (2) whether the function of the bacteria is different.

The majority of bacterial species have so far resisted cultivation under artificial growth conditions in the laboratory. Fortunately, we can apply cutting-edge DNA sequencing techniques to learn about the identities and function of these bacteria, largely removing the need to cultivate them. DNA can be extracted from stool samples collected from those on and off the autism spectrum, as allowed by our existing ethics approvals, then high-throughput sequencing tools can be used to describe the nature of the respective bacterial communities. There are several pathways by which gut bacteria could influence the brain in autism and other neurological disorders, including direct interactions of bacteria with the enteric nervous system surrounding the gut, stimulation of the immune system leading to harmful inflammation, or passage of toxic bacterial products through a "leaky" gut lining and into the bloodstream. Our research should provide new insights into which of these pathways may be more important. Most significantly, it could help us to develop novel microbial therapies for autism (e.g. by providing an appropriate probiotic to amend problems in the gut lining) or tools for early diagnosis (e.g. if an autism microbial "signature" can be identified).

*Current group members on this project: Elahe Kia, Corinne Sellers, Brett Wagner*

# Inaugural Minds for Minds Scientific Research Day

The first Minds for Minds scientific research day was held at the Sir Peter Blake Marine Education and Recreation Centre at Long Bay, Auckland, on December 16<sup>th</sup> 2013. The day, organised by Jessie Jacobsen and Mike Taylor, was a huge success with 30 attendees in total. These included staff and students from across the University of Auckland (including School of Biological Sciences, Centre for Brain Research, School of Psychology), as well as clinicians from the Auckland and Waitemata District Health Boards. There were 15 seminars during the day, on diverse topics ranging from genetics, microbiology and immunology through to psychology, neurophysiology and speech science. There was also ample time for networking, against the stunning backdrop of Long Bay. Importantly, this day represented the first real opportunity for autism researchers from different disciplines at The University of Auckland to find out what others were working on, with presentations kept jargon-free and accessible to those from other fields. As expected, numerous opportunities for collaboration were identified and exciting times lie ahead. In the future, we hope to have a day of research presentations which will be open to other researchers from around New Zealand and also to all of our Minds for Minds supporters, as it's very important to us to keep you all in the loop about what is happening with our many research projects.



*Professor Suzanne Purdy presenting her research*



*Forming new collaborations*

New Date



**minds for minds**  
Unlocking Autism Together

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IT IS WITH PLEASURE  
THE MINDS FOR MINDS TRUST INVITES  
YOU AND GUESTS TO A FUN AND  
FUNDRAISING COCKTAIL PARTY

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SAPPHIRE ROOM PONSONBY CENTRAL  
6 - 8.30pm Wednesday 27 August

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RSVP Mon July 28. [vinorosso@slingshot.co.nz](mailto:vinorosso@slingshot.co.nz)  
Mobile 021836568

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The Minds for Minds Trust is fundraising to allow leading New Zealand scientists to sequence the genome in Autism Spectrum disorder.  
[www.mindsforminds.org.nz](http://www.mindsforminds.org.nz)

Fundraising committee: Karin Allan, Jo Wallis, Ros Hill, Deborah Hill Cone, Liz Kirschberg, Angela Griffen, Rosie Lang, Ann Hill.

Tickets \$75 all inclusive.  
Bank acct no: 12-3198-00068345-00



supporting projects in



CENTRE FOR  
BRAIN RESEARCH  
THE UNIVERSITY OF AUCKLAND

With thanks to



*Even though the RSVP date has passed we would still love for you to join us at the charitable trust's cocktail function. Please RSVP to Liz (details above).*

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## News from some of our community groups

### Autism NZ

[Russell Snell](#), [Mike Taylor](#) & [Chantelle Fourie](#) from the Minds for Minds team will be presenting a keynote speech at the Autism New Zealand 2014 conference in Nelson, 22/23 August. [Looking to the Future](#) is a research and technology focused conference and features other keynotes [Dr Catherine Lord](#), Director of the Center for Autism and the Developing Brain; [Craig Smith](#), Educational Outreach consultant for Autism Spectrum Australia (Aspect), and [Neil Stuart](#), Autism New Zealand Training and Education Director. Autism New Zealand would be delighted to see you there. For more information see the [conference programme](#), or contact [conference@autismnz.org.nz](mailto:conference@autismnz.org.nz)

### Children's Autism Foundation

The Children's Autism Foundation supports families of children with ASD. They provide families with support and professional advice to help manage the emotional and practical impacts of autism. They understand that Children with ASD can be low or high functioning and this can lead to social, friendship and family challenges. They offer services that equip families with the knowledge, skills and confidence, so their children can have rewarding and meaningful lives within their families and the community, now and in the future.

The Children's Autism Foundation programmes include:

- \* Join In Programme – Social and Friendship skills programme for children aged 7 to 16.
- \* Outreach Programme - In the home family support for up to 21 years of age
- \* Skills Through Play for 2-5 years.
- \* Stepping Stones - Individualised Positive Parenting Programme.
- \* Workshops with popular topics including understanding autism, strategies for behaviour, sensory processing, staff education and social and friendship skills.

Children's Autism Foundation - Building brighter futures for families. [www.autism.org.nz](http://www.autism.org.nz)

### Autism Intervention Trust

The Autism Intervention Trust is run by parents and supports children with autism and their families in the Wellington region. Their mission is to support other families affected by autism in practical and positive ways. <http://www.autisminterventiontrust.org.nz>

Working with Victoria University of Wellington, the Autism Intervention Trust is currently fundraising to support a PhD student to work with children on the spectrum, their families and others who support them. The programme will use evidence based behavioural approaches, will be child focused and tailored to their individual needs. The programme will also provide the opportunity to teach everyone involved with each child: how best to communicate with them and support them.

If you are interested in supporting this project, please go to their givealittle page:

<http://www.givealittle.co.nz/cause/Therapyclinic>

### Altogether Autism

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.

<http://www.altogetherautism.org.nz>

## Research participation opportunities

### Genetics and Microbiology study - update

We currently have over 900 participants who have registered their interest for the genetics and microbiology project (1/3 self-registered, 2/3 registered by a carer). Within this group, we have an ASD research cohort that includes 684 diagnosed with ASD (or Asperger's), with a male to female ratio of 5:1. The self-attributed ethnic background reflects New Zealand's population. We are currently sequencing our first cohort and we are about to trial self-assisted saliva collection kits with a small group of participants for our genetics study. This will increase our ability to collect samples from the wider cohort. As the microbiology study ramps up too, we will be in touch with many of you to request relevant (stool and/or urine) samples. It still may take some time for us to be in contact with you to be formally consented for the project, however we anticipate our capabilities to increase as we gain more resources and funding. We are still accepting registrations from those on and off the autism spectrum - you can register here: [www.mindsforminds.org.nz](http://www.mindsforminds.org.nz)

*Approved by the Northern B Health and Disability Ethics Committee (12/NTB/59)*

### Psychology study

Do you have a diagnosis of high functioning autism? ASD and other conditions such as ADHD, anxiety and obsessive-compulsive disorder occur together 30-50% of the time. Why is there such a strong association between these disorders? We are seeking research participants with high functioning ASD and healthy controls to try to find out if there is a brain-based reason for these co-existing conditions. This project requires adult participants with a diagnosis of ASD. We will ask participants to come to our lab at The University of Auckland and attend two sessions over the period of one year. This will involve questionnaires, computer based tasks, and a recording of your brain activity using electroencephalography (EEG). Each session will take no longer than 2 hours and participants will be rewarded with \$20 in petrol or grocery vouchers for each session they attend. Data collected from this research project will serve as a basis for the researcher's PhD thesis. First-degree relatives also have the opportunity to participate in the research. If you are interested in participating or would like to know more please contact Ashleigh Saunders on [ashleigh.saunders@auckland.ac.nz](mailto:ashleigh.saunders@auckland.ac.nz) for more information.

*Approved by The University of Auckland human ethics committee on 16/11/2012 for 3 years, reference number 8697*

### Is your child a picky eater?

Does your child only eat certain foods? Refuses to try new things? You can't get them to eat any veggies or fruits? Would you like some help improving their diet? You can be a part of a Masters project at The University of Auckland. Please contact Marianna: [mgro039@aucklanduni.ac.nz](mailto:mgro039@aucklanduni.ac.nz), 021 76 06 76, for more information.

*Approved by The University of Auckland Human Ethics Committee on 14/05/14 for 3 years, reference number 011491*



FOR MOST CHILDREN WITH AUTISM, MORNING ROUTINES NEED TO BE FOLLOWED EVERY DAY BREAKFAST HAS TO START AT 7 O'CLOCK IN THE MORNING IN ORDER TO KEEP THEIR MINDS AT EASE. IT IS IMPORTANT THAT EVERYTHING IS EXACTLY THE SAME BOWL SAME CEREAL SAME MILK SAME SPOON BECAUSE EVEN THE SLIGHTEST DEVIATION FROM THIS ROUTINE CAN HAVE AN OVERWHELMING EFFECT ON THEIR WELL-BEING IN A NOISY ROOM MAKES MY EARS HURT A LOT THE JUG BOILING SOUNDS LIKE DAD IS MOWING THE LAWNS INSIDE AND WE WANT TO FIND OUT WHY DOES EVERYONE KEEP YELLING AT ME ALL THE TIME THIS HAPPENS, AND HOW WE CAN HELP TO MANAGE IT. RESEARCH IS CURRENTLY UNDERWAY BY A TEAM OF NEW ZEALAND'S TOP SCIENTIFIC MINDS TO DEVELOP A GREATER UNDERSTANDING OF WHAT MAKES A MIND AFFECTED BY AUTISM TICK TOCK TICK FROM THE CLOCK IS LIKE THUNDERSTORMS IN MY EARS AND I WANT IT TO STOP IT'S TOO LOUD I NEED IT TO STOP AND BY DONATING AT [MINDSFORMINDS.ORG.NZ](http://MINDSFORMINDS.ORG.NZ) YOUR GENEROSITY CAN SOMEBODY PLEASE MAKE IT STOP BECAUSE I CAN'T CONTINUE THE DNA SEQUENCE ANALYSIS THAT COULD PROVIDE US WITH THE VITAL INFORMATION WE NEED TO RECOGNISE THE GENETIC SIGNATURE OF AUTISM IN PEOPLE SOUND LIKE THEY'RE SCREAMING I TRY TO BLOCK IT OUT WITH MY HANDS BUT IT WON'T WORK I WANT TO RUN AWAY I WANT TO HIDE BECAUSE WHEN WE CAN UNDERSTAND AUTISM, THEN WE CAN HELP ME

