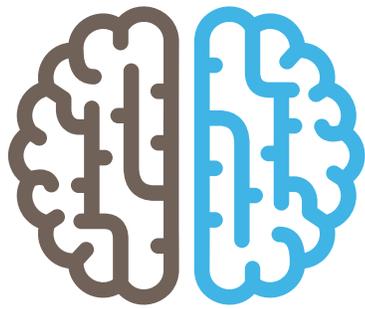


## Newsletter Issue #4

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**minds** for **minds**  
Unlocking Autism Together

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## Contact Us

[WWW.MINDSFORMINDS.ORG.NZ](http://WWW.MINDSFORMINDS.ORG.NZ)

[INQUIRIES@ARNNZ.ORG](mailto:INQUIRIES@ARNNZ.ORG)

## News from our Charitable Trust

The Minds for Minds Charitable Trust supports the important work of the research team. A monthly meeting is held by the Trust to organise events and explore new fundraising avenues. Our major fundraiser for 2015 was a cocktail function, held on June 30<sup>th</sup> at the Sapphire Room, Ponsonby.

The evening was a great success, attracting an enthusiastic crowd keen to support the Minds for Minds research team. A large range of silent auction items had been donated, together with a number of prestigious items for auction under the hammer. These big-ticket items included:

- A Police Dog experience
- Dinner with Minds for Minds Trustee Deborah Hill Cone
- An iPhone 6
- A tour on the set of upcoming TV series *Filthy Rich*
- A trip on the TranzAlpine railway
- A chance to tour the lab of Minds for Minds researchers, and see cutting-edge research first-hand
- A ride in a Havilland aeroplane
- A tour of Auckland Medical Research's Anatomy Museum
- Lunch with Winston Peters

And our premier item:

- An Ice Axe signed by Sir Edmund Hillary

These items drew some lively bidding and the sale of Sir Edmund Hillary's signed Ice Axe garnered publicity in the NZ Herald and other media outlets around the country. [http://www.nzherald.co.nz/nz/news/article.cfm?c\\_id=1&objectid=11473697](http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=11473697)

Also on sale were limited edition Minds for Minds t-shirts, designed for us by the talented Ken Griffen. A small number of these t-shirts are still available for purchase. See page 3 for more details.

In summary the evening was a great success, raising \$30,000 towards the vital work of our dedicated research team. Minds for Minds Charitable Trust would like to extend our heartfelt thanks to everyone – sponsors, attendees and bidders - who contributed towards making the event so successful.

*Did you know you can support the work of Minds for Minds? Donations are welcomed through [www.mindsforminds.org.nz](http://www.mindsforminds.org.nz)*

**ARTIST KEN GRIFFEN CREATES LIMITED EDITION SIGNED T SHIRTS AS FUNDRAISER FOR MINDS FOR MINDS**

Ken Griffen is a young New Zealand artist, based internationally, who earlier this year exhibited at the Allpress Gallery in Auckland and the show was a complete “smash” and sold out.

He has created an exclusive image for Minds for Minds for a limited edition of signed T Shirts to raise funds for the project. There are only 250 available. The signature is on the sleeve.

Before moving to Europe Ken was Senior Graphic Designer and Creative Director for the Huffer Brand.

As one commentator said of his art, “I have not been to an exhibition or come across a new artist that has made me this excited in a very long time.”

Ken is now based in Berlin. Check out <http://kengriffen.co/> to see Ken’s exhibition image, and <http://roaringfork.co.nz/> to see his design and art work.

The adult shirts are \$75 and the kids and young adults \$50. There are a number of sizes in mens’, womens’ and kids’ t-shirts, in black or white. *Available online at TradeMe (just search for “Charity Auction Minds for Minds”*. Modelled here by Gloria Griffen.



## Updates from our Minds for Minds Researchers

### **Update on the genetics project (Jessie Jacobsen, Russell Snell, Klaus Lehnert and PhD students Brendan Swan and Whitney Whitford)**

This past year has seen the number of participants registered for this autism spectrum disorder (ASD) project rise to over 1200. It is hoped that the collated information from this research-focused ASD database will advance relevant research in many areas through data sharing and the reporting of research results to the scientific and ASD communities. A preliminary analysis of the database is providing insight into some of the most pressing health concerns for those on the spectrum in New Zealand. For instance, the predominant self-reported comorbidity for those over the age of 18 years is anxiety and depression, while in younger children (age 0-7) it is attention-deficit hyperactivity disorder. It is anticipated that this correlation of basic biological research with clinical presentation will improve health outcomes and help advise educational, social and health policies in New Zealand.

From this database we have formally consented over 300 individuals and sequenced 27 families with ASD and/or a neurodevelopmental disorder (56 individuals). We have completed full DNA analysis on 21 individuals, and of those we have found clinical diagnoses for 16 individuals. Two papers have been provisionally accepted describing two of these cases. In two families with ASD, we have refined their child's diagnosis to a specific syndrome (Rett syndrome and Bainbridge Ropers Syndrome). Furthermore, for three families with neurodevelopmental disorders, the genetic diagnosis has directly informed treatment options. This work has resulted in strong clinical collaborations, and we now interact with over 20 physicians around the country.

This year we have also been establishing a whole genome sequencing (WGS) platform, to analyse DNA from the entire human genome (including all the non-coding parts). This is an important development as WGS provides the opportunity to detect structural DNA changes. This is outlined in more detail in PhD student Whitney Whitford's project description (page 5).

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 causes of ASD. If you would like to participate in this research, please register your interest at [www.mindsforminds.org.nz](http://www.mindsforminds.org.nz).

## **Whitney Whitford – new genetics PhD student**

Whitney Whitford is a new PhD student working with Dr Jessie Jacobsen, Associate Professor Klaus Lehnert and Professor Russell Snell at the Centre for Brain Research and School of Biological Sciences at The University of Auckland. The aim of her project is to identify structural variants (large regions of DNA that are deleted, duplicated or inverted in our genome) that are associated with neurodevelopmental disorders, particularly Autism Spectrum Disorder. She will use bioinformatics techniques to identify these big structural DNA changes within the genome of affected individuals and their families here in New Zealand. Individuals will be sequenced using the latest next-generation sequencing technologies and analysed using cutting edge bioinformatic techniques that she will help develop. Her hope is to create new protocols to identify these sorts of structural DNA changes, many of which are not detectable by current diagnostic methods. Transferring these protocols into the clinic will enable accurate molecular diagnoses for families, which will help individuals plan for their future. It will also contribute to the international effort to better understand the underlying biology of these conditions.

## **Kelsey Flynn – new PhD student in psychology**

Impairments in symbolic and abstract reasoning are salient features of verbal language deficits in autism spectrum disorders. These impairments may extend beyond the verbal domain to other cognitive areas, including visual processing, as an over-reliance on perceptual information may be an important underlying factor or compensatory mechanism. As minimally-verbal autistic children are often dependent on picture-based facilitated communication systems, understanding the symbolic nature of pictures is critical. However, simple associative mechanisms may be relating these pictures to words and objects, rather than meaningful understanding of the nature of these visual symbols. Through cognitive assessments, electroencephalogram (EEG) testing, and functional magnetic resonance imaging (fMRI) analysis, this study will assess the distinct cognitive and neural mechanisms by which abstract and photographic images are processed, and how these may differentially facilitate symbolic learning and understanding. The results may help to determine whether impairments in symbolic and abstract reasoning are unique to language, or are an underlying pervasive feature of autism spectrum disorder, as well as elucidate potential compensatory mechanisms.

*Kelsey is supervised by Associate Professor Karen Waldie.*

## Focus On:

### Dr Javier Virués-Ortega



Pictured (L-R): Javier with PhD students Jessica McCormack and Sarah Leadley

emotional, behavioural and neural aspects of problem behaviour, especially among people with developmental issues.

**Javier Virués Ortega** is a Senior Lecturer in Psychology at the University of Auckland. Originally from Spain, he joined the University (and also the Minds for Minds team) in 2014, after a four-year spell at the University of Manitoba in Canada. His research focuses on the

Some behaviours associated with autism spectrum disorder (ASD) cause major concerns for both children with ASD and their families. These can range from disruptive and stereotypic behaviours right through to aggression or self-injury in certain cases. An important task is to develop standardised protocols to assess these types of behaviour; once an individual's behaviours are more fully understood, the less desirable ones can be worked on and that child should hopefully benefit by improving their potential to learn. Resulting improvements in quality of life for caregivers and family must also not be underestimated. Javier has examined a range of treatments for such behaviours, and looked at effective strategies to develop vocalisations and early social behaviours in infants deemed to be at risk for developmental delays.

Clinical trials around the world have indicated that early behavioural intervention (following early diagnosis) can be highly effective in improving academic, social and daily living skills of individuals with ASD. However, as is the case for many of the therapies associated with ASD, it is not always straightforward for parents to know which types of intervention may be available, and even then which are actually supported by empirical (scientifically collected) data. Javier has thus been involved in a number of initiatives to increase public awareness of scientifically-supported interventions, as well as providing training opportunities for practitioners. A particular interest of his is applied behaviour analysis (ABA), for which he directs the professional training programme at the University of Auckland. ABA is widely used with children (and some adults) on the autism spectrum, and involves the use of principles such as positive reinforcement to increase desirable behaviours and lessen the impact of behaviours that may be harmful (e.g. by interfering with learning at school).

Javier also has two PhD students working this area. **Sarah Leadley's** PhD study focuses on behavioural assessment and treatment provided in the home to help children transition from tube feeding to oral

feeding. This study involves intensive involvement with caregivers and their children as well as a high degree of collaboration with the child's health professionals. The study is funded by a Senior Health Research Scholarship. Sarah is a graduate of the Auckland ABA Programme (Registered Psychologist and Board Certified Behavior Analyst). [Jessica McCormack](#)'s research is concerned with the Differential Outcomes Procedure, a reinforcement procedure that may be used to improve accuracy and efficiency of learning in children with autism. The differential outcomes procedure looks to improve learning by pairing the objects or labels being learnt with unique reinforcers, which provide an extra cue to correct responding. This research involves teaching new skills to children with autism and intellectual disabilities, such as letter recognition and sight words. Jessica's research is a continuation of her Masters research, which she conducted as part of the Auckland ABA program.

## News from our Community Partners

### **Autism New Zealand** ([www.autismnz.org.nz](http://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](http://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.

### **Altogether Autism** ([www.altogetherautism.org.nz](http://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](http://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.

## Autism Intervention Trust

### Early Start Denver Model introductory workshop | Wellington | 19 October

Victoria University, in conjunction with Wellington's [Autism Intervention Trust](#), are pleased to announce a one day workshop in the Early Start Denver Model (ESDM). ESDM is an evidence-based programme that shows huge promise in the treatment of autism in pre-schoolers.

**What is ESDM?** Named as one of Time Magazine's 'top ten medical breakthroughs of 2012', ESDM is an evidence-based intervention specifically developed for very young children with autism. ESDM is a naturalistic, play-based intervention that fuses behavioural and developmental principles into an integrated approach. ESDM aims to reduce the challenges of autism and targets all developmental areas.

**What will you learn?** In this introductory workshop you will learn about the theoretical and empirical framework, curriculum and teaching principles of ESDM (course notes/materials included in workshop price).

#### About the presenter: Elizabeth Fulton



[Elizabeth presented at the recent Brisbane APAC conference](#), and has been working with children with autism and their families for many years. She is also on staff at the University of NSW, Faculty of Medicine (School of Psychiatry). Elizabeth is a certified ESDM therapist and ESDM Trainer in Australia. Her clinical experience includes:

- assessing children with ASD
- developing and supervising Group ESDM intervention programs
- ESDM Clinics
- ESDM Parent Training

<b>What:</b>	<b>ESDM Introductory workshop</b>
<b>When:</b>	Monday 19 October, 9:30am – 4:30pm
<b>Where:</b>	Victoria University Karori campus (Donald Street), Theatre Block, Lecture Theatre 1
<b>Cost:</b>	\$105* Family/whanau \$105* Students \$155* Professionals *plus booking costs. Morning/afternoon tea and lunch provided.

For more information on ESDM email: [Hannah.Waddington@vuw.ac.nz](mailto:Hannah.Waddington@vuw.ac.nz)

Registrations close 12 October

[Click here to register for the workshop.](#)

## Research Participation Opportunities & Other News

### Study on ASD and vitamin D / Omega-3 supplementation

Massey University are currently recruiting children with ASD aged between 3 and less than 8 years old to take part in the world's first randomly controlled research study with vitamin D and Omega-3 supplementation. To be part of this pioneering research register your interest at [www.massey.ac.nz/vidoma](http://www.massey.ac.nz/vidoma). More information on the study along with contact details are available on the website. "Like" our facebook page - <https://www.facebook.com/groups/vidoma/>

*This project has been reviewed and approved by the Health and Disability Ethics Committee: 14/NTA/113*

### Staying Connected

In 2016, psychologists Marijke Batenburg and Nathan Gaunt will be facilitating a 2 hour session for couples once a month for 10 months (February - November). One or both members of the couple has ASD characteristics. The aim of the 10 month course is to maintain and improve connection within romantic and intimate relationships. The sessions will be held in Ponsonby on Tuesday evenings, 6 – 8 pm. Actual dates are to be confirmed. The numbers in the group will be limited.

Please send expression of interest to Marijke E [marijke@mindfulpsychology.co.nz](mailto:marijke@mindfulpsychology.co.nz) or call (09)6309297.