



VAL LISHMAN
Health Research Foundation



PROGRESS REPORT May 2015

Autism in Rural Communities

Thank you so much for your generous support of the **Val Lishman Health Research Foundation** project, "**Autism in Rural Communities**" that is being run in conjunction with researchers from **Curtin University** (led by Professor Torbjorn Falkmer) and with the support of **South West Autism Network (SWAN)**.

There were several delays that held up the start of the project, including extensive discussions with Disability Services Commission (DSC) to reach agreement regarding the dissemination of the project survey to stakeholders, pilot testing the survey with families of children with ASD and incorporating the feedback of the families into the survey.

The project commenced in August 2014. Since then the bulk of the money paid by the Val Lishman Health Research Foundation has gone to the employment of a Research Assistant in the South West (Janine Slaven). Curtin University has been supporting the work of the Perth researcher (Research Fellow - Dr Sharmila Vaz) as part of their in-kind contribution to the project. The survey was launched on February 24, 2015 and focuses on the processes families with a 2 - 18 year old child/ young person with Autism Spectrum Disorder go through to obtain an ASD diagnosis and to access services, the additional costs associated with having a child with ASD, and the impacts of having a child/ young person with ASD on the family's everyday life.

This survey will be the most comprehensive longitudinal survey on the experiences of families of children with ASD, and has been designed to capture the change in the needs of families with a child with ASD over time (every 3 years). By comparing the experiences of families in the South- West to the rest of Western Australia, the findings of this survey will inform future services delivery and policy.

To date, 75 families have completed the survey. Interested families can access the survey at <http://goo.gl/GmsIVR>. Responses from 200 families are required and it is anticipated that this will be achieved during the next six months.

The Autism in Rural Communities Project Advisory Committee (PAC) has been established and has held two meetings in Bunbury. The committee comprises researchers from Curtin, members of the VLHRF Board, a local paediatrician and community representatives with relevant skills and experience. Meetings are held regularly and the PAC is seen as an integral part of the project.

The second part of the project, is an intervention study that aims to determine if there are ways services can be delivered remotely to families of a child with ASD. Imminent roll out of this part of the project is anticipated. The end date of the project has been revised and the project is now anticipated to end November 2016. This time extension will mean more research dollars will be spent in the South West.

Thank you again for your support of this project. The Val Lishman Health Research Foundation sincerely appreciate your support and are confident that this project will really make a difference to families in the South West, and indeed other parts of rural Western Australia, who are living with ASD.

Further questions regarding the project can be emailed to: autismstudy@curtin.edu.au
For more information about autism go to www.swanautism.org.au