

**Parent/Guardian and Older Child Information Statement  
for the Research Project: The Australian Childhood Vision  
Impairment Register**

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Dear Parent/Guardian,

This letter is to inform you about the Australian Childhood Vision Impairment Register. The Register is a database of clinical information about childhood vision impairment. The Register aims to provide a national picture of childhood vision impairment to be used in planning and delivering better services for children. The findings will also be used in research into eye and vision conditions which cause vision impairment in childhood.

Participation is open to children aged 0-18 years who have vision impairment in both eyes, diagnosed by an ophthalmologist or eye doctor. We would like all children with vision impairment to participate as this will help us to get an accurate picture of the numbers. Participation in the study is up to you, however if you decide not to participate, you will not be disadvantaged in any way.

**Q: What will you be asked to do?** If you agree to register your child we will ask for information from your child's eye health professional. We will ask you to complete the enclosed Parent/Guardian Consent Form & the Parent/Guardian Data Form. These forms take about 10 minutes to complete. Also, if you agree we will send your child a welcome certificate for joining the Register.

**Q: How safe is the information in the register?** Very safe. Your confidentiality and privacy are strictly observed at all times. The information is stored on a secure database and no information that can identify you or your child is revealed in the use of the data. We keep your child's data until he or she reaches their 18th birthday. When they turn 18 we will ask them directly if we can hold onto their de-identified data for another 5 years.

You are welcome to see all the information held about your child. If you wish you can ask for information to be removed. You or your child can decline to have your child's information included on the Register or withdraw the information at any time.

**Q: How do I register my child?** Please read this information sheet and make sure that you understand it before you agree to register your child. If you do agree to register your child please complete the enclosed Parent/Guardian Consent Form and the Parent/Guardian Data Form. You can do this using paper forms or online using our website at: [www.vifamilynetwork.org.au](http://www.vifamilynetwork.org.au). If you prefer you can contact Register staff who will help you complete the forms on the telephone: (02) 9872 0303. You can also email Register staff for help: [jill.watson@ridbc.org.au](mailto:jill.watson@ridbc.org.au).

**Q: Where can I get further information?** You can contact Sue Silveira using the address on this sheet. This sheet is also available in large print, in various community languages, Braille and on MP3. You can also visit our website at [www.vifamilynetwork.org.au](http://www.vifamilynetwork.org.au).

Thank you very much for considering registering your child with the Australian Childhood Vision Impairment Register.

Sue Silveira

**Complaints about this Research:** This project has been approved by the Hunter New England Human Research Ethics Committee, Reference Number 08/09/17/5.04. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Hunter New England Human Research Ethics Professional Officer, Hunter New England Research Ethics Unit, Locked Bag 1, New Lambton, NSW 2305. Telephone: (02) 49214950. Email [nicole.gerrand@hnehealth.nsw.gov.au](mailto:nicole.gerrand@hnehealth.nsw.gov.au)