ACVIR

Newsletter

September 2017

Welcome

This newsletter updates information available from the Australian Childhood Vision Impairment Register. It has been produced in an accessible format for people with vision impairment to be able to read as easily as possible.

Sue Silveira

What is the Australian Childhood Vision Impairment Register (ACVIR)?

ACVIR was initially developed to gather data on children living in Australia who have vision impairment. This data is essential as children with vision impairment need integrated and specialised services including health, education, and low vision support. To help plan these services, accurate data is required on the number, causes and needs of children with vision impairment and their families. Before ACVIR there was no coordinated gathering of this data.

The Royal Institute for Deaf and Blind Children sponsors the Australian Childhood Vision Impairment Register, in partnership with families and children with vision impairment, key Australian service providers, health professionals, and government departments.

Information from the Register is being used to more accurately plan for the present and future service needs of children with vision impairment. It is also available to researchers who are investigating the many causes and potential treatment for conditions related to vision impairment. All information on the Register is held in the strictest confidence, and families can withdraw from the Register when they wish. ACVIR has ethics approval in every state and territory of Australia.

To ensure success from the Register, it is vital to have as many children with vision impairment involved as possible. Details of the Register and online registration can be found at the website that supports the project called the VI Family Network, located at: [www.vifamilynetwork.org.au](http://www.vifamilynetwork.org.au).

Families can register online at [www.vifamilynetwork.org.au](http://www.vifamilynetwork.org.au) or request registration forms by calling (02) 9872 0248. Once they have registered their child, families are asked to provide brief details related to their child’s vision impairment, and for consent for ACVIR staff to contact their child’s eye health professional, for similar details on the child’s condition.

Enquiries can be made by emailing: [acvir@ridbc.org.au](mailto:acvir@ridbc.org.au).

# list of links in websiteVIFN website better than ever!!

The VIFN website aims to provide you with up-to-date information and resources to use. Have a look at the site – we’d love to know what you think of it.

Some things you will find at this website include: links to useful websites, information on education, vision aids, agencies which might be able to provide help or information, newsletters, current events, ACVIR online registration and much more.

There are links to organisations which can provide you with information, assistance/support and/or networking opportunities.

Click on the link below to access the site:

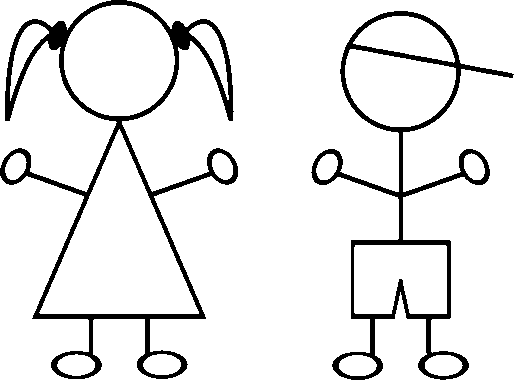
<http://vifamilynetwork.org.au/>

Our latest data

There are now over 800 complete registrations of children with vision impairment, living in all states and territories of Australia, aged 0-18 years of age, on the Register. This newsletter will provide you with an update on what is known about their demographics, levels of vision and the type of aids they use.

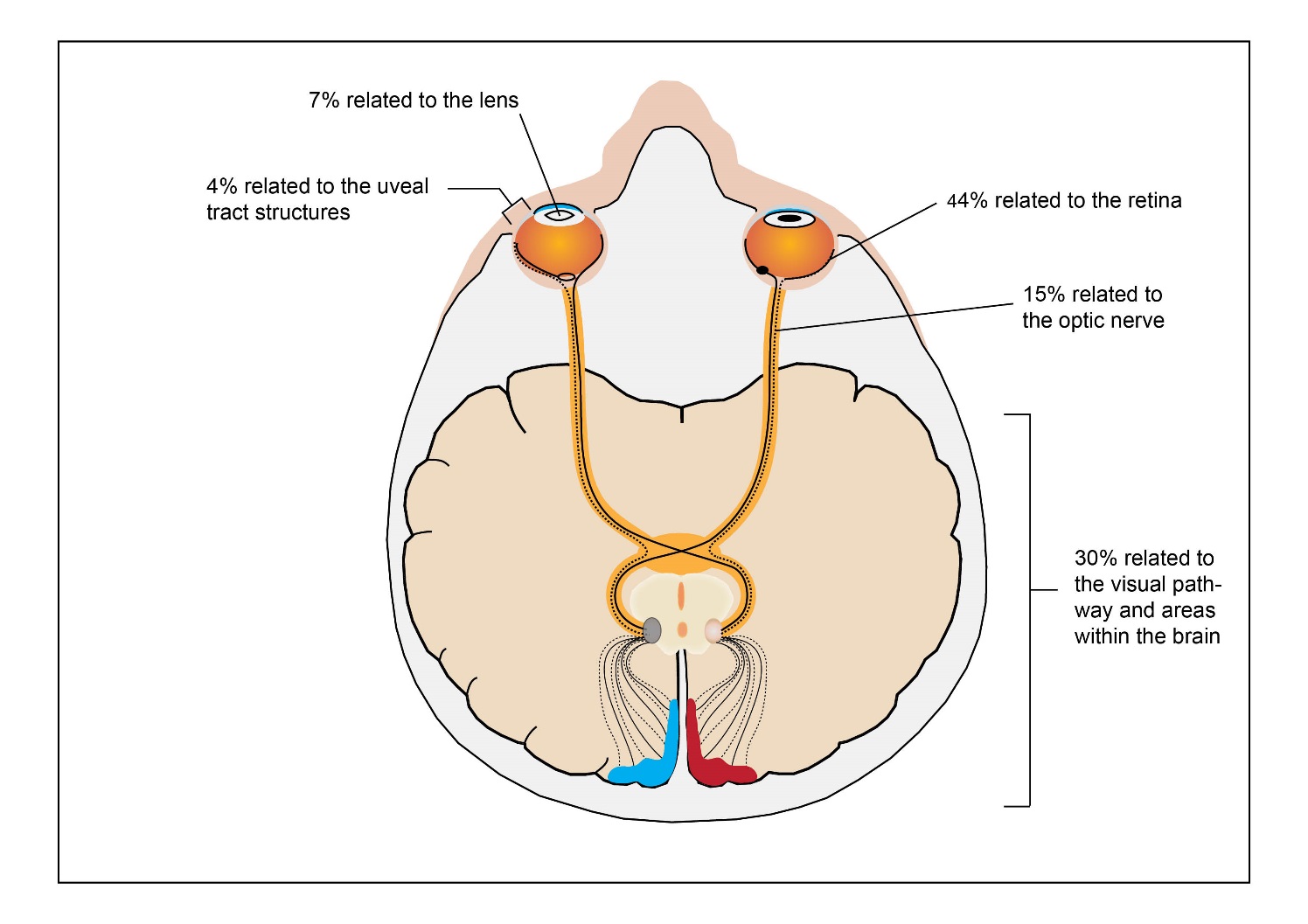
At the end of this newsletter is a copy of the ACVIR Inclusion Criteria, for your information.

## Some interesting facts about our registered children:

* 98% were born in Australia and speak English.
* The next most commonly spoken language is Arabic.
* 58% are boys, 42% girls
* NSW has the highest number of registrations, followed by Victoria & SA, then QLD, WA, Tasmania, NT and Canberra
* Importantly, 13% of children are Braille users

Here is a snapshot of data from ACVIR on Australian children with vision impairment.

The diagram below shows the areas within the eye and visual system that are affected by the ten most common conditions that cause vision impairment:



## Our children have varying levels of vision impairment which range from moderate vision impairment to blindness. The chart below gives you an idea of how many children have these different levels of vision impairment:

## Our children use a variety of aids to support their vision. These include:

We love to hear from families and ask for their comments about their own experiences. Here are some examples of what they have had to say about their children:

Sophie is very well adapted and is coping with her vision. We were surprised to find how little vision she has as she can get around just fine and is a very bright girl, reading above her year level.

Isabella is a happy and healthy 2 year old, making excellent progress in her development. Her talking has been slow but we have great support from a caring team of professionals and have been reassured by them that she is doing well.

Since receiving a diagnosis for Chad we have not looked back, luckily we have had great support, but at times we have all felt challenged. We have found he loves sport and is very talented. It has been a great way to make friends and has helped enormously with his coordination and strength. We are really proud of Chad and the way he is learning to manage his vision, he is now happy to let us know when he can’t see something.

Regardless of his decreasing vision, my son continues to excel in sport and his attitude to his condition has inspired me. Every day he gives me strength in my struggle to come to terms with his eye condition.

Thank you to the families that have kindly registered their child. We protect this information very carefully and it has already been used to represent children with vision impairment in research, planning and support.

For further information, please contact:

Sue Silveira

JAFF Research Fellow and Orthoptist

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Email: [sue.silveira@ridbc.org.au](mailto:sue.silveira@ridbc.org.au)

Inclusion Criteria for the Research Project: The Australian Childhood Vision Impairment Register Version 1 Thursday 21st June, 2012.

ACVIR Inclusion Criteria

For children to be included in the Australian Childhood Vision Impairment Register, they must be aged between 0-18 years and must have had their vision impairment diagnosed by an eye doctor or ophthalmologist.

Inclusion criteria mean the characteristics that your child needs to have to join the Register. There are different inclusion criteria - **your child only needs one** of these to qualify for the Register:

### Inclusion Criteria 1: Visual Acuity

If your child has had their vision tested using both eyes, wearing their distance glasses or contact lenses (if needed), and they have a visual Acuity of 6/18 or less.

The arrow pointing on the vision chart shows the line of letters that equals 6/18. Your eye health professional may use a different type of vision test to this chart to work out your child’s visual acuity.

### flower as seen by people with good visionInclusion Criteria 2: Visual Field



If your child has had their visual field or peripheral vision tested using both eyes and they have 20 degrees of less of remaining visual field.

The picture demonstrates loss of visual field.

### Inclusion Criteria 3: Cortical Vision Impairment

If your child has any form of cortical vision impairment.

Your eye health professional will be able to advise you if your child meets the inclusion criteria for the Australian Childhood Vision impairment Register. If you have any questions please contact Register staff on [acvir@ridbc.org.au](mailto:acvir@ridbc.org.au) or call (02) 9872 0248.

**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) 4921 4950.

# Our supporters

Click on a link to go directly to an organisation’s website:

<http://www.visionaustralia.org/home>

[](http://www.visionaustralia.org/home)

NSW/ACT <https://www.guidedogs.com.au/>



QLD <https://www.guidedogsqld.com.au/>



VIC <https://www.guidedogsvictoria.com.au/>



SA <https://www.guidedogs.org.au/>

WA <https://www.guidedogswa.com.au/>

TAS <https://guidedogstas.com.au/>

<https://www.visability.com.au/>

<http://www.senses.asn.au/>

[Senses Australia](https://www.senses.org.au/)

<http://www.cando4kids.com.au/>

[Logo can do 4kids](http://www.cando4kids.com.au/)

<http://www.ridbc.org.au/>

ridbc logo

<https://www.cerebralpalsy.org.au/>

cerebral palsy alliance logo

<https://www.downsyndrome.org.au/index.html>

[](https://www.downsyndrome.org.au/index.html)

<http://www.retinaaustralia.com.au/index.htm>



<http://albinismaustralia.org/>

