

The Australian Childhood Vision Impairment Register

April 2013 Update!

Welcome

Welcome to the April 2013 Newsletter for the Australian Childhood Vision Impairment Register. This newsletter will present an update on our data and will highlight what we know about children on the Register who have been born prematurely.

What is the Australian Childhood Vision Impairment Register and does my child qualify to join?

The Register is the first of its kind in Australia, and gathers data on children (0-18 years) who have vision impairment. 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.

Inclusion Criteria 2: Visual Field

If your child has had their visual field or peripheral vision tested using both eyes and they have 20 degrees or less of remaining 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 or call (02) 9872 0303.



You might be interested to read “A Picture of Australia’s Children”

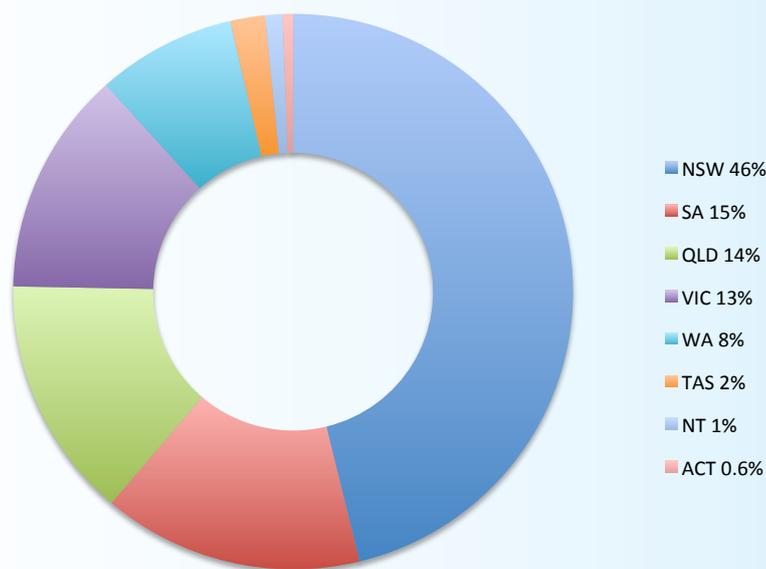
The Australian Institute of Health and Wellbeing recently released a report titled “A Picture of Australia’s Children 2012”. You can find this report at: <http://www.aihw.gov.au/publication-detail/?id=10737423343>.

Page 26 of this report talks about the most common disability types experienced in Australian children, and these include intellectual in 3.9% of children, and sensory/speech which includes vision, hearing impairment and deaf blindness in 2.9% of children.

As the Register grows we are in a position to provide accurate information on Australian children with vision impairment.

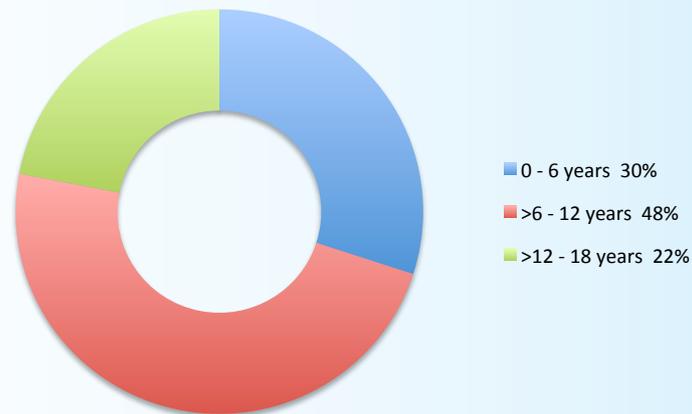
Where do registered children live in Australia?

The Register has been collecting data since 2009. We now have over 850 children registered. Thanks to all the families who have provided information on their children, and eye health professionals who have provided information on children in their care. We have an amazing support network that constantly passes on information to families for us. This includes Guide Dogs, Vision Australia, Carers Australia, the Senses Foundation, Cando4kids, public hospital eye clinic staff, private ophthalmic practice staff, Department of Education staff, Catholic Education staff and Independent school staff. Thanks to everyone for their ongoing support. We recruit across Australia and the graph below shows where our children live:



What are the ages of registered children?

We accept children from birth to 18 years of age and the graph below shows the ages of the children currently registered:



How many registered children have been born prematurely and what do we know about them?

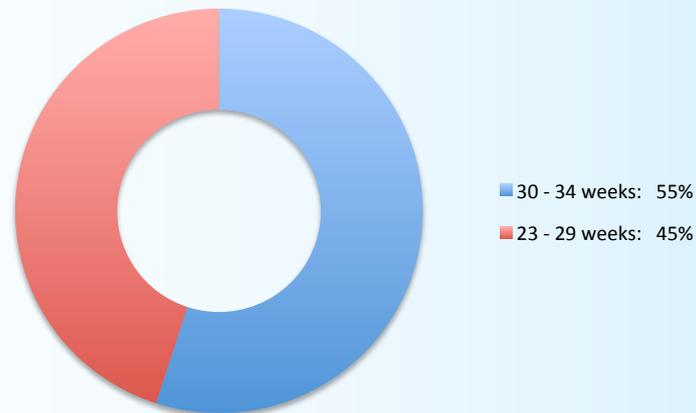
It is quite common to hear of a baby being born early or prematurely. In fact, the World Health Organization released a report called “Born Too Soon: The Global Action report on Preterm Birth”, which you can find at:

http://www.who.int/maternal_child_adolescent/documents/born_too_soon/en/index.html.

In this report preterm birth is defined as less than 35 weeks of gestational age. Gestational age can be explained as the age of the baby from the time of conception to when it has been born. The average human gestational age is 37-42 weeks. The World Health Organization reports a staggering 15 million babies are born preterm globally. This report also states that vision impairment is reported in approximately 25% of preterm babies globally.

Australia has also reported on preterm birth in a report by The Australian Institute of Health and Wellbeing titled “Australia’s Mothers and Babies, 2010”, which you can find at: <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442472762>. In 2010 there were nearly 300 000 live births in Australia and 8.3% of babies were born preterm.

Currently, 11% of children on the Australian Childhood Vision Impairment Register have been born prematurely, with 40% being girls and 60% being boys. The graph below shows the gestational age of registered children born prematurely, with the average gestational age being 29 weeks.



Another important consideration for babies born prematurely is their birth weight. Children on the Register born prematurely are more likely to have a low birth weight, with the average birth weight being 750 grams. In fact 84% of children born prematurely weighed between 750 grams-2000 grams at their birth. The remaining 16% weighed between 2000-4500 grams at their birth.

Due to the link between eye conditions and prematurity, preterm babies frequently have eye screening done whilst in hospital, so hopefully any eye diseases can be detected and treated early, to reduce the impact on the baby's developing visual system. The most common eye condition found in children on the Register born prematurely is Retinopathy of Prematurity (40%), followed by Cortical Vision Impairment (30%). Children on the Register born prematurely also have a variety of other conditions such as Oculocutaneous Albinism, Optic Nerve Hypoplasia, Optic Atrophy, Severe Myopia and Retinal Detachment.

It is also common that children on the Register born prematurely have other health conditions which include:

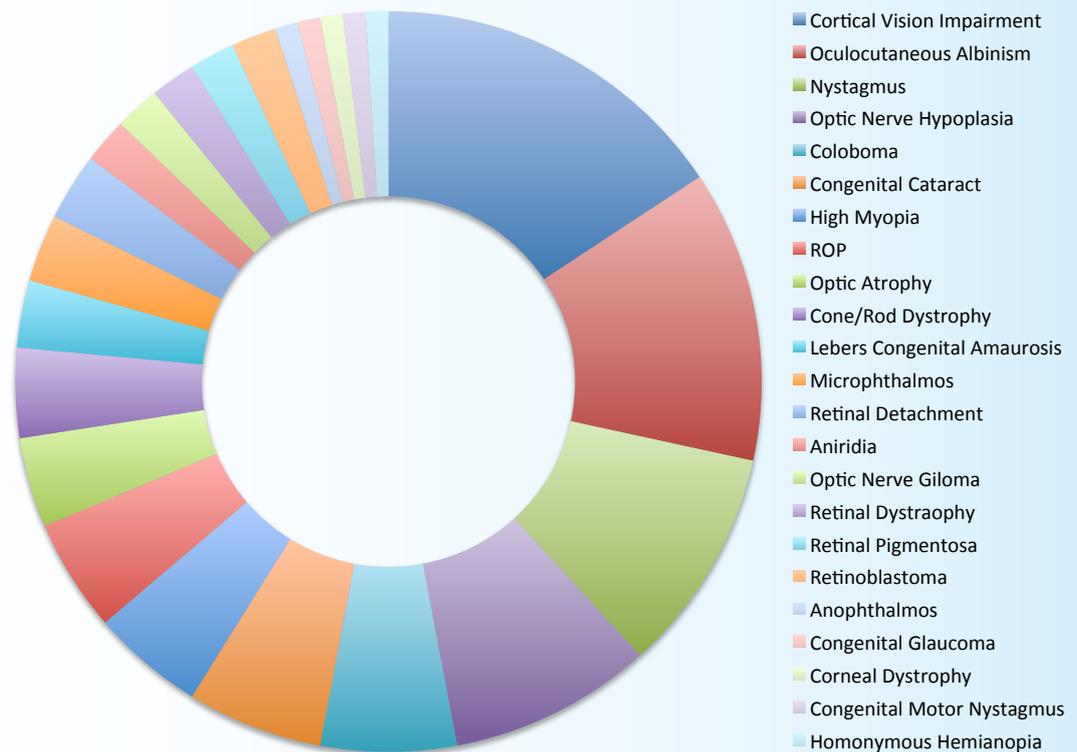
- Cerebral palsy: 55%
- Epilepsy: 21%
- Autism: 15%
- Low muscle tone: 12%

Their parents also report these children having other conditions such as chronic lung and kidney disease and Hydrocephalus.

When looking at the vision of children on the Register born prematurely we find that 60% have mild vision impairment, 30% have moderate vision impairment and the remaining 10% have severe vision impairment.

What types of eye and vision conditions do registered children have?

There are many reasons why registered children have vision impairment. In fact we have over 70 diagnoses - it is nearly the same amount of uncommon eye conditions as there are common eye conditions. The chart below shows the most frequent conditions reported:



The VI Family Network and our Facebook Page

Don't forget to check into our website – the VI Family Network <http://www.vifamilynetwork.org.au>. This website provides access to online registration for families wishing to register their children. It also has a diverse section on resources which include family support, education and related issues, Braille and low vision aids, technology supporting vision impairment and newsletters from support groups.

We now have a Facebook page - just search VI Family Network when you are in Facebook and you will find it!

Getting to know children on the Register

We have recently changed the data form that families complete and we have added a section which says

“The information you have kindly provided will help to build a picture of childhood vision impairment in Australia. We would like to improve this picture by adding your own experience of vision impairment with your child. Please use the space below to describe your child's strengths, achievements and any other messages you would like to convey.”

Parents and guardians have told us about the challenges they and their children face every day, but also about the triumphs and joys and how wonderful their children are. Thanks to everyone who has completed this section and we will provide a summary as responses grow over time.

If you didn't have the opportunity to answer this question on your data form and would like to, please email jill.watson@ridbc.org.au, we are happy to add your feedback to your child's information.

Please help us to spread the word about the Australian Childhood Vision Impairment Register

Our biggest challenge is to reach families to let them know about the Register. Please spread the word whenever you can. The more children we have registered, the more accurately we can report to present a complete picture of these wonderful children.

Wishing you and your family all the best.

Sue Silveira
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