

# ***The Australian Childhood Vision Impairment Register Newsletter, August 2012.***

The Australian Childhood Vision Impairment Register is hosted by the Royal Institute for Deaf and Blind Children and is the first national register of children in Australia with vision impairment. The Register has been collecting data since 2009, and this data is providing important information about the types of eye disease and vision disorders children have and the support they need. The data is also used by service providers and researchers.

For children to be included on the Register they need to be aged between 0-18 years, with their vision impairment diagnosed by an eye specialist or ophthalmologist. Inclusion criteria or the characteristics the child needs to have to join the Register are outlined below. A child only needs one of these inclusion criteria to join:

- If the child has had their vision or visual acuity tested, using both eyes at the same time with glasses or contact lenses worn if they are needed to see for distance, with vision of 6/18 or less. A variety of vision tests can be used to determine the level of vision.
- If the child has had their visual field or peripheral vision tested using both eyes at the same time and their visual field is found to be restricted to 20 degrees or less.
- If the child has any form of cortical vision impairment.

An eye health professional will be able to advise if a child meets the inclusion criteria to join the Australian Childhood Vision Impairment Register. Register staff are also available to answer questions on: (02) 9872 0303 or: [acvir@ridbc.org.au](mailto:acvir@ridbc.org.au).

The Australian Childhood Vision Impairment Register continues to grow and we are pleased to report that we now have 720 children registered. A key part of gathering data is receiving information back from families and eye health professionals - large numbers on the Register mean that we can report more accurately on Australian children with vision impairment. Thanks so much to the families and eye health professionals who have made the effort to return information to us. We know that we ask you to take time out of your day to do this and we're very grateful.

If you're unsure whether you have returned your data form you are welcome to contact Register staff at anytime on (02) 9872 0303 or via email at [acvir@ridbc.org.au](mailto:acvir@ridbc.org.au) and we can sort this out with you.

## ***The Australian Childhood Vision Impairment Register findings are presented at the International Orthoptic Congress, Toronto Canada June 2012.***

In June 2012 findings from the Register were presented at an international conference in Toronto, Canada – the International Orthoptic Congress. The conference was attended by orthoptists and ophthalmologists from across the world. It was exciting that we could put our kids on the global map and it was interesting to see that very few countries are doing research like ours. This makes us more committed to ensuring our kids have a voice through the data we can provide from the Register.

## ***Help us tell the world how great your child is.***

Up until now the Register has gathered information about children, their eye and vision conditions, other health conditions and their low vision needs. There is no doubt this is really important information, but it only tells part of your child's story. Here at the Register we would also like to be able to report on the amazing things achieved by registered children.

Things like playing sport, music, being a great artist and other personal achievements. We'd love you to tell us the message you would like to convey to the world about how wonderful your child is...and we need your help to do this. If you're interested to help us out with developing a survey, please email us at: [acvir@ridbc.org.au](mailto:acvir@ridbc.org.au). We'll send you the questions we have put together for your feedback.

***Have you visited [www.vifamilynetwork.org.au](http://www.vifamilynetwork.org.au)?***



**vi family network**

The VI Family Network can be found at: [www.vifamilynetwork.org.au](http://www.vifamilynetwork.org.au). It is the website which supports the Australian Childhood Vision Impairment Register. Families can use the website to complete online registration. It also provides information on eyes and vision; family support; education and related issues; braille and low vision aids; technology supporting vision impairment; newsletters from Australian low vision agencies and support groups, and news and events that might interest families across Australia.

The website also hosts a parent forum where families can meet and chat with one another, share their stories and get advice.

We're always looking for useful resources and news to share with families – please let us know if you have something you would like to contribute: [contactus@vifamilynetwork.org.au](mailto:contactus@vifamilynetwork.org.au) or call (02) 9872 0303.

***Do you know about the Raising Children's Network website?***

Have you visited the Raising Children's Network, the Australian parenting website located at: <http://raisingchildren.net.au/>? Vision Impairment has recently been included on the website and you can visit the area here at:

[http://raisingchildren.net.au/articles/vision\\_impairment.html/context/1303](http://raisingchildren.net.au/articles/vision_impairment.html/context/1303).

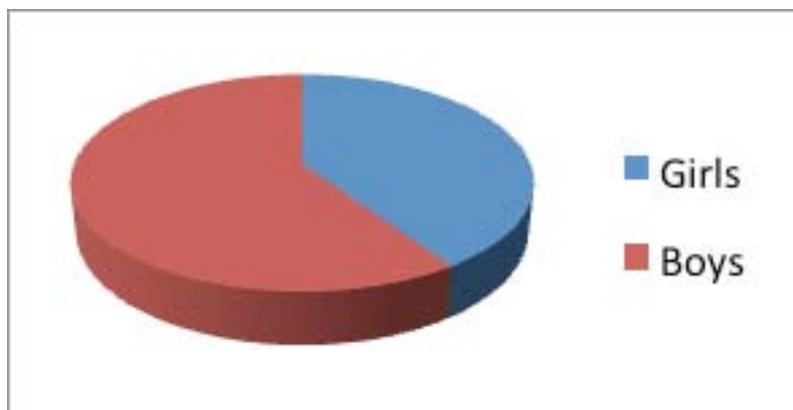
You can share your story and parenting tips here as well.

## Our Latest Data

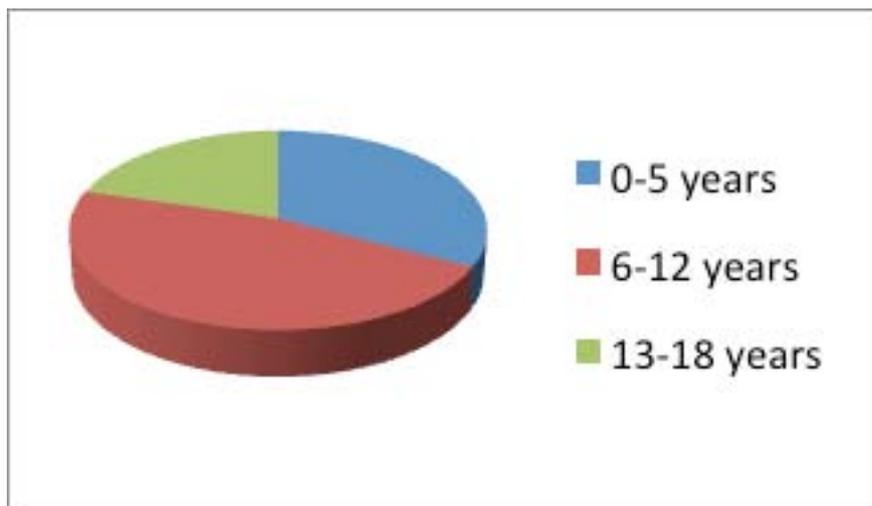
Below is a summary of some of the latest findings from the Australian Childhood Vision Impairment Register.

*Our registered children, their ages, where they have been born, where their parents have been born, and the language they speak at home*

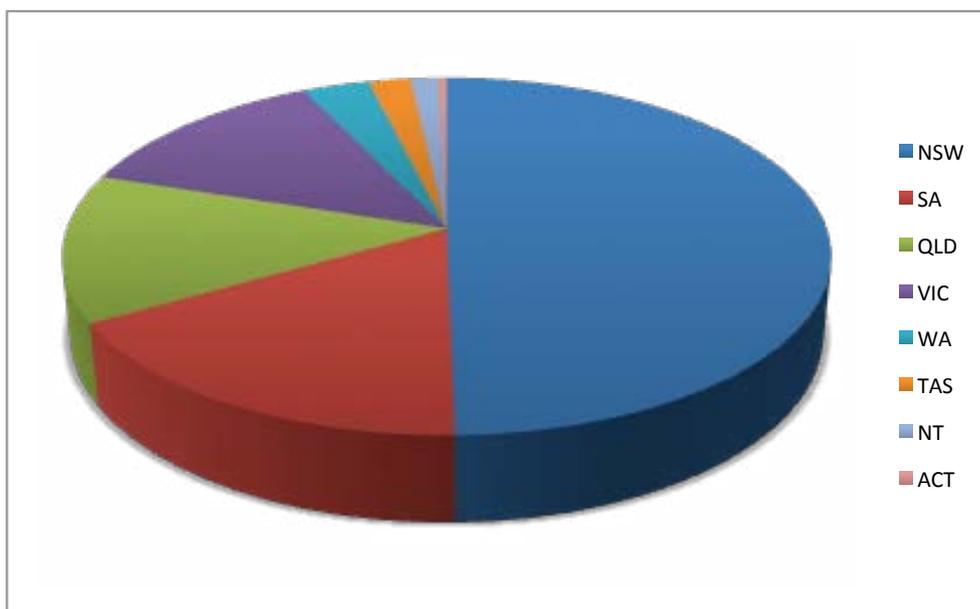
*Girls VS Boys: 41% of registered children are girls and 59% are boys.*



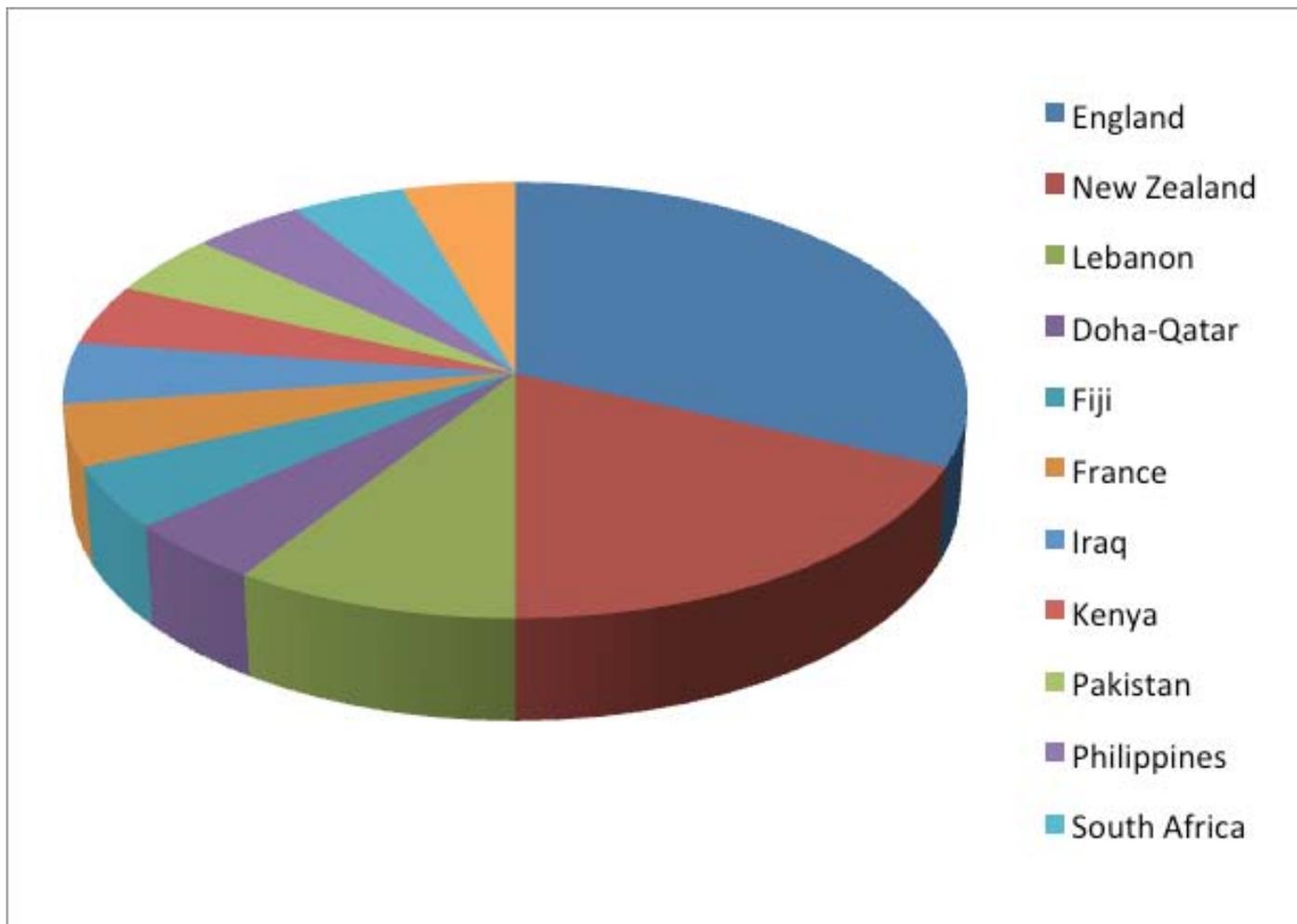
*Age of registered children: the majority of children are aged between 6-12 years, followed by 0-5 years then 13-18 years.*



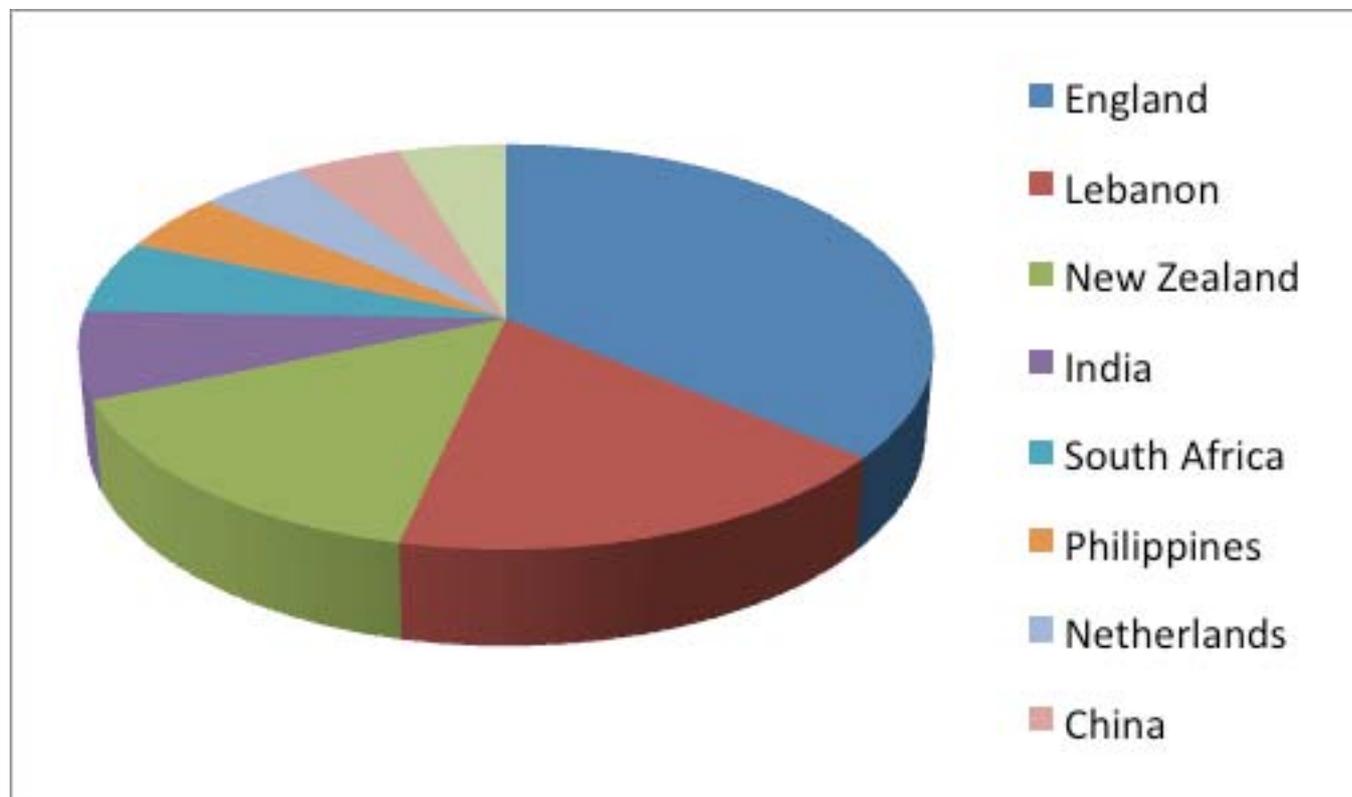
*Where registered children live:* the majority of children that are currently registered live in NSW. This doesn't mean NSW has more children with vision impairment but perhaps reflects how well we have been able to let people in NSW know about the Register. Thanks to the folks in WA for your support to increase numbers of registered WA children. Thanks also to everyone's hard work in the other states.



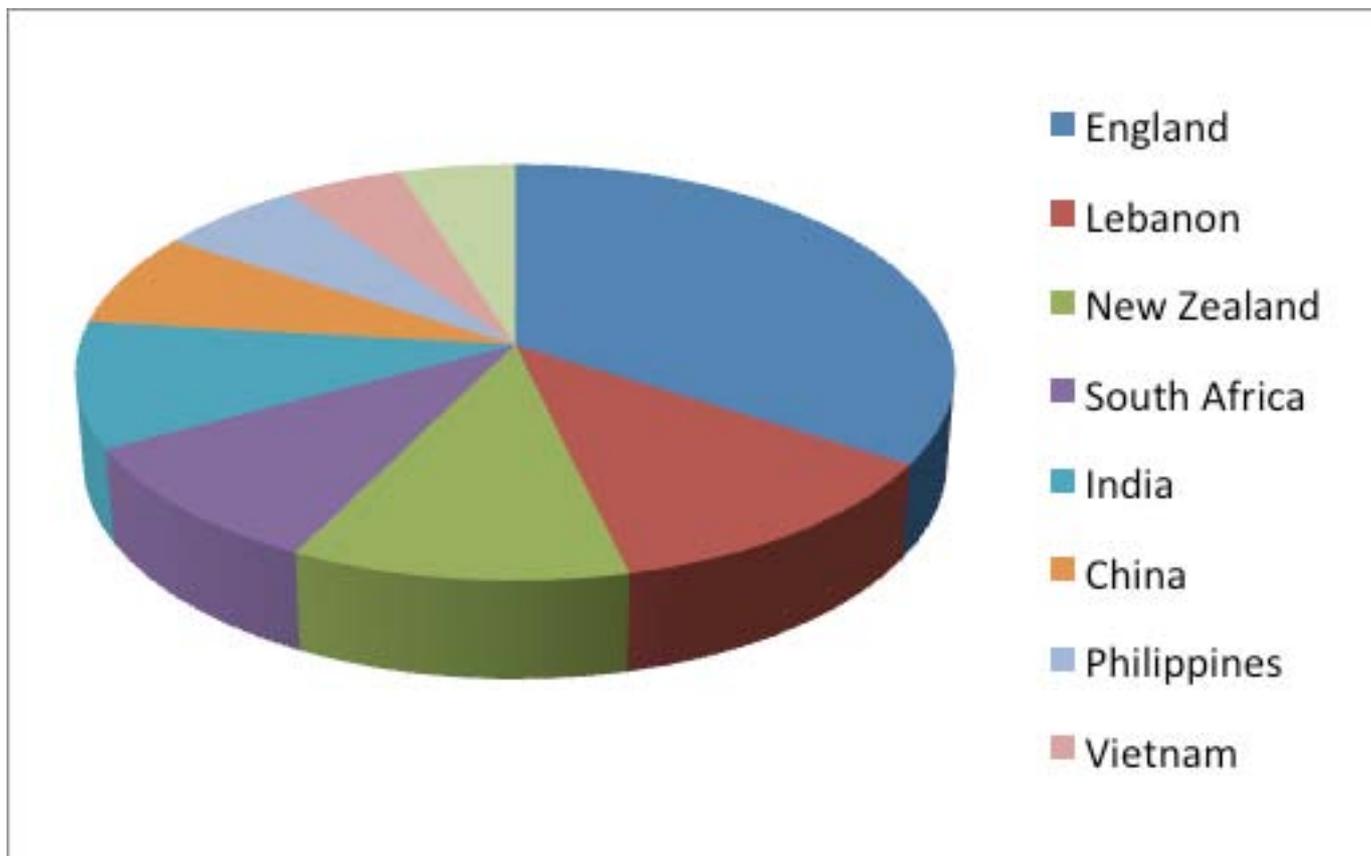
Where registered children have been born: 96% of registered children have been born in Australia, the remaining 4 % have been born overseas. The graph below show where these children have been born.



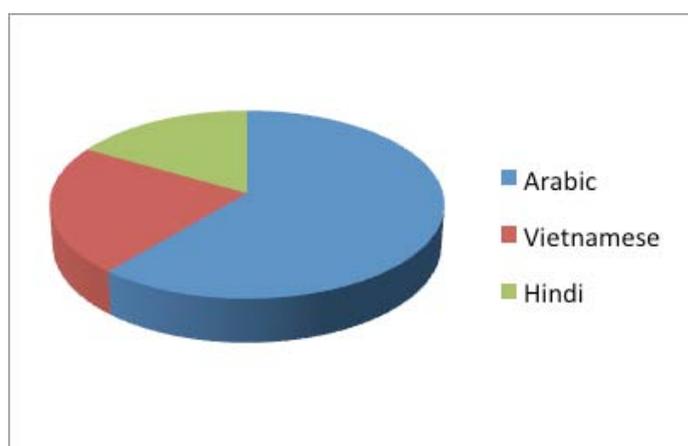
24% of dads and 20% of mums have been born overseas. Our dads are mostly from:



And our mums are mostly from:

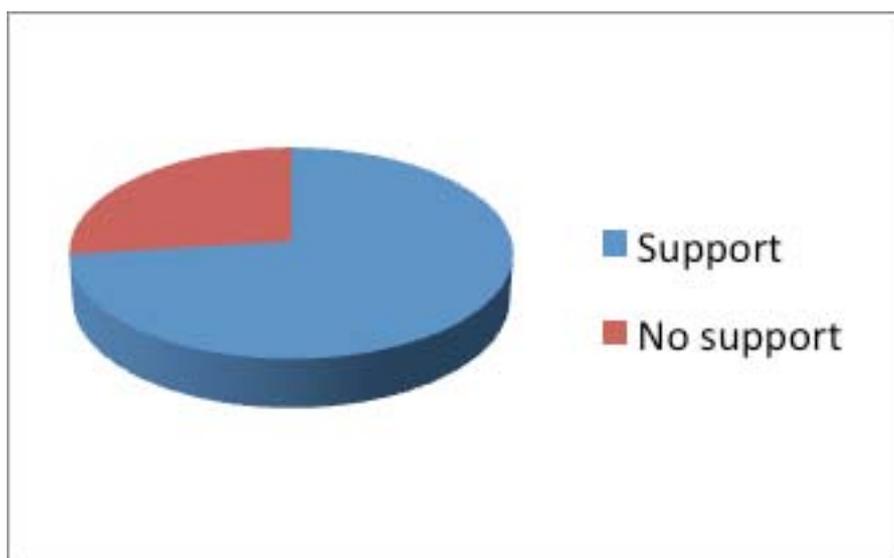


*Languages spoken at home:* 84% of registered families list their main language spoken at home as English. The other 16% mostly report their language spoken at home is Arabic, Vietnamese and Hindi:

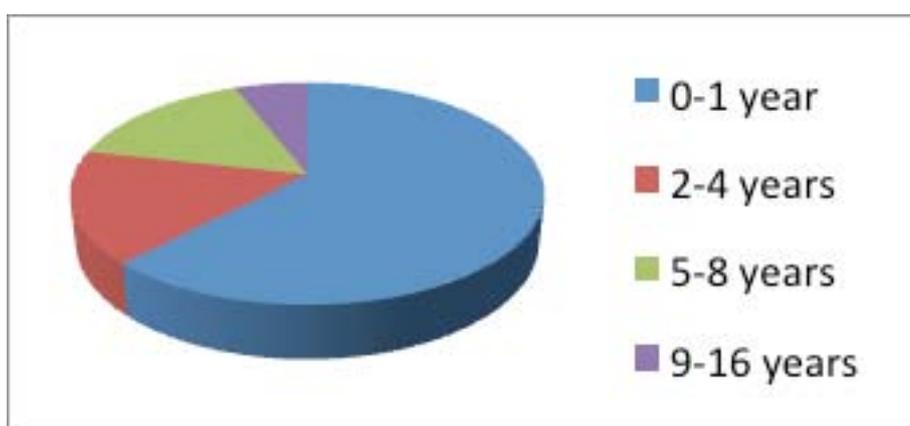


## Low vision support and low vision aids

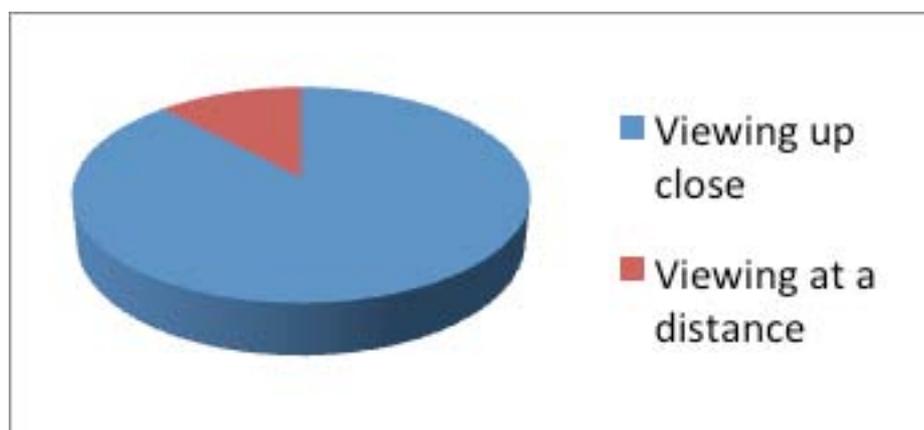
*Children receiving low vision support:* we ask families whether they are receiving any type of low vision support for their child. It's great to see that 73% of children are receiving support, however the data shows 27% of children aren't receiving low vision support. The VI Family Network provides access to low vision services and resources – this is located at [www.vifamilynetwork.org.au](http://www.vifamilynetwork.org.au).



*Age when support was first sort:* we ask families when they first sort support for their child and the majority of families have early in the child's life.

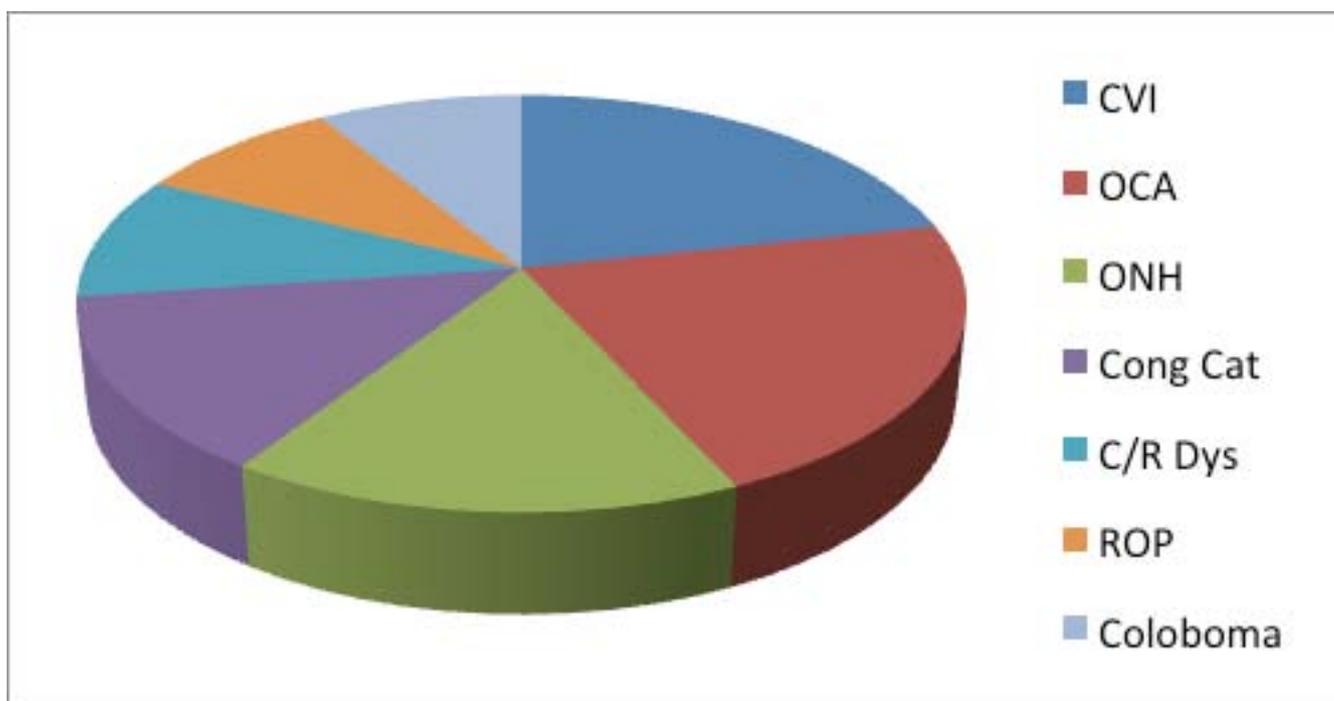


*Low vision aids:* 27% of registered children currently use low vision aids. The graph below shows the how many children use the magnifier when viewing up close or at a distance.



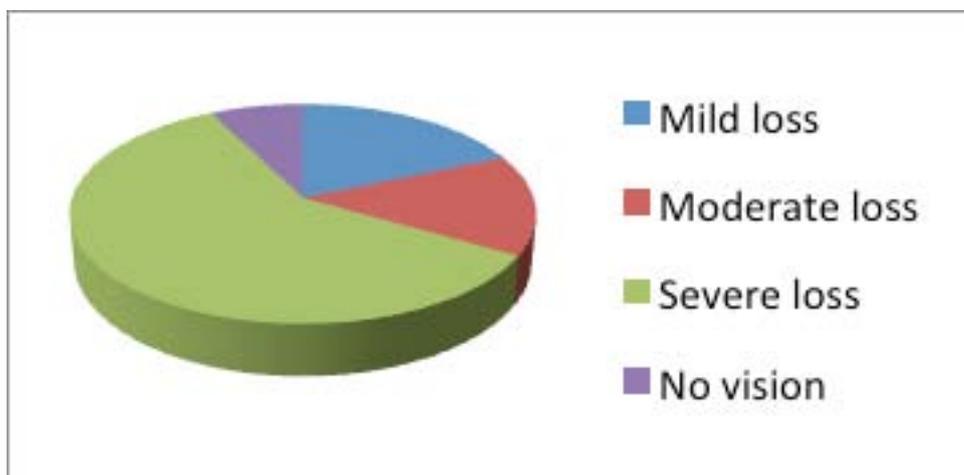
## Common diagnoses and levels of vision

*Most common diagnosis:* there are over 50 different diagnoses of eye and vision conditions in our registered children. The 7 most common are: Cortical Vision Impairment (CVI), Oculocutaneous Albinism (OCA), Optic Nerve Hypoplasia (ONH), Congenital Cataract (Cong Cat), Cone/Rod Dystrophy (C/R Dys), Retinopathy of Prematurity (ROP) and Coloboma. The chart below shows how common each of these conditions is:

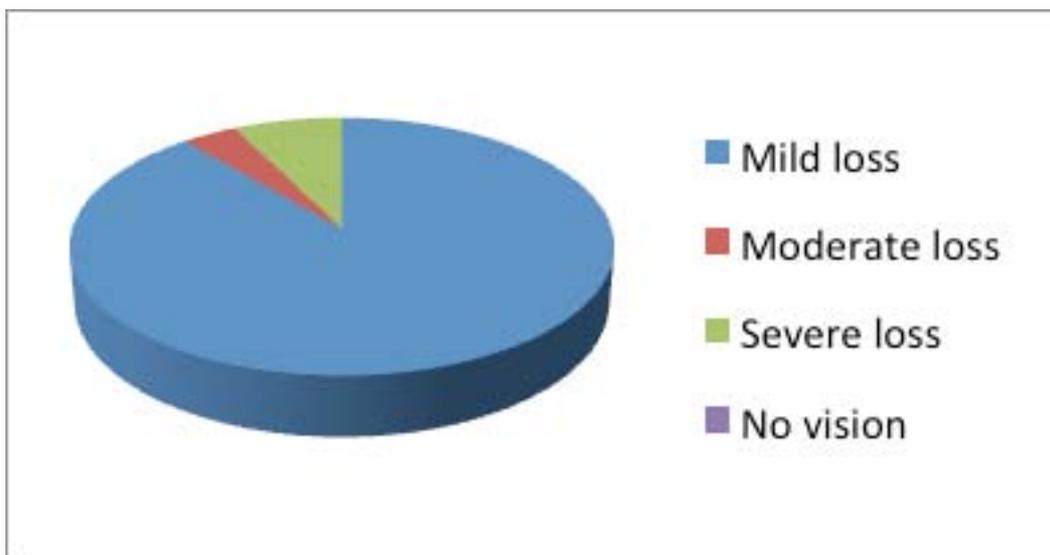


*Vision and common diagnoses:* with the data we have we can look closely at the level of vision within the 4 most common diagnoses. The graphs on the next page show the number of children who have mild, moderate, severe vision loss or no vision within each diagnosis:

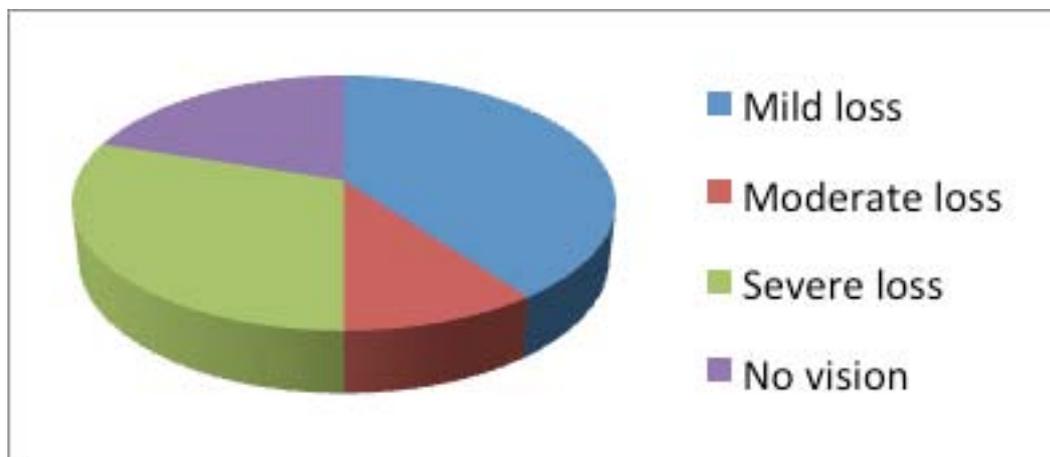
### Cortical Vision Impairment



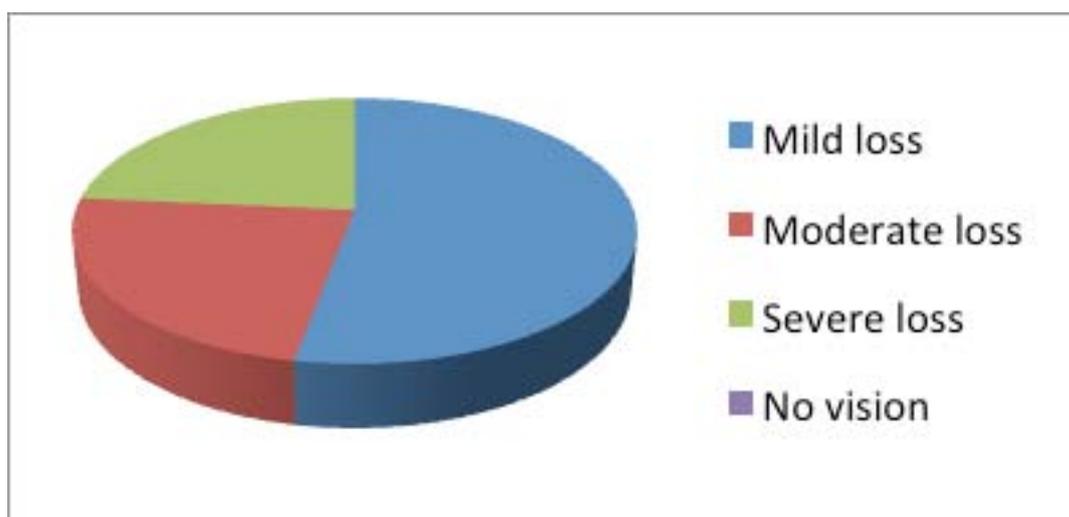
### Oculocutaneous Albinism



### *Optic Nerve Hypoplasia*



### *Congenital Cataract*



This data shows us that children with Cortical Vision Impairment are more likely to have severe vision loss; children with Oculocutaneous Albinism and Congenital Cataract have milder vision loss; and children with Optic Nerve Hypoplasia can have a range of vision loss. Children with Cortical Vision Impairment and Optic Nerve Hypoplasia are at greatest risk of having no vision.

And finally...spreading the word – we need your help!

We spend a lot of time asking groups and individuals to spread the word about the Register. We have wonderful support from Vision Australia, Guide Dogs Associations across Australia, Cando4kids, the Senses Foundation, other support agencies, Department of Education, Catholic Education Offices and independent schools across Australia. If you have contact with families with children with vision impairment please let them know about the Australian Childhood Vision Impairment Register. Families can go online at: [www.vifamilynetwork.org.au](http://www.vifamilynetwork.org.au) to find out more and how to register their child or contact us at [acvir@ridbc.org.au](mailto:acvir@ridbc.org.au). They can also call us on (02) 9872 0303.

With everyone's help we can continue to present accurate findings on this small but wonderful group of Australian children with vision impairment.

*Sue Silveira*

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