

The Australian Childhood Vision Impairment Register

March 2014 Update!

Welcome

Welcome to the March 2014 Newsletter for the Australian Childhood Vision Impairment Register. This is our 7th newsletter since the Register began and looking back to the first issue, it's interesting to see how things have changed as the number of registered children has grown. In January 2010 we had 149 children registered, and they lived in NSW, Victoria, South Australia and Western Australia. Today we have 965 registered and these children live across all states and territories of Australia.

Findings from the Register have been presented locally and internationally, at 16 conferences including those held in Australia, New Zealand and Canada. We have many support groups who continue to let families know about the Register. These include RIDBC, Guide Dogs, Vision Australia, Department of Education, Catholic Education and Independent Schools across Australia, private and public ophthalmologists and orthoptists, Carers Australia, Cando4kids, and Senses Australia. Thanks to staff of all of those organisations who have continued to distribute information on our behalf – this is our biggest challenge and we wouldn't have the numbers of registered children we have without your support. Once families know about the Register and decide to join we have a 98% return rate of the data form they complete on their child.

We're grateful to families for trusting us with the details of their child, which contribute so much to our understanding.



RIDBC
Renwick Centre
For Research and Professional Education

Why have a Register of Australian children with vision impairment?

Here are 4 excellent reasons for our Register:

- We know children with vision impairment and their families need specialised and broad based support – in health, education and general life
- We know children with vision impairment and their families need advocacy in a changing disability landscape
- International data is somewhat limited in reporting on childhood vision impairment – we could use what is available but, we are Australian and we are unique and should be reporting on our own children
- At the moment, in Australia, no other formal gathering of data is occurring on Australian children with vision impairment

What do families tell us?

In 2012 we asked families if they would like to provide us with feedback about their child's strengths, achievements and any other messages they have about their child and their experiences. Here are some of the thoughts that families have agreed we can share:

“Children and their family will learn to cope over time. When we reach a hurdle, we manage to find solutions, often which are simple and easy to implement.”

“The most important thing you can do for your child is to help them become resilient.”

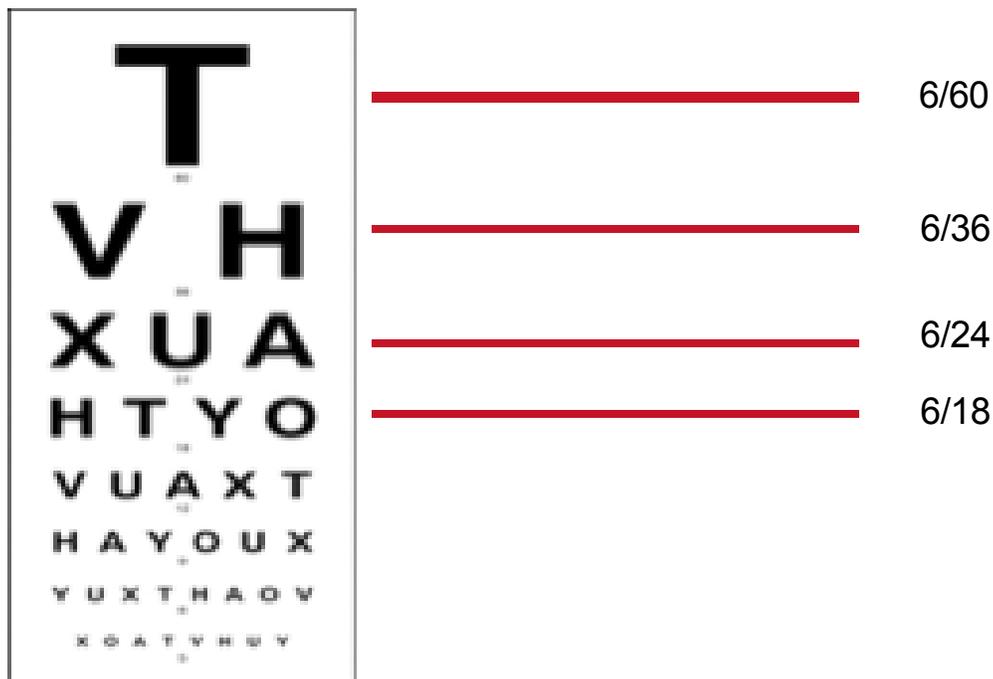
“A lot of people don't know a lot about vision impairment so we try wherever we can to educate people about our child's vision and particular needs.”

“Watch out – your baby will become a child, your child will become an adolescent and despite what you would like them to do to support their vision impairment, they may make different choices as they become the person they are destined to be. Take time to sit back, watch, support and advise, but don't impose your choices on them.”

Inclusion Criteria for the Register

For a child to meet what are known as the “inclusion criteria” for the Register, or visual standards they must have:

- Their vision impairment diagnosed by an ophthalmologist (eye doctor)
- Vision impairment in both eyes
- Their visual acuity or the finest detail they can see at a standard of 6/18 or less, when they are tested using both eyes at the same time and wearing their distance glasses or contact lenses, if prescribed. This level of visual acuity is demonstrated on the vision chart below.

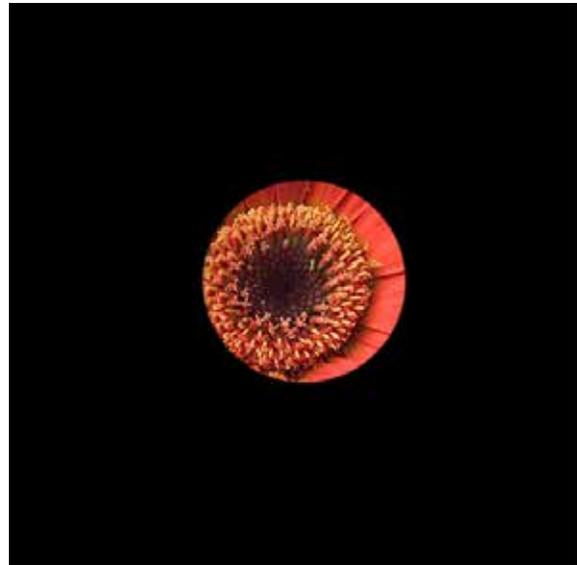


Example of Snellen Vision Chart

- Their visual field or peripheral vision reduced to 20 degrees or less, which is demonstrated in the diagram below.



Full visual field

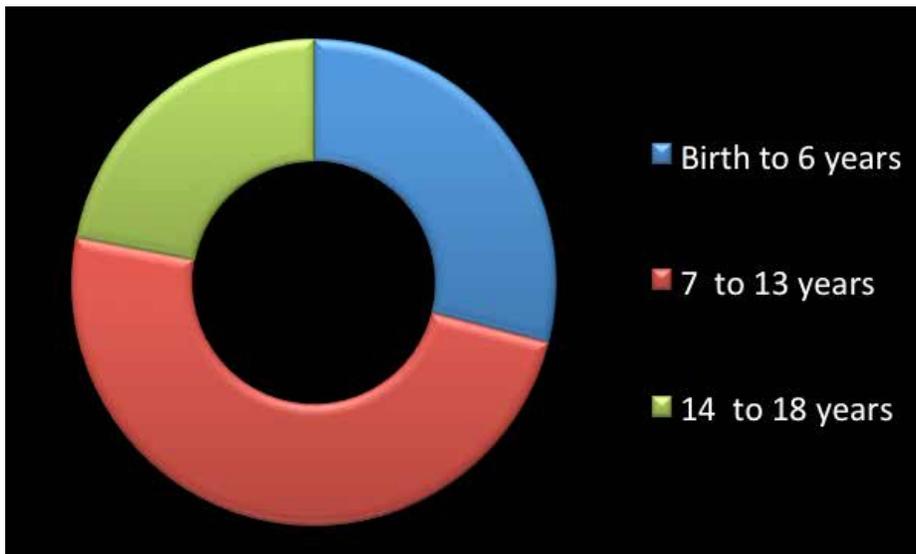


Visual field loss

- Any form of Cortical Vision Impairment

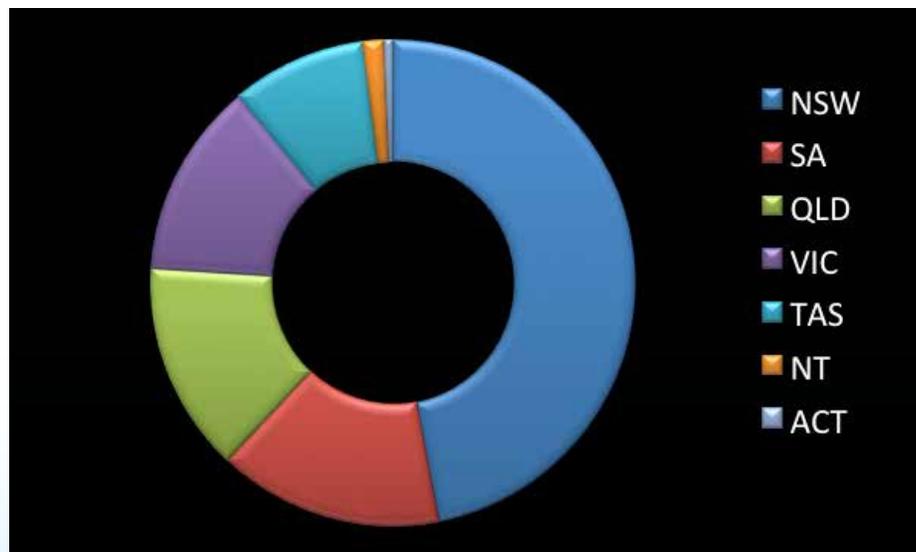
Ages of registered children

Children can be registered from birth to 18 years of age. The chart below shows the ages of registered children:



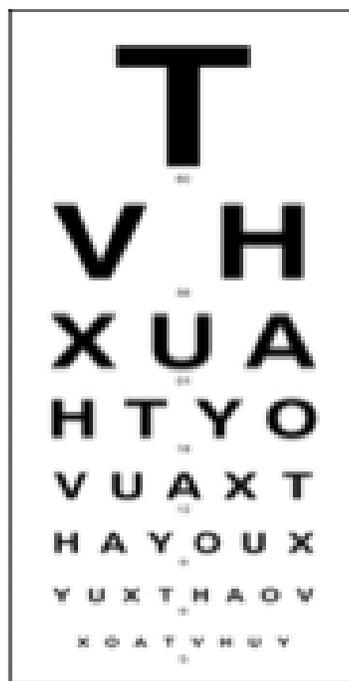
Where do registered children live in Australia?

The majority of registered children live in NSW. We need to be careful in how we interpret this as it may be that families in other states are not as aware of the Register as NSW families are. The chart below shows you where registered children live:



What is the range in visual acuity in registered children?

Visual acuity is tested in many ways in children, using different testing distances and different vision tests. When we think about having a vision test we usually think of reading letters on a vision chart. One of the most common vision charts is the Snellens Chart, which consists of a series of lines of letters, with more letters per line the smaller the letters get. We can use this chart to demonstrate one range of visual acuity recorded in registered children. This range is between 6/18 and 6/60. The red bracket on the Snellen chart below shows the lines involved – if a child reads any of the lines from the top to the 4th line down, with both eyes open, wearing their distance glasses or contact lenses, their visual acuity is in the range of 6/18 to 6/60.



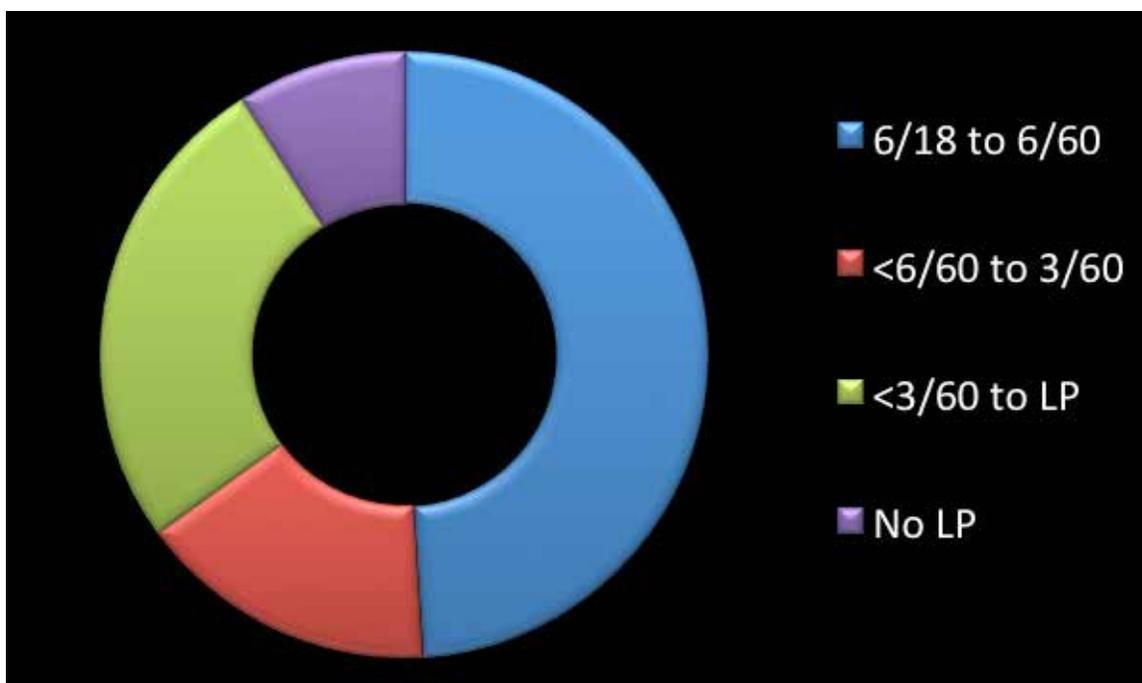
Visual acuity in the range of 6/18 to 6/60

49% of registered children have visual acuity in the 6/18 to 6/60 range.

The 6/60 letter is the top letter on the chart. Usually when this letter can't be read the distance visual acuity is tested at is reduced. The test is moved closer by one metre until the 60 sized letter can be seen. 16% of registered children have visual acuity in the range of <math><6/60</math> to

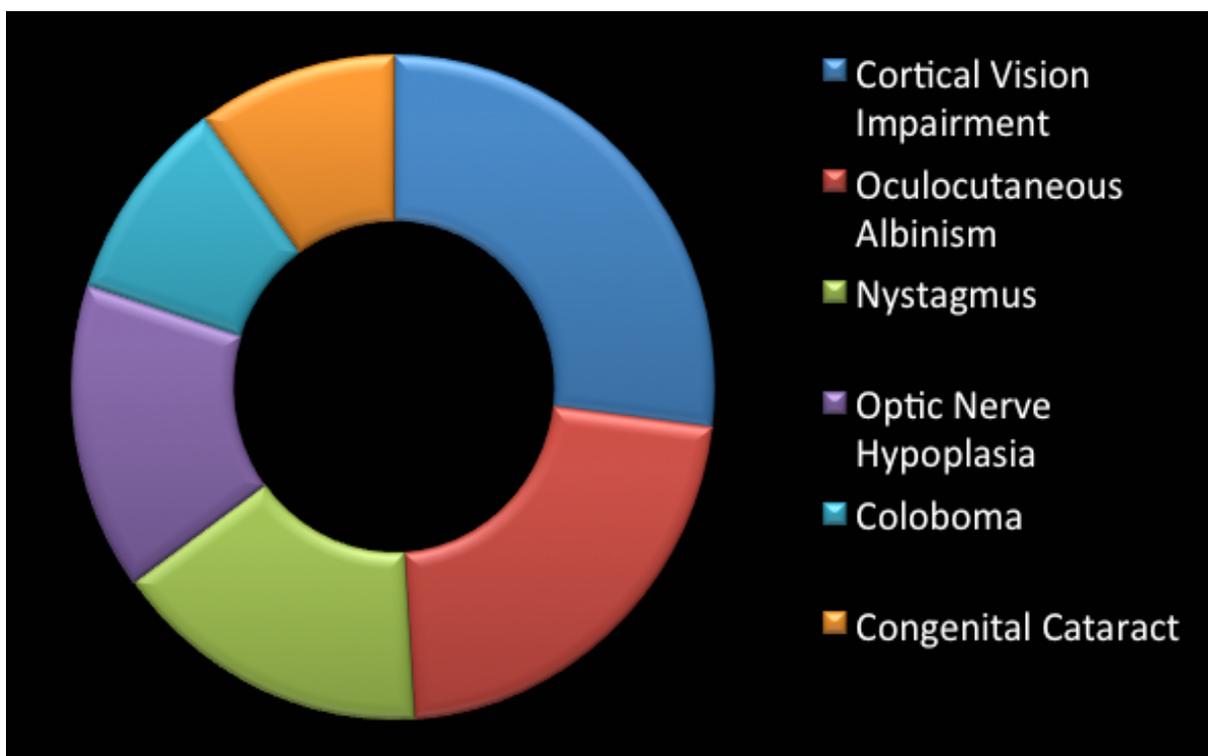
When the 60 sized letter can't be seen at 3 metres the test is moved closer, up to one meter away. Sometimes the 60 sized letter can't be seen at 1 metre, so other things are tried including if a light can be seen, known as light perception. 26% of registered children have visual acuity in the range of <math><3/60</math> to light perception.

And finally 9% of registered children don't have light perception. All of this information is combined in the chart below to show the ranges of visual acuity in registered children:



The most common conditions on the Register

Registered children have over 70 different diagnoses of eye and vision problems. The six most common conditions appear in the chart below:



Cortical Vision Impairment	27%
Oculocutaneous Albinism	22%
Nystagmus	16%
Optic Nerve Hypoplasia	15%
Coloboma	10%
Congenital Cataract	10%

Spotlight on Cortical Vision Impairment

Cortical Vision Impairment is the most common condition on the Register to cause vision impairment. It is also called Cortical Visual Impairment and Cerebral Visual Impairment. These names all refer to the same condition and indicate that the brain is involved in the vision impairment.

To understand Cortical Vision Impairment it will help to understand a little bit about how vision occurs. We are all aware that vision starts with the eyes which capture the image of the external world. The eyes convert this image into electrical signals which pass down the visual pathway to the visual cortex, located at the back of the brain. This area processes the visual information and passes it to many other important areas within the brain that rely on vision for function.

Cortical vision impairment results from damage to the visual cortex or other brain areas that process and use visual information. Common causes include brain damage as a consequence of premature birth such as a condition called Periventricular Leukomalacia; a lack of oxygen to the brain called Hypoxia; an infection of the brain called Encephalitis; an infection of the protective layers of the brain (or meninges) called Meningitis; a brain injury or bleed in the brain; and raised intracranial pressure called Hydrocephalus. Children with Cortical Vision Impairment often also have cerebral palsy, epilepsy and developmental delay.

Children with Cortical Vision Impairment may appear to have fluctuating vision, i.e. it seems they can see at some times and then not at others. This is thought to be due more to their attention rather than their vision fluctuating. How well they can see will be affected by things like their general well-being, and the impact of medication they may be taking.

There are some well recognised behaviours in children with Cortical Vision Impairment which can include:

- A tendency to use their peripheral vision rather than their central vision, i.e. they might look away from an object they are trying to reach
- A preference for looking at red &/or yellow objects

- Objects that are moving may be more interesting
- Difficulty discriminating objects when the background is cluttered
- An attraction to lights, with long periods of staring, or conversely, they may be light sensitive
- A preference for familiar objects, e.g. their dummy or bottle & avoidance of unfamiliar objects
- Difficulty with depth perception

And despite all of these visual difficulties, if they are mobile, children with Cortical Visual Impairment may be able to negotiate and navigate around obstacles in their path.

What resources are available for families on Cortical Vision Impairment?

Christine Roman-Lantzy has written some excellent books on Cortical Vision Impairment which families might like to source. The most recent book is available through the American Federation for the Blind at: <http://www.afb.org/store/Pages/ShoppingCart/ProductDetails.aspx?ProductId=978-0-89128-829-9&ruling=Yes>.

The British Journal of Visual Impairment published an interesting article titled “Problems experienced by children with cognitive visual dysfunction due to cerebral visual impairment and the approaches which parents have adopted to deal with these problems”. This article can be found at: <http://jvi.sagepub.com/content/24/3.toc>

Some of the tips they offer in the article include:

- Children with Cortical Vision Impairment tend to have vision that varies a lot.
- Try to make sure that everything they access suits their worst level of vision, so you know they should be able to see things.

- Make sure that colours are always bright and contrast is high
- Children with Cortical Vision Impairment take longer to see things, give them plenty of time
- It will be easier for them to see simple rather than complex things
- Be ready to educate everyone around you about what helps your child to see the best they can

Other helpful Cortical Vision Impairment resources can be found at the following websites:

Vision Australia

<http://www.visionaustralia.org/eye-health/eye-conditions/cortical-vision-impairment-%28cvi%29>

Texas School for the Blind

http://www.tsbvi.edu/index.php?option=com_googlesearch_cse&n=30&cx=015990192318971798441%3Axtzdnvn9ehw&cof=FORID%3A11&ie=ISO-8859-1&q=cortical+vision+impairment&sa=Search&hl=en&cr=countryUS

Perkins School for the Blind: <http://www.perkins.org/search/search.jsp?query=cortical+vision+impairment>

Visual Impairment Scotland: <http://www.viscotland.org.uk/eyeconds/cerebralvi.html>

American Federation for the Blind

<http://www.afb.org/info/living-with-vision-loss/eye-conditions/cortical-visual-impairment-traumatic-brain-injury-and-neurological-vision-loss/123>

Boston Children's Hospital

<http://www.childrenshospital.org/health-topics/conditions/cortical-visual-impairment>

American Association for Pediatric Ophthalmology and Strabismus

<http://www.aapos.org/terms/conditions/40>

Blind Babies America

<http://blindbabies.org/wp-content/uploads/2010/03/Fact-Sheet-CVI-REVISED-FINAL.pdf>

American Printing House for the Blind

<http://www.aph.org/cvi/define.html>

Courses offered by the Royal Institute for Deaf and Blind Children

RIDBC Renwick Centre is a centre for research and professional studies in the field of education for children with sensory disabilities. In partnership with the University of Newcastle, the RIDBC Renwick Centre provides a wide range of teaching and learning opportunities for professionals in the area of Special Education for students with hearing or vision impairment, research in these same areas, and related community service.

Each year the CPE Program offers a range of professional development opportunities in the areas of Hearing Impairment, Vision Impairment, Braille, Orientation and Mobility, and Multiple Disability through both face-to-face activities (seminars, workshops, conferences) and e-learning experiences. The CPE program is operated by the Centre as a service to the professional community in these small but highly specialised fields. Upcoming events can be located on the RIDBC Renwick Centre website: <http://www.ridbc.org.au/renwick/calendar-events>

The following events may be of interest to you:

Teaching Children and Adolescents with Vision Impairment Online Lecture Series (Last Friday of each month)

In this series of one-hour presentations, Dr. Karen Wolffe introduces listeners to areas of concern in the lives of children and youth with visual impairments that are often overlooked or under-represented in general education and home settings: Career Education, Social Skills, Recreation & Leisure, Transition, and Independent Living. While teachers and parents work hard to help children and adolescents integrate into academic classes and daily activities, they often report that there are not enough hours in the day to accomplish all that needs doing in areas that other children seem to master through observation – without direct instruction. This lecture series is designed to provide an overview of a special topic, strategies to teach relevant content, and resources for assessment and instruction.

Cost \$30 each or \$250 for all 10

More details and registration: <http://www.ridbc.org.au/renwick/cpe-event/social-skills-primary-and-secondary-students-vision-loss>

Social Skills and Strategies for Non Drivers with Vision Impairment (26th May)

Half Day: We're All Social: Ideas for Facilitating Social Development of Students with Visual Impairments

From the time a child is born social development is beginning with the first interactions the child has with family members. The focus of this session will be on an overview of how a visual impairment impacts the social development of children with visual impairment, methods of assessing social skills, and how to use information gained from assessment to facilitate a child's development of social skills. Participants will see photos and video clips that illustrate key points made by the presenter. They will complete several small group activities designed to assist them in taking information discussed and applying it to a

student with whom they work. Opportunity for discussion and questions will be provided throughout the session.

Half Day: When You Don't Drive Due to Vision Loss: Strategies for Succeeding in a Car-Oriented Society

We live in a society in which the majority of adults drive their own vehicles to get from place to place for employment, recreation, and meeting their basic needs. When one cannot drive due to a visual impairment, there are a wide range of skills that must be mastered to be a successful nondriver. These skills not only include orientation and mobility skills, but also skills that encompass social skills, visual efficiency, use of technology, and self-advocacy. During this session we will explore how families and professionals can begin preparing children to be nondrivers from the early years through their entire schooling experience. The curriculum *Finding Wheels* (Corn & Rosenblum, 2000) will be introduced and examples of students using the curriculum will be shared through photos and video clips. Several small group activities will enable participants to begin planning ways in which they can assist their students in becoming successful nondrivers. Opportunity for discussion and questions will be provided throughout the session.

Cost: \$50 for day

Registration and more information: <http://www.ridbc.org.au/renwick/cpe-event/social-skills-and-strategies-non-drivers-vision-impairment>

Developing Braille Literacy Skills for Young Children, Dual Readers, and Children with Additional Disabilities (27th May)

Developing a braille-rich environment and providing multiple opportunities to develop literacy skills for beginning braille readers of all ages, including those with multiple disabilities, is a comprehensive process. During this session photos and video clips will be used to demonstrate strategies teachers of students with visual impairments can use to facilitate acquisition of braille literacy skills by a variety of learners. We will explore Dr. Diane Wormsley's meaning-centered approach (previously called the functional approach) and how this individualized set of strategies can be used with a wide range of learners. Examples of

challenges experienced by some braille readers will be shared along with ideas to help these beginning braille learners meet the challenges and progress in their acquisition of literacy skills. A variety of individual and small group activities will be used to allow participants to practice the strategies being discussed. Opportunity for discussion and questions will be provided throughout the session.

Cost \$50 for day

Registration and more information: <http://www.ridbc.org.au/renwick/cpe-event/developing-braille-literacy-skills-young-children-dual-readers-and-children-additional>

Blended Technologies for Blended Learning (4-5th August)

Day 1: Blending Technologies for Blended Learning: Meeting the needs of our learners with severe and complex intellectual, physical and sensory challenges with technology.

Day 2: Appy Days: The iPad as a tool for teaching, learning and communication for students with severe and complex intellectual, physical and sensory challenges.

Cost \$100 for two days

Registration and more information: <http://www.ridbc.org.au/renwick/cpe-event/blended-technologies-blended-learning>

Please direct any enquires to Trudy Smith, Manager of Continuing Professional Education on (02) 9872 0302 or trudy.smith@ridbc.org.au

The VI Family Network

Don't forget to visit the VI Family Network at: www.vifamilynetwork.org.au. This is the hosting website for the Australian Childhood Vision Impairment Register and has lots of interesting resources and events regularly advertised and updated.

Our Facebook page

Don't forget to like us on Facebook! Our Facebook page provides updates and new content on the VI Family Network website, as well letting you connect with other members of the VI Family Network Community. To find us on Facebook, type in VI Family Network to the Facebook search bar.

Our contact details

We're always keen to meet our families and prospective families. We are easy to contact during business hours on (02) 9872 0248 or (02) 9872 0303. You can email us as well at: contactus@vifamilynetwork.org.au.

Wishing you and your family all the best for 2014.

Sue Silveira

Sue Silveira
JAFF Research Fellow
Renwick Centre, RIDBC