



**CATARACT
KIDS
AUSTRALIA**

**2017-18
ANNUAL REPORT**



Our mission

Working for the vision of kids with cataract

Our History

Cataract Kids Australia Ltd was established in July 2017 as a charity for childhood cataract, with the purposes of:

- a) developing and making available consistent, high-quality information about congenital cataracts and related conditions, including information about treatment, post-operative care, support services and available funding;
- b) educating and supporting families and carers of children with cataracts;
- c) identifying limitations in current clinical practice regarding cataracts and advocating for research and practice guidelines to improve and standardise clinical care;
- d) raising awareness about the need for research into management and treatment of cataracts, particularly tailored to the needs of children with cataracts and their families;
- e) assisting to disseminate the findings of high-quality research about cataracts; and
- f) liaising and partnering with tertiary hospital clinics, ophthalmologists, optometrists, orthoptists, support staff, service providers, researchers and research institutions.

CONTENTS

Our mission	2
Our history	3
Section 1 – An overview of Cataract Kids Australia	
About us	5
Our people	5
Section 2 – Governance	
Structure & management	6
Chairperson's report	7
Our Objectives and Activities	8
Section 3 – Our Finances	
Financial statements	11
Section 4 – Our other important information	
Acknowledgements	13
How you can help	14
Contact us	15

SECTION 1**AN OVERVIEW OF CATARACT KIDS AUSTRALIA****ABOUT US**

Families of babies and children whose vision is affected by cataracts face many challenges. They may feel isolated and unsupported, have difficulty in accessing appropriate care, and find the practicalities of managing their child's condition overwhelming. Cataract Kids Australia was founded by parents concerned about the impacts of these challenges on other families.

Our goal is ultimately to improve the visual outcomes of children with cataract. We aim to enhance the support and information provided to families, work with clinicians to optimise treatment outcomes and link with researchers to improve the flow of information.

OUR PEOPLE**Board members 2017-18**

Megan Prictor
*Founding Director and
Chair*



Susan Silveira
Director



Sonia Law
Director

SECTION 2**GOVERNANCE****STRUCTURE & MANAGEMENT**

Cataract Kids Australia Limited is registered with the Australian Charities and Not-for-profits Commission (ACNC). It is a company limited by guarantee; ABN 26619252130.

Cataract Kids Australia Limited is registered to fundraise in the following states and territories.

- NSW fundraising number: CFN/24854
- SA fundraising number: CCP3336
- TAS fundraising number: C/10513
- VIC fundraising number: FR-000014566

Fundraising registration is not required in the Northern Territory and Australian Capital Territory.



CHAIRPERSON'S REPORT

Megan Prictor



As Cataract Kids Australia celebrates its first year of operation, we reflect that over this period around 100 babies have been born in Australia affected by congenital cataract. This condition, which can impact one or both eyes of a newborn, or which may develop in the first months or years of life, can arise from heredity, trauma, infection during pregnancy, as part of a genetic syndrome, or in response to medication. Many infantile and childhood cataracts have no known cause. The diagnosis may come as a great shock to families, often in the first days or weeks of a baby's life.

For babies and children affected by cataract, treatment may simply involve patching, but commonly it requires surgical removal of the cataract-affected lenses. This is the start of a difficult and complex lifelong journey for these children and their families. It may involve parents learning how to insert and remove contact lenses from their infant's eyes each day; heroic efforts to persuade toddlers to leave their eye patch on; and support for school aged kids with vision impairment. It often necessitates more than one surgery, many eye drops, and regular surveillance for the signs of glaucoma which can lead to further vision impairment.

As a parent of a child affected by bilateral congenital cataract, I was motivated to establish Cataract Kids Australia in 2017 by not only my own family's story, but also the stories of other families and the health professionals caring for them. The rarity of the condition means that many caregivers feel isolated, especially around the time of diagnosis, initial surgery, and in the early months and years as they may struggle with contact lenses, glasses and patches. Health professionals practising in this field walk alongside families and provide the optimal care they can, but there is sometimes a lack of evidence to guide their decisions, and even within Australia, patterns of care may vary considerably.

Cataract Kids Australia aims to ensure that babies and children affected by cataract, and their families, have access to the best support and information available and are able to connect to the services they need. We aim to work with clinicians in support of their information and professional development needs, and to better connect both clinicians and families with those who conduct research into childhood cataract causes, diagnosis, treatment, and ongoing management. We hope that by working together - families, researchers and clinicians - we can achieve the best possible outcomes; not only the visual outcomes for our cataract kids, but also benefits for family wellbeing, clinical expertise and research relevance and impact.

Cataract Kids Australia has had a tremendous start. I am sincerely grateful to my fellow directors Sue Silveira and Sonia Law for their assistance and support. I thank everyone who has helped make this vision a reality.

A handwritten signature in black ink that reads "Megan J. Prictor". The signature is written in a cursive, flowing style.

Megan Prictor
PhD, LLB (Hons), BMus (Hons), MMus

OUR OBJECTIVES AND ACTIVITIES

Objectives	Activities and future plans
<p>a) High-quality information</p>	<p>We created a comprehensive website (www.cataractkids.org.au) which has been further developed since its August 2017 launch. The clinical information was reviewed by clinicians and families for accuracy and readability prior to publication. Family stories, events and new research papers are added regularly. The Cataract Kids Australia Facebook page helps to direct people to the website, as well as providing informational snapshots, and alerts to new research and new family stories. The Facebook page has 260 followers. Cataract Kids also regularly posts to the key Facebook groups, both in Australia and internationally, for parents of aphakic children.</p> <p>We promote the website to families and clinicians via social media and face to face events; we have also distributed 500 postcards to clinicians to give to new patients' families. The website averages around 1000 unique visitors each month.</p> <p><i>We plan to further update the website and promote it widely as a trustworthy source of high-quality information on childhood cataract.</i></p>
<p>b) Education and support to families</p>	<p>The Cataract Kids website includes a comprehensive list of resources for families including sources of financial and practical assistance from the government and not-for-profit organisations.</p> <p>We have provided one-on-one support to a number of recently diagnosed families.</p> <p>We held public events in Melbourne and Sydney (approximately 80 attendees at each) and participated in a Vision Australia Open Day in Melbourne. The Sydney event was live-streamed and recorded in its entirety to facilitate involvement by people in different locations.</p> <p>We are promoting a new educational resource for the general public to assist in early identification of vision problems ('Glint or Squint' handout)</p> <p><i>We are exploring a range of options to enhance the education and support available to families as Cataract Kids Australia grows. These may include further face-to-face events, webinars and videos, podcasts, and a buddy system for new families.</i></p> <p><i>We intend to conduct a formal assessment of the practical and informational needs of families of children diagnosed with cataract to inform our activities.</i></p>

Objectives	Activities and future plans
c) Advocating for improvements to clinical care	<p>Cataract Kids Australia has been involved in discussions with families and clinicians about the problem of late diagnosis of cataract.</p> <p><i>We plan to be involved in a project which will map diagnostic pathways, to identify the nature and extent of the problem of late diagnosis, with a view to pursuing further research, education and changes to clinical practice to help address this issue.</i></p>
d) Advocating for research tailored to families' needs	<p>We have built relationships with a range of researchers both in Australia and overseas as the first step towards this objective. We invite families to advise us on the research they would most value.</p> <p>We contributed to media activity in support of Dr. Michael O'Connor's stem cell research in early 2018.</p> <p><i>In addition to the diagnostic pathways project described above, we plan to conduct a formal research priority setting exercise involving families.</i></p>
e) Disseminating research findings	<p>We use our website and social media to highlight journal articles reporting on well-conducted research relevant to childhood cataract. We have successfully negotiated with journal publishers to permit open access via our website to a number of 'paywalled' articles.</p> <p>We have included speakers from diverse research fields at our Melbourne and Sydney events who have discussed the latest research into the timing of intraocular lens placement, the need for better education of maternal and child health nurses in the red reflex test, and new developments in stem cell research.</p> <p><i>We plan to build the existing research listing on our website into a more comprehensive collection, organised by topic areas.</i></p> <p><i>We will consider other options for disseminating research findings, and engaging families and researchers, such as a research showcase.</i></p>
f) Building partnerships	<p>In our first year of operation, Cataract Kids Australia has established valuable connections with researchers, optometrists, orthoptists, ophthalmologists and support staff, hospital clinics and other not-for-profit organisations in the field of vision impairment, both Australia and overseas. These are listed in this Report at Acknowledgements. Our face-to-face events, held in Melbourne and Sydney in 2018, successfully brought together the different childhood cataract 'communities' and strengthened links with them.</p> <p><i>We will continue to build existing relationships and seek to establish new partnerships with key stakeholders in the childhood cataract field.</i></p>

Objectives	Activities and future plans
<p>Operational objectives</p>	<p>In 2017-18 Cataract Kids Australia was registered as a company and a charity, obtaining tax-exempt and deductible gift recipient status. We obtained fundraising registration in five states, set up an online fundraising platform (GiveNow), and established our core operational and finance systems.</p> <p>Our communications mechanisms were set up; these include our website, email, social media sites, and promotional material for public events.</p> <p>We have acquitted the requirements of registration with the Australian Charities and Not-for-Profits Commission including submitting an annual information statement for 2017-18.</p>

SECTION 3**OUR FINANCES****FINANCIAL STATEMENTS 2017-18****Income/receipts**

Donations and bequests:	\$5,765.00
Revenue from government including grants:	\$0.00
Revenue from providing goods or services:	\$0.00
Revenue from investments:	\$5.00
Other revenue/receipts:	\$0.00
Total revenue/receipts:	\$5,770.00
Other income (for example, gains):	\$0.00
Total income/receipts:	\$5,770.00

Expenses/Payments

Employee expenses/payments:	\$0.00
Grants and donations made for use in Australia:	\$0.00
Grants and donations made for use outside Australia:	\$0.00
Other expenses/payments:	\$3,139.00
Total expenses/payments:	\$3,139.00
Net surplus/(deficit):	\$2,631.00

Note: As a 'small' charity (see <https://www.acnc.gov.au/tools/topic-guides/charity-size>) Cataract Kids Australia is not obliged to have its financial statements reviewed or audited..



Images: Sarah Craven Photography

SECTION 4**OUR OTHER IMPORTANT INFORMATION****ACKNOWLEDGMENTS**

The establishment and success of Cataract Kids Australia would not be possible without the generous donation of time, expertise, goods and services by many people. We thank the following organisations and individuals for their assistance and support.

**Ophthalmology Department, Royal
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Children, Sydney**
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Fred Hollows Foundation
Essilor Foundation
Parents of Vision Impaired, New Zealand
Orthoptics Australia
Kids Eye Gear

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Subcon Pty Ltd
Jenny Cummings
Tobias and Elizabeth Cummings
Jessica Kaufman
Damien Pearse
Sabrina Gonsalves
Gladys McGown

HOW YOU CAN HELP

Volunteer your time

Cataract Kids Australia welcomes the input of volunteers, for administrative support, research, events, communications and fundraising. Interested in contributing? Email info@cataractkids.org.au

Make a donation

Financial donations are gratefully received. All donations over \$2 are tax-deductible. Visit our [GiveNow page](#).

Hold a fundraising activity

Our website supports 'Crowdraisers' where you can raise funds for Cataract Kids Australia by an activity you choose – for instance, a morning tea, a sponsored walk or fun run, a bike ride or a cake stall. Visit <https://www.givenow.com.au/crowdraiser> to set up your activity and receive donations for Cataract Kids.

Host an event in your location

We'd love to hold more face-to-face events all over Australia, bringing together families, researchers and clinicians to discuss best-practice treatment, cutting edge research, and the support that families need. If you'd like to help organise a local event, please contact us.

Become a corporate partner

Cataract Kids Australia benefits from relationships with corporate Australia; corporate partners benefit too. More than just a donation, your partnership will help us work for a better vision for kids with cataracts. Contact us for more information.



Image: Sarah Craven Photography

CONTACT US

Email info@cataractkids.org.au

www.cataractkids.org.au

facebook.com/cataractkidsaustralia/

twitter.com/CataractKidsAus

instagram.com/cataractkidsaustralia

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