



**CATARACT
KIDS
AUSTRALIA**

**2021-22
ANNUAL REPORT**

Our mission

Working for the **vision** of kids with cataract



Image credit: Sarah Craven Photography

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.

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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.

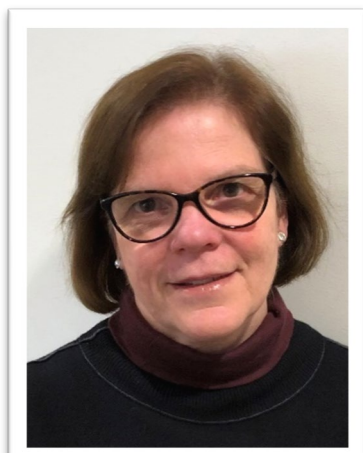
Our goal is ultimately to improve the visual outcomes of children with cataract. We aim to enhance the support and information provided to families, work with clinicians to optimise treatment outcomes and link with researchers to improve the flow of information.

OUR PEOPLE

Board members 2021-22



Megan Prictor
*Founding Director and
Chair*



Susan Silveira
Director



Anu Mathew
Director

"Cataract Kids Australia is committed to providing a forum for parents with children with cataract and to empower them with knowledge through online resources, discussion groups and expert Q & A sessions. As a clinician, I find CKA a valuable resource for my patients' families as they navigate the difficult journey with childhood cataracts and all the consequences that come with treatment."

Dr. Anu Mathew, Director

SECTION 2**GOVERNANCE AND ACTIVITIES****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: FR0014566



In the ACT, charities registered with the ACNC are exempt from requiring a license to fundraise in the ACT. Fundraising licenses are not required by the Northern Territory Government.

"The impact of the global COVID-19 pandemic has seen disruption to health provision across Australia, including essential services related to the identification and treatment of congenital cataract. Through this difficult time, Australian health professionals and Cataract Kids Australia have committed to ongoing treatment, support and advocacy for families. A new initiative called the Paediatric Vision Impairment Alliance has emerged, with Cataract Kids as a founding member. The Alliance members include support groups across all forms of childhood eye disease, and leaders in education, research and eyecare. This Alliance will advocate for Australian children with vision loss, to influence policy that addresses identified unmet and emerging health and education needs. The Alliance will focus on sharing resources that educate parents, carers, community and clinical staff to ensure children with vision impairment live life to its full potential. Cataract Kids is an active member of the Alliance and will represent families of children with cataract."

Dr Susan Silveira, Director

CHAIRPERSON'S REPORT

Megan Prictor



I'm delighted to have served as Director and Chair of Cataract Kids Australia again in 2021-22; a year in which we are (continually!) finding our feet in the latest phase of the COVID pandemic. Some particular highlights have been our monthly Zoom catch-ups, which have reached new families as well as those a little further along the journey; and presentations by expert speakers from across the country on topics critical to families of children affected by cataract.

We've also expanded on our successful 2021 pilot of practical financial support, our CKA Microgrants, increasing both the value and number of grants available to families. We know that many families are doing it tough – all of those eye patches, spectacle frames and contact lenses really add up. It is really pleasing to be able to help with many expenses that are not covered by any other source, and we are so grateful to our many financial supporters who make these grants possible.

Some of the other highlights this year include supporting publication of a picture book, *Rabbit's Special Eyes*, written by an Aussie parent and sibling of a little boy affected by this condition. It's a great read for our little cataract and patching people, ages 2-8 - do check it out! We also received a kind donation of many copies of another gorgeous picture book, *Afloat in Venice* by Australian author Tina Wilson, accompanied by an audio CD, which many of our families have got to enjoy – thank you so much Tina for your generosity.

One of the best things about getting Cataract Kids Australia off the ground, back in 2017-18, was the opportunity to bring people together in person, and I'm delighted that we are taking cautious, COVID-safe steps to do so again. In October 2022 we'll attend the major professional conferences of Orthoptics Australia and the Royal Australian and New Zealand College of Ophthalmologists in Brisbane, and take the opportunity to host a fun event in Brisbane for families too. When my own baby was diagnosed and we were struggling with contact lenses, that sense of isolation was very hard. So while Cataract Kids devotes a lot of attention to advocacy, community awareness, practical support, and elevating research, providing a space to bring 'our' families together for mutual support is perhaps the most rewarding – and certainly the most fun - thing we do.

Thanks as ever to the remarkable Susan Silveira and Anu Mathew who give their time, energy and passion to Cataract Kids Australia as Board members, and to the many eyecare professionals, researchers, community advocates and families from across the country who walk alongside us.

A handwritten signature in cursive script that reads "Megan J. Prictor".

Megan Prictor, Founding Director

OUR OBJECTIVES AND ACTIVITIES

Objectives	Activities and future plans
a) High-quality information	<p>We have maintained our comprehensive website (www.cataractkids.org.au) which has been further developed to include more links to resources for parents. The Cataract Kids Australia Facebook page helps to direct people to the website, as well as providing informational snapshots, and alerts to new research, family stories, funding opportunities and the monthly meetings. The Facebook page has 705 followers. Cataract Kids also regularly posts to the key Facebook groups, both in Australia and internationally, for parents of aphakic children. We promote the website to families and clinicians via social media, online and face to face events.</p> <p>In 2021-22 we advanced our messaging to promote early diagnosis through significant mainstream media, involving families from the Australian cataract kids community.</p> <ul style="list-style-type: none"> • Lauren Roberts, 'Australian parents urged to be on lookout for early signs of cataracts in babies', ABC News (Lauren Roberts): 8 July 2021. https://www.abc.net.au/news/2021-07-08/cataracts-and-kids-parents-urged-to-be-on-lookout-for-warnings/100274468 • Nadia Soley, 'My baby was born with cataracts' <i>That's Life</i> 2 Dec. 2021. • Alex Chapman, 'Zara was only three days old when she was diagnosed with an eye condition usually associated with people decades older' 7News.com.au, 25 June 2022. https://7news.com.au/lifestyle/real-life/zara-was-only-three-days-old-when-she-was-diagnosed-with-an-eye-condition-usually-associated-with-people-decades-older-c-7273620 <p><i>We will continue to update the website and promote it widely as a trustworthy source of high-quality information on childhood cataract. We will continue our pursuit of engagement with various media outlets to promote the key messaging around early diagnosis and awareness-raising of childhood cataract.</i></p> <p><i>In October 2022 we plan to host a public event in Brisbane, disseminating high-quality information to families and the wider community.</i></p>
b) Education and support to families	<p>Our key initiative in this domain in 2021-22 has been the expansion of our successful Microgrants scheme for families of children affected by cataract. In 2021 the scheme provided grants of \$100 per child per calendar year, for any expense related to the condition.</p> <p>Although \$3000 had been allocated to pilot test the scheme, through generous donations we were able to maintain it for the full calendar year, providing 40 grants (\$3997.21) in total in 2021. The scheme was expanded to \$150 per child per year for 2022, and from January to June 2022 16 grants totalling \$2349.96 were awarded.</p>

This funding scheme is purposefully designed to cover a wide range of expenses including eye patches, contact lenses, spectacles, out of pocket specialist costs, arm immobilisers, eye drops and even hospital parking fees. This is in recognition of the variety of costs affecting families of children with cataract that are not recoverable from any other source. Grants paid in the first half of 2022 were primarily for patches.

Throughout 2021-22 we have continued to host a **monthly 'Cataract Kids Catch-Up' online via Zoom**, which is open to anyone interested; these have been very popular with families of both newly-diagnosed and older children and attended by people across the country. They have been a valuable forum for sharing experiences and ideas, providing reliable information and problem solving. Some children have also enjoyed being able to see others wearing eye patches or glasses. We will continue these regular meetings and go on promoting them to the community.

Interspersed between monthly Zoom calls we have hosted the following **guest speakers for a series of 'Expert Q&As'**.

- Dr Anu Mathew, RCH Melbourne, *IOLs and kids with cataract*: May 2022.
- Theresa El-Weddy, NextSense, *NDIS and children with cataract*, November 2021.
- Cathy Lewis, RCH, and Natalia Kelly, La Trobe University/Vision Matters: *Vision testing in babies and children*, July 2021.

The Cataract Kids website includes a comprehensive and up-to-date list of resources for families including sources of financial and practical assistance from the government and not-for-profit organisations.

We provided **one-on-one phone and email support** to a number of families of both newly-diagnosed and older babies and children affected by cataract.



We supported two other important initiatives for young children affected by cataract.

In one, multiple copies of a new picture book 'Afloat in Venice' with an accompanying audio CD were kindly donated by author Tina Wilson. We arranged their free distribution to 20 lucky families.



In another, east coast mum Kathy Thach, with her daughter Amanda, wrote and illustrated a beautiful picture book 'Rabbit's Special Eyes' in honour of Amanda's brother who was born with cataract. Amanda said 'I hope that this story will bring positive messages to families of children with congenital cataract and those who require patching. This book also helps to build awareness and understanding about patching therapy.'

Cataract Kids Australia contributed financially to the book's publication, and thanks to the generosity of Kathy and the community, has secured multiple copies to give away at upcoming events. This book is available for purchase at <https://www.doctorzed.com/books/rabbits-special-eyes/>.

We are exploring a range of options to enhance the education and support available to families as Cataract Kids Australia grows.

c) Advocating for improvements to clinical care

In 2021-22 we continued to work on the issue of **late diagnosis of congenital and childhood cataract**. The clinical audit mapping the diagnostic pathways of children presenting with cataract to the Royal Children's Hospital Ophthalmology department is ongoing. We are grateful to Dr. Sandra Staffieri and colleagues for leading this research, which was reported in *Insight* magazine in June 2022 (<https://www.insightnews.com.au/research-partnership-for-childhood-cataract-diagnosis/>).

We will continue to pursue further research and policy activities to help address the problem of late diagnosis.

We were also invited to prepare a video on childhood cataract and the patient/family experience for Doctor of Optometry students at the University of Melbourne (May 2022), in addition to the video previously prepared for Orthoptics students at La Trobe University.

<p>d) Advocating for research tailored to families' needs</p>	<p>We continue to be involved in clinical audits in Melbourne and Sydney to map diagnostic pathways (see above).</p> <p>We provided a \$500 bursary to support a research orthoptist working on the RCH clinical audit (matching a Lions Club bursary).</p> <p>Megan Pictor peer reviewed several systematic reviews of paediatric vision interventions for the Cochrane Eyes and Vision group and joined the group's Editorial Board.</p> <p>We also endorsed funding applications by Assoc. Prof. Michael O'Connor (Western Sydney University) to progress cutting-edge research on stem cell lens replacement technology.</p> <p><i>We will advocate for research that is tailored directly to the needs of children affected by cataract in Australia, with a short-term focus on early diagnosis.</i></p>
<p>e) Disseminating research findings</p>	<p>We continue to use our website and social media to highlight journal articles reporting on well-conducted research relevant to childhood cataract. Recent presentations by clinical ophthalmologists in our Expert Q&A sessions have emphasised important research on which clinical decision-making relies.</p> <p><i>We will consider other options for disseminating research findings, and engaging families and researchers, such as a research showcase.</i></p>
<p>f) Building partnerships</p>	<p>Cataract Kids Australia is a founding member of the Paediatric Vision Impairment Alliance, an umbrella organisation established in late 2019 bringing together entities including Usher Kids Australia, CVI Community Australia, CHARGE Syndrome Australasia, the Children's Tumour Foundation of Australia and Batten Disease Support and Research Association Australia, as well as key individuals, to advocate for children with vision impairment of all types.</p> <p>This Alliance is initially working to improve the responsiveness of the National Disability Insurance Scheme to our community. Megan Pictor contributed to the latest <i>Insight</i> article on the Alliance (https://www.insightnews.com.au/paediatric-vision-impairment-alliance-forms-for-common-cause/, 15 July 2022).</p> <p>Cataract Kids Australia continues to establish and build upon our 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 <i>Acknowledgements</i>.</p>

f) Building partnerships (cont'd)

In January 2022 we signed an updated **Memorandum of Understanding (MOU) with Orthoptics Australia (OA)**, to work together to deliver a uniform message to the public, the professions, government, and other stakeholders on matters concerning children with cataracts. In this MOU, OA recognised and committed to supporting Cataract Kids Australia as a peak body committed to making a difference to those families whose children have cataracts. The outputs of this agreement (in place since the previous year) have included publication of material about Cataract Kids Australia in the OA newsletter and website, including: Megan Pictor and Sandra Staffieri, 'Research partnership for childhood cataract diagnosis' *Insight News* 21 June 2022 (<https://www.insightnews.com.au/research-partnership-for-childhood-cataract-diagnosis/>).

We are grateful to OA for this opportunity to increase awareness of our organisation, and childhood cataract more broadly, amongst their membership. We were delighted to sponsor the OA 77th Annual (Virtual) Conference in February 2022 and the upcoming 78th Annual Conference to be held in Brisbane in October 2022.

We will continue to build existing relationships and seek to establish new partnerships with key stakeholders in the childhood cataract field.



Emily and friend

(Image credit: Ashlee Kalinic)

SECTION 3

OUR FINANCES

FINANCIAL STATEMENTS 2021-22

<u>Balance brought forward from 30 June 2021</u>	\$10261.48
<u>Income/receipts</u>	
Donations and bequests:	\$8061.96
Revenue from government including grants:	\$0.00
Revenue from providing goods or services:	\$0.00
Revenue from investments:	\$1.26
Other revenue/receipts:	\$0.00
Total revenue/receipts:	\$8063.22
Other income (for example, gains):	\$0.00
Total income/receipts:	\$8063.22
<u>Expenses/Payments</u>	
Employee expenses/payments:	\$0.00
Grants and donations made for use in Australia:	\$5349.41
Grants and donations made for use outside Australia:	\$0.00
Other expenses/payments:	\$1979.03
Total expenses/payments:	\$7328.44
Net surplus/(deficit):	\$10,996.26

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. It complies with requirements to submit an Annual Information Statement to the Australian Charities and Not-for-profits Commission.



If you notice:

- a white spot on child's pupil, or
- crossed eyes, turned eyes or wandering eyes after a couple of months of age (even if it only happens sometimes)

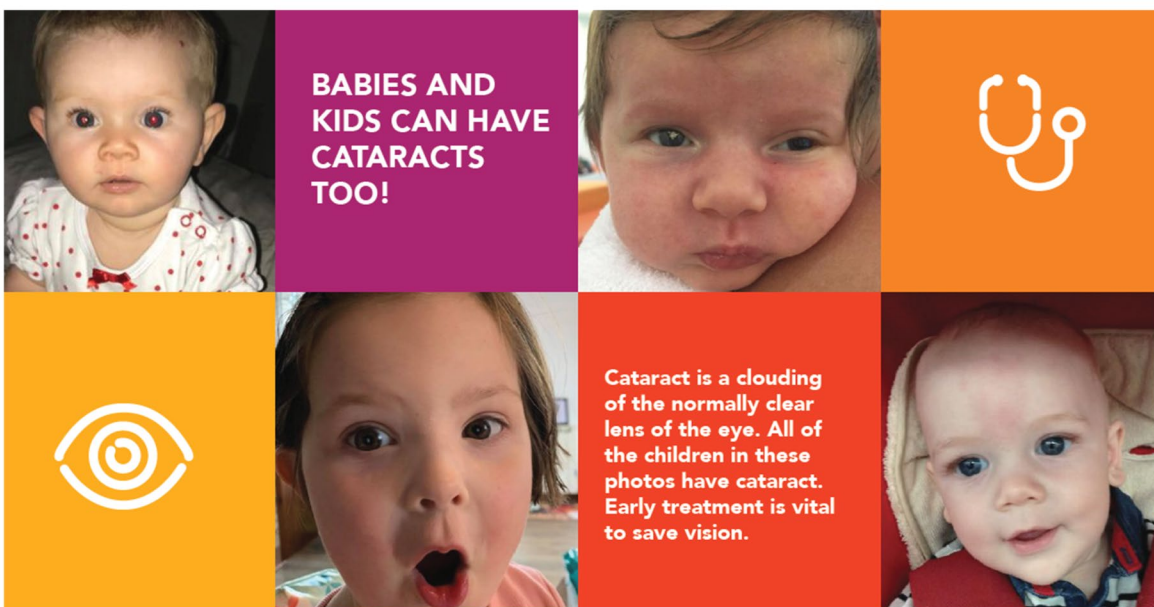
see your GP or local optometrist without delay.



CATARACT
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AUSTRALIA



www.cataractkids.org.au



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CATARACT
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AUSTRALIA



www.cataractkids.org.au

SECTION 4**OUR OTHER IMPORTANT INFORMATION****ACKNOWLEDGEMENTS**

The success of Cataract Kids Australia would not be possible without the generous donation of time, expertise, goods and services by many people. **In 2021-22 we particularly thank Anu Mathew, Sue Silveira, Sandra Staffieri, Louise Brennan, Natalia Kelly, Theresa El-Weddy, Tina Wilson, Kathy Thach, and Antony Clark.**

We also thank the following organisations and individuals for their assistance and support.

Ophthalmology Department, Royal Children's Hospital Melbourne	Kids Eye Gear
Richard Lindsay & Associates Optometry	Centre for Eye Research Australia
Ophthalmology Department, Westmead Children's Hospital Sydney	Save Sight Institute
NextSense, Sydney	Paediatric Vision Impairment Alliance Australia
Orthoptics department, La Trobe University	Arnold Bloch Leibler lawyers
Orthoptics Australia	Carla Silveira Design
Eyetechn Optometrists	Sarah Craven Photography
	Australian Charities and Not-for-Profits Commission
	Usher Kids Australia

We thank our generous financial donors, without whose help our work would not be possible.

Our anonymous donors	Daniela Colledani	Josie Crea
Jane Schuller	Phillip Barneyt	Brendan Smith
Heather O'Leary	Michelle Prasad	Merrin Pictor
Hima Mariam Jose	Nicolas Mersiades	Darren Camilleri
Stephanie Puris	Jasmina Ribarovska	Michael Huckle
Marco Faccio	Mariolena Lambrellis	Vesna Sivevski
Jutharmart Natthanyanop	Dominic O'Brien	Etta Biondo
Sandra Staffieri	Vasko Vancev	Erin Trebley
Jacob Craven	Gail Weckert	Bill Kontoulis
Damien Pearse	Bronne Drabsch	Jenna Petkov
Nicola Rivett	Claudia Ahern	Jennifer Gulbransen
Diaa Ahmed	Lisa Picking	Emma Lampard
Philip Saikaly	Helen Corry	Mike Merritt
Natalie Dimovski	Joy Clulow	Rob Ruxton
	Dianne Lowe	Julie Hawkins
	Christina Validakis	Ellie Kreutzberger
	Mel Thomas	Robyn Cavendish

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@catarackids.org.au

Make a donation

Financial donations are gratefully received. All donations over \$2 are tax-deductible. Visit our [GiveNow page](#) or donate on Facebook via the [PayPal Giving Fund](#).

Hold a fundraiser

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.



Image: Sarah Craven Photography

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.

CONTACT US

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facebook.com/catarackidsaustralia/
twitter.com/CataractKidsAus

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