



**CATARACT  
KIDS  
AUSTRALIA**

**2020-21  
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. 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 2020-21**

Megan Pictor  
*Founding Director and  
Chair*



Susan Silveira  
*Director*



Anu Mathew  
*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: 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.



## CHAIRPERSON'S REPORT

### Megan Prictor



The ongoing impact of the COVID-19 pandemic has affected individuals and organisations nationally and internationally very deeply during 2020-21, and we send our warmest wishes to each of you weathering this storm.

Nonetheless, there have been many wins for Cataract Kids Australia over this period. The monthly online gatherings we introduced early in 2020 as a stop-gap measure have become a wonderful permanent fixture. These free Zoom meetings have provided families from disparate locations with the opportunity to connect with Cataract Kids Australia and, more importantly, with each other, every few weeks. Families' contexts and experiences differ but all value the opportunity to connect, ask questions, check their understanding and talk with others who just 'get it'. I'm grateful

to Ashlee Kalinic for hosting some of these meetings with her beautifully friendly and supportive style.

These regular informal events have helped to build our community as well as helping our organisation to see where more help and information are needed. As a result, we have introduced several 'Expert Q&A' sessions which have proved highly popular, with discussions about new research into stem cells for cataract, and patching and visual acuity testing.

I'm extremely proud of Cataract Kids' 2021 introduction of practical financial support to families, with the launch of a Microgrants programme. We are piloting the provision of small grants to families for any costs associated with the care of children with cataracts that are not recoverable from another source.

Our media engagement has also chalked up some notable wins this year, with significant mainstream media in December 2020 and in June 2021 for Global Cataract Awareness month. Our work has resulted in ABC radio and online stories and a Channel 7 news story in the evening bulletin, helping to raise community awareness about childhood cataract and in particular the warning signs that can aid early diagnosis.

In terms of organisational impact we are also cementing our role as the peak body representing childhood cataract. We signed a Memorandum of Understanding with Orthoptics Australia and became a foundation member of the national Paediatric Vision Impairment Alliance.

Although sometimes we still feel like the new kid on the block, next year will mark 5 years since Cataract Kids Australia was established, and on a personal note, 8 years since my son was born with bilateral cataracts. I am profoundly grateful to everyone who has helped smooth the path; in particular Peter Seidel from Arnold Bloch Leibler, my fellow Directors Dr. Susan Silveira and Dr. Anu Mathew; my own family; every parent who has trusted Cataract Kids to support them; and absolutely *everyone* who has pitched in – whether by donating money, giving advice, spending time on the phone or Zoom, making sandwiches, pitching an *actual* tent back in times we could meet together, or sharing your personal stories with our community and the wider world. Last year I wrote that Cataract Kids was making a difference. This year I recognise it is really all of you.

A handwritten signature in black ink 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 <b>our comprehensive website</b> (<a href="http://www.cataractkids.org.au">www.cataractkids.org.au</a>) which has been further developed to include more links to resources for parents. The Cataract Kids Australia <b>Facebook page</b> 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 640 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><b>In 2021 we advanced our messaging to promote early diagnosis through printed posters and significant mainstream media.</b> There were ABC radio and online stories in December 2020 and July 2021, and a Channel 7 News story in June 2021. Director Megan Pricor wrote an article for 'Your Child' magazine published in July 2021 and recorded a Renwick Centre (now NextSense) podcast that was released in November 2020.</p> <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 2022, pandemic permitting, we plan to host 1-2 public events to disseminate additional high-quality information to families and the wider community.</i></p>
b) Education and support to families	<p><b>Our key initiative in this domain in 2021 has been the launch of a new Microgrants scheme for families of children affected by cataract.</b> This scheme provides grants of \$100 per child per year, for any expense related to the condition. As a 2021 pilot scheme, we set aside \$3000 to fund the Microgrants. By 30 June, some 20 grants totalling \$1997.76 had already been claimed.</p> <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. The first 20 grants were for:</p> <ul style="list-style-type: none"> <li>• Out of pocket costs for specialist visits (6)</li> <li>• Patches (5)</li> <li>• Contact lenses (4)</li> <li>• Glasses (4)</li> <li>• Eye drops (1)</li> </ul> <p>The success of the scheme in 2021 means that Cataract Kids Australia hopes to expand on it in future years.</p>



	<p>Throughout 2020-21 we have continued to host a <b>monthly ‘Cataract Kids Catch-Up’ online via Zoom</b>, which is open to anyone interested; these have been very popular with families of both newly-diagnosed and older children and attended by people from South Australia, Queensland, the Australian Capital Territory, Northern Territory, Victoria and New South Wales. 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.</p> <p>Building on these monthly Zoom calls we have hosted the following <b>guest speakers for a series of ‘Expert Q&amp;As’</b>.</p> <ul style="list-style-type: none"> <li>• Dr. Michael O’Connor, Western Sydney University: <i>Stem cells and cataracts</i> (November 2020)</li> <li>• Cathy Lewis (Royal Children’s Hospital): <i>Patching</i> (April 2021)</li> <li>• Cathy Lewis (RCH) and Natalia Kelly (La Trobe University / Vision Matters): <i>Vision testing in babies and children</i> (July 2021)</li> </ul> <p>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.</p> <p>We provided <b>one-on-one phone and email support</b> to a number of families of both newly-diagnosed and older babies and children affected by cataract.</p> <p>We added to our <b>collection of videos of contact lens insertion and removal</b>, involving children of different ages, on the <b>Cataract Kids YouTube channel</b> at <a href="https://bit.ly/CKAvid">https://bit.ly/CKAvid</a></p> <p>We continue to promote an <b>evidence-based educational resource for the general public</b> to assist in early identification of vision problems (‘Glint or Squint’ handout)</p> <p>Finally, as an additional service to families, in 2020 the Board agreed <b>to list private providers of low vision services on our website</b>. Orthoptists are welcome to request listing with us if they are registered with both the Australian Orthoptic Board and the National Disability Insurance Scheme.</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><b>c) Advocating for improvements to clinical care</b></p>	<p>In 2020-21 we continued to work on the issue of <b>late diagnosis of congenital and childhood cataract</b>. 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.</p>



	<p>With Dr. Staffieri, we also continue to advocate strongly to the Victorian government in relation to early diagnosis, particularly with reference to information provision to parents, and embedding vision assessments more thoroughly into the early childhood routine health checks. We met with a representative of the Royal Australian College of General Practitioners (RACGP) to discuss improving GP awareness of congenital cataract to prompt timely referral.</p> <p>In 2020, Board members Megan Pricor and Sue Silveira accepted an invitation to join the Technical Working Group for Congenital Cataract, for the World Health Organisation's Package of Eye Care Interventions project, which is also connected with the Cochrane Eyes and Vision Group. We completed work to identify high quality clinical practice guidelines relating to congenital cataract, to guide practice globally.</p> <p><i>We will continue to pursue further research and policy activities to help address the problem of late diagnosis.</i></p>
<b>d) Advocating for research tailored to families' needs</b>	<p>We have successfully advocated for the initiation of clinical audits in Melbourne and Sydney to map diagnostic pathways (see above).</p> <p>We continue to be involved in a project at Australian Catholic University 'Testing the 'Measure of Early Vision Use' (MEVU)' – ensuring that the project is tailored to the experience of parents of children with vision impairment and encouraging families to respond to researcher invitations for feedback.</p> <p>Megan Pricor peer reviewed several systematic reviews of paediatric vision interventions for the Cochrane Eyes and Vision group and was recently invited to join the group's Editorial Board.</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>
<b>e) Disseminating research findings</b>	<p>We continue to use our website and social media to highlight journal articles reporting on well-conducted research relevant to childhood cataract.</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>
<b>f) Building partnerships</b>	<p>Cataract Kids Australia is a founding member of the <b>Paediatric Vision Impairment Alliance</b>, 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. This Alliance is initially working to improve the responsiveness of the National Disability Insurance Scheme to our community.</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 *Acknowledgements*.

In December 2020 we signed a **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 have included publication of material about Cataract Kids Australia in the OA newsletter and website, and a survey of OA members in relation to childhood cataract knowledge needs. We are grateful to OA for this opportunity to increase awareness of our organisation, and childhood cataract more broadly, amongst their membership.

In July 2020 Megan Pictor recorded a brief webinar to be used as part of the Bachelor of Orthoptics course at La Trobe University.

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



Image credit: Sarah Craven Photography

*Despite a world class health system that sees many healthy babies delivered in Australia each year, we still hear of late diagnosis of children with cataract, an eye condition that needs early detection and prompt, ongoing management. Families inspire us with their courage at their child's diagnosis, and their determination to have the best outcome for their child by committing to treatment that becomes more challenging when delayed.*

*CKA is committed to evaluating systems that will provide the tools to ensure cataracts are not missed. We know if cataract is picked up as soon as possible, and then treated, the development of a child's eye and vision can be resumed, giving the child their best visual chance.*

**Sue Silveira (PhD)**  
**Director, Cataract Kids Australia**

## SECTION 3

## OUR FINANCES

## FINANCIAL STATEMENTS 2020-21

<b><u>Balance brought forward from 30 June 2020</u></b>	<b>\$7139.08</b>
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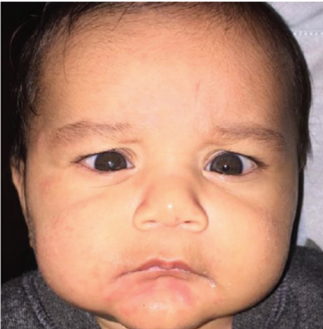





**Income/receipts**

Donations and bequests:	\$7124.45
Revenue from government including grants:	\$0.00
Revenue from providing goods or services:	\$0.00
Revenue from investments:	\$2.23
Other revenue/receipts:	\$0.00
<b>Total revenue/receipts:</b>	<b>\$5136.80</b>
Other income (for example, gains):	\$0.00
<b>Total income/receipts:</b>	<b>\$7126.68</b>

**Expenses/Payments**

Employee expenses/payments:	\$0.00
Grants and donations made for use in Australia:	\$1997.76
Grants and donations made for use outside Australia:	\$0.00
Other expenses/payments:	\$2006.52
<b>Total expenses/payments:</b>	<b>\$4004.28</b>
<b>Net surplus/(deficit):</b>	<b>\$10,261.48</b>

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.

	<b>BABIES AND KIDS CAN HAVE CATARACTS TOO!</b>		
		<b>Cataract is a clouding of the normally clear lens of the eye. All of the children in these photos have cataract. Early treatment is vital to save vision.</b>	

**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 KIDS AUSTRALIA**



[www.cataractkids.org.au](http://www.cataractkids.org.au)

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**CATARACT KIDS AUSTRALIA**



[www.cataractkids.org.au](http://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 2020-21 we particularly thank Anu Mathew, Sue Silveira, Sandra Staffieri, Louise Brennan, Stacey Alexander, Michael O'Connor, Ashlee Kalinic, Tina Wilson, and Genetic Support Network Victoria.**

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

**Ophthalmology Department, Royal  
Children's Hospital Melbourne  
Richard Lindsay & Associates Optometry  
Ophthalmology Department, Westmead  
Children's Hospital Sydney  
NextSense, Sydney  
Vision Australia  
Stem Cells Australia  
Orthoptics department, La Trobe  
University  
Orthoptics Australia  
Dr. James Best, RACGP  
Lauren Roberts, Nancy Notzon, ABC  
Rachel Ward, Seven News**

**Kids Eye Gear  
Centre for Eye Research Australia  
Save Sight Institute  
Paediatric Vision Impairment Alliance  
Australia  
Arnold Bloch Leibler lawyers  
Carla Silveira Design  
Sarah Craven Photography  
Eyetechn Optometrists  
Australian Charities and Not-for-Profits  
Commission  
Usher Kids Australia  
Trudy Smith, Renwick Centre (now  
NextSense)**

We also thank our generous donors, without whose financial help our work would not be possible, including anonymous donors. Thank you.

Our anonymous donors  
City of Burnie Lions Club  
Nisa Muhammad  
Colin Mountney  
Brydee Masters  
Nicholas Whitaker  
Matthew Hoelscher  
Emily Kell  
Sharon Williams  
Nyree Rafton  
Amanda Wentzel  
Jacob Craven  
Della Ashley  
Alexia Harding

Jessup Angela  
Rachel Livapulu  
Danielle Quinn  
Jess Stokeld  
Sanaz Badeleh  
Sonia Law  
Courtney Swanson  
Zinnia Lobb  
R.H.  
Bronne Drabsch  
Bronne Drabsch  
Gail Weckert  
Merrin Pictor  
Nicola Rivett

Dianne Lowe  
Steve Esposito  
Damien Pearse  
David Hobbs  
Mladenka Lugonja  
Fran Salvestrin  
Jasmina Ribarovska  
Darren Camilleri  
Tom Rados  
Marina Teixeira  
Angela Cram  
Nicole Floyd  
Ali Fretwell



## 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](mailto:info@cataractkids.org.au)

### Make a donation

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

Email [info@cataractkids.org.au](mailto:info@cataractkids.org.au)  
[www.cataractkids.org.au](http://www.cataractkids.org.au)  
[facebook.com/cataractkidsaustralia/](https://facebook.com/cataractkidsaustralia/)  
[twitter.com/CataractKidsAus](https://twitter.com/CataractKidsAus)

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