



**CATARACT
KIDS
AUSTRALIA**

**2019-20
ANNUAL REPORT**



Image credit: Sarah Craven Photography

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 2019-20**

Megan Pricor
*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



CHAIRPERSON'S REPORT

Megan Prictor



Like many organisations, Cataract Kids Australia has needed to adapt in 2020 to accommodate the impact of the COVID-19 pandemic. The main way this has affected our work has been the deferral of plans for face-to-face events and the introduction, in their place, of monthly online gatherings for families. This has proved to be a highly effective, inexpensive approach that enables Cataract Kids Australia to easily connect with families – and for them to connect with each other – nationwide. We have been delighted to see some families return each month and others dip in when they need to. You've told us the meetings give you hope, reduce your sense of aloneness in the cataract journey, and enable you to ask questions and get reliable answers. It has been

wonderful to see many babies and children popping up on these calls and we especially hope that seeing others wearing eye patches will help our kids feel encouraged too.

Our advocacy and research activities have continued despite the impact of COVID. We are delighted that a project is now underway at Melbourne's Royal Children's Hospital to analyse the diagnostic pathways of children with cataract, so that the problems can be pinned down, and in the future better ways to fast track diagnosis can be put in place. We have also met with government departments in Victoria and nationally about infant vision screening and better information for health professionals. We will continue this effort because we consider it critical in seeking to reduce future instances of vision impairment related to missed cataract diagnosis in Australia.

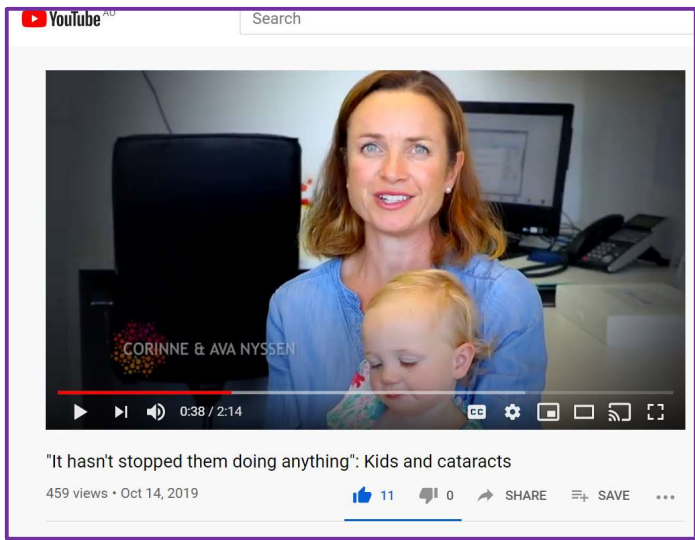
Cataract Kids Australia was established with three areas of work: supporting families, engaging with clinicians, and advocating for research. I am delighted that we are starting to gain traction in the latter arena, with involvement of Dr Sue Silveira and myself in a World Health Organisation Technical Working Group to identify high-quality clinical guidelines for congenital cataract that can be adopted internationally, and participation in a project at Australian Catholic University to test and refine a new tool for evaluating vision in children.

Once again, I am exceptionally grateful to my fellow Directors Dr Sue Silveira and Dr Anu Mathew, to our many supporters, and to every family who trusts Cataract Kids Australia to walk alongside them in their child's cataract journey. I am confident we are making a positive difference.

A handwritten signature in dark ink, reading 'Megan J. Prictor'. The signature is written in a cursive, flowing style.

Megan Prictor
PhD, LLB (Hons)

OUR OBJECTIVES AND ACTIVITIES

Objectives	Activities and future plans
<p>a) High-quality information</p>	<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 and new family stories. The Facebook page has 465 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, online and face to face events.</p> <p>In October 2019 we released a short video: <i>"It hasn't stopped them doing anything": Kids and cataracts</i> filmed at Richard Lindsay and Associates Optometry. The video is available at https://bit.ly/3m3nkeL.</p> <div data-bbox="589 863 1279 1398">  <p>The image shows a screenshot of a YouTube video player. The video features a woman with blonde hair, identified as Corinne & Ava Nyssen, holding a young child. The video title is "It hasn't stopped them doing anything": Kids and cataracts. The video has 459 views and was uploaded on Oct 14, 2019. The player interface includes a search bar, a play button, a progress bar, and a share button.</p> </div> <p><i>We will continue to update the website and promote it widely as a trustworthy source of high-quality information on childhood cataract.</i></p> <p><i>In 2021, pandemic permitting, we plan to host 1-2 public events to disseminate additional high-quality information to families and the wider community.</i></p>

Objectives	Activities and future plans
b) Education and support to families	<p>In December 2019 we held a get-together in Melbourne attended by children affected by cataract and their families, as well as optometrists, ophthalmologists and their support staff. The event was a huge success (see photo below). We especially thank Fran and Giuliano Salvestrin for donating the catering.</p>  <p>Since April 2020 we have hosted 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 from South Australia, Queensland, the ACT, 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 meetings each month and go on promoting them to the community.</p> <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 one-on-one phone and email support to a number of families of both newly-diagnosed and older babies and children affected by cataract.</p> <p>We added a collection of videos of contact lens insertion and removal, involving children of different ages, to the Cataract Kids YouTube channel at https://bit.ly/CKAvid</p> <p>We continue to promote an evidence-based educational resource for the general public 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 to list private providers of low vision services on our website. 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>

Objectives	Activities and future plans
c) Advocating for improvements to clinical care	<p>In 2019-20 we continued to work on the issue of late diagnosis of congenital and childhood cataract. The Diagnosis Working Party initiated a clinical audit to map the diagnostic pathways of children presenting with cataract to the Royal Children's Hospital Ophthalmology department, which is underway. 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.</p> <p>We also met with representatives of the National Children's Digital Health Collaborative to discuss the pilot phase of an online nationwide early childhood record (National Child Health Record). We emphasised the need for vision screening to be thoroughly and consistently embedded in early childhood screening.</p> <p>In 2020, Board members Megan Prictor 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. Work has commenced 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>
d) Advocating for research tailored to families' needs	<p>We have successfully advocated for the initiation of clinical audits in Melbourne and Sydney to map diagnostic pathways (see above).</p> <p>We are 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>We also endorsed an application for funding submitted by Associate Professor Michael O'Connor to the Medical Research Future Fund Stem Cell Therapies Mission, for his project on "Investigating lens regeneration via lens cell transplantation for improved childhood cataract treatment". Though the application was not successful, we continue to engage with Dr. O'Connor's work.</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>

Objectives	Activities and future plans
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 several 'paywalled' articles.</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>Cataract Kids Australia is a founding member of the Paediatric Vision Impaired Alliance, an umbrella organisation established in late 2019 bringing together entities including Usher Kids Australia, CVI Community Australia, Centre for Eye Research Australia and the Royal Institute for Deaf and Blind Children, 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> <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> <p>In July 2020 Megan Pricor recorded a brief webinar to be used as part of the Bachelor of Orthoptics course at La Trobe University.</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>



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 2019-20

<u>Balance brought forward from 30 June 2019</u>	\$3806.77
<u>Income/receipts</u>	
Donations and bequests:	\$5130.96
Revenue from government including grants:	\$0.00
Revenue from providing goods or services:	\$0.00
Revenue from investments:	\$5.84
Other revenue/receipts:	\$0.00
Total revenue/receipts:	\$5136.80
Other income (for example, gains):	\$0.00
Total income/receipts:	\$5136.80
<u>Expenses/Payments</u>	
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:	\$1804.49
Total expenses/payments:	\$1804.49
Net surplus/(deficit):	\$7139.08

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.



Images: Sarah Craven Photography

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 2019-20 we particularly thank Anu Mathew, Sue Silveira, Sandra Staffieri, Louise Brennan, Stacey Alexander, and Fran Salvestrin.

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	Essilor Foundation
Ophthalmology Department, Westmead Children's Hospital Sydney	Centre for Eye Research Australia
Dr. Michael O'Connor, Western Sydney University	US Pediatric Glaucoma & Cataract Family Association
Royal Institute for Deaf and Blind Children, Sydney	Arnold Bloch Leibler lawyers
Vision Australia	Carla Silveira Design
Prof. Bryan Shaw, Baylor University Stem Cells Australia	Sarah Craven Photography
Orthoptics department, La Trobe University	Elizabeth Fermanis: <i>Image, Story, Script and Screen</i>
Orthoptics Australia	Eyetechn Optometrists
	Australian Charities and Not-for-Profits Commission
	Usher Kids Australia

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

Nicola Rivett	Heather Thomson	Fran Salvestrin
Jason Calleja	Damien Pearse	Helen Lehmann
Dianne Lowe	Susan Gordon	Lauren Tippet
Lesley Collins	Mary Whelan	Sandra Staffieri
Jacob Craven	Gatt Family	Yuuka Matsukawa
Alana Ribarovska	Marco Faccio	Kaye Anderson
Nicola Vermaat	Ellie Kreutzberger	Jessica Bell
Merrin Pictor	Yvonne Soper	Gail Quinn
Tim Burke	Sarah Hetrick	Sonya Sal
Christina Validakis	Mark Taylor	Jennifer Cummings
Ashlee Kalinic	Danya Vears	Jaymee-Lee Kerr
Angela Booth	Harriet Teare	Tracey Kerr
Dave Foresto	Emma Heupt	Rachael Halley
Rudolf Dorweiler	Angela Reynolds	Clare Collins
		Kelly Campbell

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 our Facebook 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

Our event plans for 2020 have been affected by COVID-19, but next year 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 when this becomes possible again, 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
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