

CATARACT KIDS AUSTRALIA

2022-23 ANNUAL REPORT

Our mission

Working for the vision of kids with cataract

Cataract Kids Australia acknowledges the traditional custodians of the lands on which we work, and their connections to the land, sea and community.

We acknowledge that their sovereignty was never ceded, and we pay our respect to their elders past and present.

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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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 2022-23



Megan Prictor Founding Director and Chair



Susan Silveira Director



Anu Mathew Director

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.

GOVERNANCE AND ACTIVITIES

CHAIRPERSON'S REPORT Megan Prictor

Cataract Kids Australia has continued to serve its communities through 2022-23 and pursue its overarching goal of working for the vision of kids with cataract.

Particular highlights this year were being able to see families face-to-face, with successful events in Brisbane, Melbourne and Adelaide. We tested a novel workshop in Melbourne in January, designed to provide one-to-one support and practice with contact lens insertion and removal, which was well



received. Our regular Zoom catch-ups and webinars also assisted both newly-diagnosed families and those a little further along the journey.

In a difficult financial climate, we were also pleased to continue our successful Microgrants scheme. It is rewarding to be able to provide practical help to families grappling with the costs of contact lenses, patches and glasses amid a cost-of-living crisis.

Another highlight for the year was attending the major professional conferences of Orthoptics Australia and the Royal Australian and New Zealand College of Ophthalmologists in Brisbane in October 2022.

We are a proud partner of Dr. Michael O'Connor's new I-CaRe research initiative at Western Sydney University, leading new research into stem cells as a potential game changer for childhood cataract treatment. Visit <u>https://www.westernsydney.edu.au/give/cataract</u> to find out more.

Thank you once again to my fellow Directors, Drs Susan Silveira (NextSense) and Anu Mathew (Royal Childrens Hospital), for their support, time and expertise, as well as to the many eyecare professionals, researchers, community advocates and families from across the country who walk with us on this journey.

Myun J. Portor

Megan Prictor, Founding Director

OUR OBJECTIVES AND ACTIVITIES

A) High-quality information

We have maintained our comprehensive website (<u>www.cataractkids.org.au</u>) which continues to provide clear and reliable information for families. The Cataract Kids Australia Facebook page helps to direct people to the website, as well as providing informational snapshots, and alerts to new research, webinars, fundraising opportunities and Zoom meetings. The Facebook page has 784 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.

b) Education and support to families

In 2022-23 we continued our successful Microgrants scheme for families of children affected by cataract. In 2022 we provided 39 grants in total (\$5844). The scheme was maintained at \$150 per child per year for 2023, and from January to June 2023, 15 grants totalling \$1998 were awarded.

This funding scheme is 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 2023 were primarily for patches, as well as glasses and contact lenses.

Another major new undertaking in 2023 was our first Contact Lens Confidence workshop for families with a child affected by cataract. This event was led by Andrew Huhtanen, Clinic Director of the Melbourne Eyecare Clinic, and we were grateful to be able to utilise the University of Melbourne clinical teaching space at no cost. We had 5 families attend to practice contact lens handling, insertion and removal on a calm adult volunteer. Lots of support was available from expert optometrists and we thank them for their invaluable contribution: Jillian Campbell (Richard Lindsay and Associates) and Jessica Chi (Eyetech). We also thank optical dispenser Imogen Prictor (Leverett and Kindler) and other members of the Prictor/Sorensen family for their assistance. The workshop was followed by a free BBQ lunch with face painting for the kids at Lincoln Square in Carlton.

We spread the fun of face-to-face meet ups for families more widely this year, visiting Brisbane in October 2022 and supporting an Adelaide meet-up run by Zinnia and Bec in March 2023.

Throughout 2022-23 we held six '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.

We also hosted an 'Expert Q&A' with Dr Antony Clark, Lions Eye Institute, *Glaucoma and childhood cataract*, in October 2022.

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

c) Advocating for improvements to clinical care

Late diagnosis of congenital and childhood cataract continues to affect our community. The clinical audit mapping the diagnostic pathways of children presenting with cataract to the Royal Children's Hospital Ophthalmology department is ongoing. "Data collection has been completed, with data cleaning and analysis continuing. Consideration is being given to extend the study to include children diagnosed with cataract from January 2020 to December 2022 to explore the impact of COVID on referral pathways and time to diagnosis. We are grateful to Dr. Sandra Staffieri and colleagues for leading this research.

d) Advocating for research tailored to families' needs

We were pleased to be a partner in Dr. Michael O'Connor's new I-CaRe research initiative into stem cells for childhood cataract at Western Sydney University. We hope that this will be a catalyst for major investment into this world-leading research.

e) Disseminating research findings

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.

f) Building partnerships

We were especially pleased to draw upon our connections with ophthalmologists and optometrists in Melbourne for our Contact Lens Confidence workshop, and to participate in the Brisbane Orthoptics Australia and RANZCO Conferences in October 2022.

We continue to partner with Orthoptics Australia through our Memorandum of Understanding (MOU), working together to deliver a uniform message to the public, the professions, government, and other stakeholders on matters concerning children with cataracts. 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 78th Annual Conference in Brisbane in October 2022.

We are grateful to two parents, Zinnia and Bec, who took the initiative to run a vibrant family meet-up for Cataract Kids Australia in Adelaide. We also thank Jason Calleja who ran the New York Marathon in November 2022, raising both money and awareness for cataract kids.

Adelaide Meet-up, March 2023



Contact Lens Confidence Workshop and Family Meet-Up, Melbourne, January 2023







Brisbane Meet-up, October 2022



Brisbane Meet-up, October 2022





OUR FINANCES

FINANCIAL STATEMENTS 2022-23

| <u>Balan</u> | ce brought forward from 30 June 2022 | \$10996.26 | | |
|-----------------|---|------------|--|--|
| Income/receipts | | | | |
| | Donations and bequests: | \$7859.62 | | |
| | Revenue from government including grants: | \$0.00 | | |
| | Revenue from providing goods or services: | \$0.00 | | |
| | Revenue from investments: | \$0.93 | | |
| | Other revenue/receipts: | \$0.00 | | |
| | Total revenue/receipts: | \$7860.55 | | |
| | Other income (for example, gains): | \$0.00 | | |
| | Total income/receipts: | \$7860.55 | | |

Expenses/Payments

| Employee expenses/payments: | \$0.00 |
|--|-------------|
| Grants and donations made for use in Australia: | \$5543.21 |
| Grants and donations made for use outside Australia: | \$0.00 |
| Other expenses/payments: | \$6778.43 |
| Total expenses/payments: | \$12,321.64 |
| Net surplus/(deficit): | \$6535.17 |

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.

ACKNOWLEDGEMENTS

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The success of Cataract Kids Australia would not be possible without the generous donation of time, expertise, goods and services by many people. In 2022-23 we particularly thank Anu Mathew, Sue Silveira, Sandra Staffieri, Louise Brennan, Jillian Campbell, Jessica Chi, Natalia Kelly, Antony Clark, and Zinnia Lobb and Rebecca Wescombe.

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 Orthoptics Australia Eyetech Optometrists Usher Kids Australia Kids Eye Gear Save Sight Institute Paediatric Vision Impairment Alliance Australia Arnold Bloch Leibler lawyers Carla Silveira Design Sarah Craven Photography Australian Charities and Not-for-Profits Commission

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

CONTACT US

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