



**CATARACT
KIDS
AUSTRALIA**

**2018-19
ANNUAL REPORT**



NEWS

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Tomorrow's Medicine: Micro-lenses bring new cataract treatments in sight

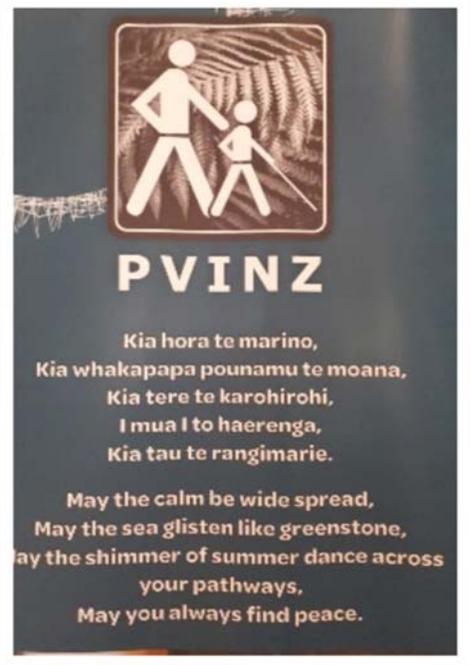
28 May 2019



Michael and Megan and team were brought together by Stem Cells Australia.

Stem cells are being used to rapidly test and improve treatments for cataracts, thanks to an innovative solution developed by Dr Michael O'Connor and his team from Western Sydney University.

With novel stem cell technology, Michael has created human micro-lenses similar to the ones in the human eye. This is a way to rapidly improve drug research and offer the best transplants in the future.



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.

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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 2018-19**

Megan Prictor
*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: FR-000014566

Cataract Kids Australia is not required to obtain fundraising registration in the Northern Territory, Queensland and the Australian Capital Territory.



CHAIRPERSON'S REPORT

Megan Prictor



The past year has seen Cataract Kids Australia move beyond the set-up phase and start consolidating. Two things stand out. The first is that the organisation is making strong progress in forging connections with health practitioners and researchers, as well as in the government/policy space. We have continued to build our reputation as a trusted, reputable and responsive information source about cataract and related conditions affecting children, and an important advocate for families. Our Director Megan Prictor was invited to present on the Cataract Kids agenda at the national conference of Orthoptics Australia as well as the annual meeting for Parents of Vision Impaired (New Zealand).

Our second achievement of the past year is establishing the early detection and diagnosis of cataract and related eye conditions in babies and children as a research priority. This was motivated by hearing repeatedly from families about their distress, anxiety, guilt and frustration that their child's eye condition was not picked up as early as it might have been. We have also heard from health professionals about the challenges of screening babies for vision problems, including a lack of suitable training and support. For childhood cataract, the impairment of visual development resulting from a late diagnosis can be significant. We do not want *any* child, any family, to be put in that position. That's why we have surveyed families this year about their experiences leading to their child's diagnosis. We have helped to initiate clinical audits of diagnostic pathways at major children's hospitals in Victoria and New South Wales. And we are starting a journey of advocacy with government and policy-makers around childhood vision screening.

Day to day, as new babies and children are diagnosed, as families struggle to understand this condition, and as they battle wills with their toddlers and young children over contact lenses and patching, Cataract Kids Australia continues to provide high-quality information, advice and links to resources that can help. I am exceptionally grateful: to my fellow directors Sue Silveira (Royal Institute for Deaf and Blind Children) and Anu Mathew (Royal Children's Hospital Melbourne) for their tremendous input, advice, support and advocacy; to Stacey Alexander who has assisted behind the scenes this year; and to every person who has given of their money, time, energy and attention to our organisation's work.

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)

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 family stories, information about intra-ocular lens (IOL) placement, and 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 364 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 more than 1000 postcards to clinicians to give to new patients' families. The website continues to average 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><i>In 2020 we plan to host 1-2 public events to disseminate additional high-quality information to families and the wider community.</i></p>
<p>b) Education and support to families</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 informational support to a number of recently diagnosed families.</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><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>c) Advocating for improvements to clinical care</p>	<p>For 2019 Cataract Kids Australia prioritised work to address the problem of late diagnosis of congenital and childhood cataract. A working party comprising families, clinicians and researchers was established, which meets monthly. In early 2019 we designed and distributed an online survey to parents to gather data about diagnosis. More than 80 families responded. The main findings of this survey included:</p> <ul style="list-style-type: none"> • Parents are most often the first to notice a problem with their child's eyes. • Often, cataracts were visible to the naked eye.

	<ul style="list-style-type: none"> • Strabismus (eye turn) was also an important early sign of cataract. • Sometimes cataracts are missed, and sometimes families who notice that something is wrong don't get timely referral to an ophthalmologist. <p>The diagnosis working party has since initiated two clinical audits to map diagnostic pathways of children presenting with cataract to the Royal Children's Hospital Ophthalmology department, and the Westmead Children's Hospital.</p> <p><i>Building on the significant work conducted by Dr. Sandra Staffieri at the Centre for Eye Research Australia to map childhood vision screening processes across Australia, we have established connections with government departments in several states that are responsible for infant and childhood screening. We plan to pursue further research and policy activities to help address the problem of late diagnosis.</i></p>
<p>d) Advocating for research tailored to families' needs</p>	<p>We have successfully advocated for the initiation of clinical audits in Melbourne and Sydney to map diagnostic pathways (see above).</p> <p>In 2019, led by Stacey Alexander, we also reviewed information about apps to identify eye disease in children, identifying and gathering further information on the CRADLE white eye detector app developed by a parent in the USA. We disseminated information about the app to families and invited them to share photos of their children with the researchers developing the app in order to 'train' the algorithm to more easily identify potential cases of cataract in babies.</p> <p><i>We will continue to 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 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><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>
<p>f) Building partnerships</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 Acknowledgements.</p> <p>In October 2018 Megan Pictor was invited to give a keynote address at the Parents of Vision Impaired (New Zealand) annual conference.</p>

In November 2018 we participated in the national conferences of Orthoptics Australia (OA) and the Royal Australian and New Zealand College of Ophthalmology (RANZCO) in Adelaide, including through staffing a resource table and speaking at the OA conference.

Our association with Dr Michael O'Connor at Western Sydney University was recognised in an article by Stem Cells Australia (stemcellsaustralia.edu.au).

Our work was also featured in an article by the Australian Charities and Not-for-Profits Commission (<https://www.acnc.gov.au/media/news/getting-know-cataract-kids-australia>, June 2019).

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

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 2018-19**

<u>Balance brought forward from 2017-18</u>	\$2630.97
<u>Income/receipts</u>	
Donations and bequests:	\$3399.88
Revenue from government including grants:	\$0.00
Revenue from providing goods or services:	\$0.00
Revenue from investments:	\$18.14
Other revenue/receipts:	\$0.00
Total revenue/receipts:	\$3418.02
Other income (for example, gains):	\$0.00
Total income/receipts:	\$3418.02
<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:	\$2242.22
Total expenses/payments:	\$2242.22
Net surplus/(deficit):	\$3806.77

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. In 2018-19 we particularly thank Stacey Alexander for her kind assistance, as well as our diagnosis working party members (Anu Mathew, Sue Silveira, Sandra Staffieri, Louise Brennan, Martin Allen, Stacey Alexander).

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

Ophthalmology Department, Royal Children's Hospital Melbourne	Fred Hollows Foundation
Richard Lindsay & Associates Optometry	Essilor Foundation
Ophthalmology Department, Westmead Children's Hospital Sydney	Parents of Vision Impaired, New Zealand
Sydney Ophthalmic Specialists	Orthoptics Australia
Natalie Ainscough, Women's and Children's Hospital, Adelaide	Kids Eye Gear
Dr. Michael O'Connor, Western Sydney University	Centre for Eye Research Australia
Royal Institute for Deaf and Blind Children, Sydney	US Pediatric Glaucoma & Cataract Family Association
Vision Australia	Arnold Bloch Leibler lawyers
Prof. Bryan Shaw, Baylor University	Carla Silveira Design
Stem Cells Australia	Sarah Craven Photography
	Elizabeth Fermanis: Image, Story, Script and Screen
	Jessica Chi, Eyetech Optometrists
	Australian Charities and Not-for-Profits Commission

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

Dianne Lowe	Vikki Monroe
Damien Pearse	Troy Lim Joon
Jacob Craven	Sandra Staffieri
Marco Faccio	Sue Silveira
Denny Burhan	Suzie Khalil
Heather and Brendan Thomson	Harriet Teare
Gary Goodman	Jessica Bell
Merrin and Bill Pricor	Tess Whitton
Piers Thomas	Fran Salvestrin
Gareth Hoyle	Sabrina Gonsalves
Narelle Da Silva	

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](#) 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

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

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