

CleftPALS  
VICTORIA INC.

CleftPALS VICTORIA Inc.  
Annual General Meeting

Sunday 19 May 2024  
Virtual Event on Zoom



## AGENDA

2:00 pm

Welcome and Introductions

Cheng Yeo	President
Rina Bowden	Vice President
Tracey Ruse	Treasurer
Melissa Creber	Secretary
Kirsty Pekusic	Feeding Coordinator
Bridie Roberts	Social Media Coordinator
Michelle Violi	Newsletter Editor
Mark Banks	General Member
Jessica Beckman	General Member
Phillippa Morris	General Member
Leah McMahon	General Member
Beth Schultz (SA)	General Member
Katie Bellchambers (Tas)	General Member
Amy Miles	General Member
Amy Finocchiaro	General Member
Megan McIntyre	General Member (CleftStars)
Ania Kujawska	General Member (CleftStars)
Josh Williams	General Member (CleftStars)
Maddy Leijen	General Member (CleftStars)

2:10 pm

CleftPALS Victoria Inc. AGM 2024

1. Presentation of Annual Reports by Cheng Yeo
2. Presentation of Treasurer's Report by Tracey Ruse
3. Feeding Report by Kirsty Pekusic
4. Social Media Report by Bridie Roberts
5. Advocacy Update by Jessica Beckman
6. Elections
7. Other general business
8. Close

CleftPALS Victoria Inc. acknowledges Aboriginal and Torres Strait Islander people as the traditional custodians of the land on which you are participating from today. We pay our respects to Elders past, present and emerging.

We commit to working respectfully to honour their ongoing culture and spiritual connections to this culture. We recognise the role and value of culture in our community.



## **PRESIDENTS REPORT 2023-2024**

In 2024, CleftPALS Victoria will be celebrating its 50<sup>th</sup> anniversary. 50 years ago, Joel and Ruth Solomon established the Victorian branch of the Cleft Lip and Palate Society (CleftPALS). Since its inception, CleftPALS Victoria has always had a focus on the welfare of cleft-affected children and their families. Today, CleftPALS Victoria is recognised as an integral part of the support and advice network, that complements the hospital care teams. Please keep an eye out for a celebration event during Cleft Awareness Week in November this year – we would love to see families come together to celebrate our milestone anniversary, and re-connect with past committee members who have contributed to who/what CleftPALS Victoria is today.

Earlier this year, we welcomed some new members into the committee. It is wonderful to see a new injection of energy and ideas. A warm welcome to Ania Kujawska, Amy Finocchiaro, Amy Miles, Josh Williams and Michelle Violi to the committee.

I am pleased to summarise our achievements this year, which include:

1. Continued advocacy for better access to speech therapy services for cleft-affected people under Medicare. In 2022/23, in conjunction with CleftPALS NSW, we continued to engage with the Department of Health and Speech Pathology Australia. This includes raising awareness and educating Federal government MPs on the importance of speech therapy to the cleft community. We continue to engage with Speech Pathology Australia (as the national governing body for speech pathologists) on affordable speech therapy.
2. Education and awareness of the ongoing speech needs of cleft-affected children and adults to grow the pipeline of speech pathology professionals who have cleft specialisation. CleftPALS Victoria collaborated with Victoria University in October 2023 in the delivery of a presentation of the parent perspective, so that final year students can integrate that knowledge with their clinical care.
3. Helping young people with a cleft to form connections. Through a re-invigorated committee who will be focussing on CleftStars, the committee is exploring how we can facilitate some small format virtual and in-person events in 2024, that enable young people and their families to form meaningful connections to peers who share lived experiences of growing up with a cleft. The committee is intending to start with virtual events that create a safe space for young people with a cleft to get to know each other, with the intention of running in-person events once we have a large enough cohort to run in-person events.
4. Cleft Awareness Week. Our Cleft Awareness Week event was held on 12 November 2023 at the Library@ Docklands. The small group of attendees, 25-30 people, listened to our guest speaker, Sam Branham, share his insights about resilience and self esteem. Sam is an Australian Paralympic swimmer who was born missing a part of his limb, and had his leg amputated when he was 5 years old. Sam competed in the 2004 and 2008 summer Paralympics, winning two gold medals, two silver medals and a bronze medal. Sam commits a lot of his time to charity - working with young kids with disability, disadvantaged and underprivileged youth, victims of bullying and upskilling troubled teens. He is an ambassador for Disability Sport and Recreation, Bully Zero Australia, OzChild and Group Training Association of Victoria.

5. Continued funding for newborn care packs. We are pleased to report that we have secured funding to continue providing newborn care packs for the next 12-18 months. Through support from Craniofacial Australia, we are pleased to be able to create another 100 newborn care packs, that we are now also able to distribute to families in Tasmania and South Australia. As part of the communications for the newborn care pack expansion to the cleft units in Tasmania and South Australia, we are taking the opportunity to grow awareness of our online support group on Facebook with posters that can be put up for cleft clinics.

We acknowledge the contribution from Craniofacial Australia to make this a reality, and we thank them for their support.

Lastly, we were presented with an opportunity for cleft families to participate in a Funflight Charity Event. FunFlight is a charity that provides an aviation experience for children facing challenges. A handful of CleftPALS Victoria families enjoyed joy flights in a light aircraft on 22 October 2023 at Lilydale Airport with FunFlight pilots and crew, who are volunteers and experienced pilots. We thank Dr Tony Collett and FunFlight for the opportunity for our families to enjoy a day out.

I will be stepping down from the President role this year. My involvement with CleftPALS Victoria began when my son Josh (who is now 13) was born – in different roles as a moderator on our Facebook group, General Committee Member, Grants Officer and President. I have enjoyed my time volunteering with CleftPALS Victoria, and formed many cherished friendships and connections over the years. I will remain on the committee to support a transition for the new President-elect.

To the committee, I want to thank every single one of the committee for their dedication and their support for me in the President role. I remain in awe of their hard work and dedication in our collective goal to be here to support and help the cleft community.

Cheng Yeo, President.

Donating to CleftPALS Victoria Inc. is one click away!

Every dollar (\$2 and above is tax deductible) helps us reach our goals and supports our cleft community. As a non-for-profit Australian charity, with no government funding, we rely on donations and grants in order to continue to run our programs. Please visit our website [www.cleftpalsvic.com](http://www.cleftpalsvic.com) or scan our QR code.



## TREASURER'S REPORT 2023-2024

At the end of the 2023/2024 financial year, CleftPALS Victoria had total funds of \$73,298.47. This is \$4726.37 more than the previous financial year end for 2022/2023. This is the sixth year in a row that we have made a profit. New membership for this financial year totalled \$900, down by \$125 from the previous year – this was total of 10 new lifetime memberships.

The addition of the donation option to the Facebook pages and website has continued to allow for convenient and easy payment options via PayPal. The community generously donated \$2,223.30 – down by \$8,682.29 from the previous year. The promotion of Cleft Awareness Week in November and End of Year donation opportunities were again when the majority of these funds were received.

The improved interest rates on our term deposits saw a significant increase in bank interest of over \$1000 this year.

Feeding equipment income was \$3,455.05, a decrease of \$859 from the year before. Feeding equipment costs were \$2,512.53, an expenditure increase from the previous year of \$345.

This year we were granted \$8,560 to support the continued offering of our newborn care packages across Victoria, South Australia and Tasmania.

We continued to support many universities in their midwifery awards, with students receiving between \$250 and \$500 to be recognised for their studies and to support their nursing careers.

Our storage facilities and insurance costs are consistent from the previous year.

Since 20 January 2014, CleftPALS Vic has been managing CleftPALS Tasmania's funds, which is currently \$3,713.41, with no continued sign of this becoming active again in the near future.

## STATEMENT OF CASH RECEIPTS AND PAYMENTS

1 April 2023 – 31 March 2024

<b>Income</b>		<b>\$</b>
	Clancy Books	5.00
	Donations	2,223.30
	Feeding Equipment	3,455.05
	Grants	8,560.00
	Interest	1,216.78
	New Membership	900.00
	Oscar Bears	40.00
	Wonder Books	30.00
	<b>Total Income</b>	<b>16,430.13</b>
<b>Expenses</b>		
	Awards – Midwife	1,250.00
	Event Expenses	1,549.43
	Feeding Equipment Purchases	2,512.53
	Gifts and Donations	241.50
	Grant Expenses	2,127.68
	Insurance	1,516.33

	Office Expenses	675.00
	PayPal Fees	83.61
	Postage and Delivery	350.49
	Printing and Stationery	26.19
	Refund	11.00
	Storage	1,260.00
	Telephone	100.00
	<b>Total Expenses</b>	<b>11,703.76</b>
<b>Net Income</b>		<b>4,726.37</b>

<b>Opening Accounts</b>		
<b>Balance as of 31 March 2023</b>		<b>\$</b>
	PayPal Account	462.68
	Westpac Cash Reserve	10,513.76
	Westpac Community Solutions Cheque Account	24,139.43
	Westpac Term Deposit	33,455.93
	<b>Total</b>	<b>68,572.10</b>
<b>Closing Accounts</b>		
<b>Balance as at 31 March 2024</b>		
	PayPal Account	289.98
	Westpac Cash Reserve	11,166.85
	Westpac Community Solutions Cheque Account	27,321.72
	Westpac Term Deposit	34,519.92
	<b>Total</b>	<b>73,298.47</b>



## 2023-2024 PHOTO GALLERY



**2023 AGM and Family  
Fun Day  
Bounce Blackburn  
May 2023**

**FunFlight Charity Event  
October 2023  
Lilydale**

**CleftPALS families enjoyed a morning  
out with joyrides at Lilydale Airport**



**Cleft Awareness Week  
Docklands  
Nov 2023**

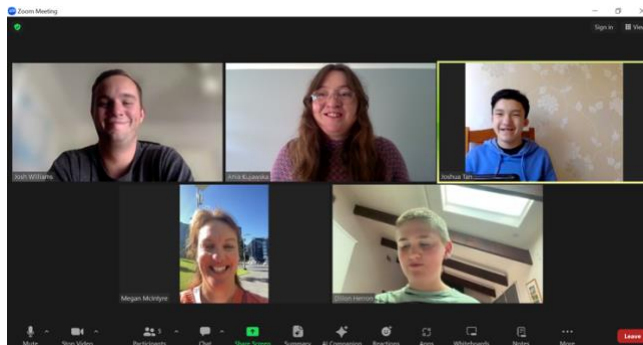
**Guest Speaker Sam  
Branham sharing  
experiences growing  
up with a disability  
with CleftPALS  
families.**

**Feb / Mar 2024**

**Feeding Coordinator, Kirsty Pekusic, sharing feeding knowledge with Australian Breastfeeding Association counsellors at the ABA 2024 Conference.**



**Committee member, Megan McIntyre, sharing the parent perspective with and speech pathologists at Speech Space**



**April 2024**

**CleftSTARS Virtual Catchup over Zoom**

**April 2024**

**Committee working bee for newborn care packs sponsored by Craniofacial Australia**



## FEEDING AND EQUIPMENT REPORT 2023-2024

The feeding and equipment hotline and CleftPALS Victoria email have continued to be important points of contact for new parents, family members and support people of cleft affected babies and children.

Throughout the last year CleftPALS have continued to receive calls and emails from new and expecting parents with general questions and concerns they have after recently being given a diagnosis that their baby will be born with or has been born with a cleft. The number of calls received each week can vary between nil to an average of two to three. The number of orders received for bottles and equipment can vary week to week also, from nil to three or four orders in a week.

Newborn care packages continue to be provided to cleft affected newborns throughout Victoria, as well as South Australia and Tasmania. New packs are set to be distributed soon with funding from Craniofacial Australia. We changed our approach when families reach out to us for newborn care packs, to tell them about our contact parent network with an offer to connect the family. This year, of the 13 families who have reached out to us about newborn care packs, we have been able to connect at least 6 families to other families.

The CleftPALS Victoria Facebook support group continues to grow with new members, and this page is a popular platform whereby many members seek feeding and equipment advice from each other and share their stories and photos.

Our website [www.cleftpalsvic.com](http://www.cleftpalsvic.com) is the best place to purchase any bottles or spare parts needed. The Dr Brown's Speciality Feeding System for cleft babies has proven to be a popular and affordable option, and we stock these alongside the Medela Special Needs Feeder and Pigeon bottles.

We also have our mascot, Oscar Cleft Bear available for sale and some books which cleft affected children love! Please do not hesitate to reach out to the hotline if you have any questions.

Kirsty Pekusic, Feeding and Equipment

## SOCIAL MEDIA REPORT 2023-2024

During 2020, it was decided that Social Media Coordinator was required to promote CleftPALS Victoria and further support members. Instagram and Facebook are integral in promoting CleftPALS Victoria and supporting families that are cleft affected.

During 2023/2024 the Facebook support group remained at 1.4K members, however it's likely to reach 1.5K members in the coming months. This Facebook group can only be accessed privately, with members needing to answer membership questions in order to be accepted. Our Facebook group allows members to connect with other members, asking questions and sharing personal experiences such as; feeding advice, cleft lip and palate repair advice and most importantly members sharing their beautiful cleft smiles! The CleftPALS Vic committee moderate this content strenuously to ensure it stays as a supportive and safe sharing space.

In April 2022, a public Facebook Page was created, in-line with our public Instagram account. This page enables followers to share posts on their social media account, which is integral to sharing much needed information and donation links.

CleftPALS Victoria's Instagram account has grown from 575 to 665 followers this past year and is able to be viewed publicly. Instagram promotes CleftPALS Victoria and allows personal stories are shared, and general cleft information is posted.

Social media played an integral part in raising much need awareness during our #cleftwordsmatter campaign in April 2022 and during Cleft Awareness Week which is held annually 8th-14th November.

During Cleft Awareness Week, the online campaigns via Facebook and Instagram, raise a substantial amount of money purely virtually. These donations have ensured CleftPALS Victoria can continue to run as a viable entity and continue to hold events to support our cleft community. We urge our members to share our posts during Cleft Awareness Week, and continue to raise much needed cleft awareness and donations to our organisation.

It has become apparent that it is difficult to have financial member exclusive information, via our social media platforms, this is an ongoing issue which the committee is further investigating.

Keep your eyes open on all our social platforms as we celebrate CleftPALS Victoria 50th Anniversary in the coming months!

Please reach out to us and tell us what you would like to see more of on our social platforms, your contributions are always appreciated and welcomed!

If you wish to join any of our social platforms, please see the links below.

- Instagram: @cleftpalsvic: <https://www.instagram.com/cleftpalsvictoria/>
- Facebook CleftPALS Victoria Support Group: [https://www.facebook.com/groups/26750563559/?ref=share\\_group\\_link](https://www.facebook.com/groups/26750563559/?ref=share_group_link)
- Facebook Page: <https://www.facebook.com/cleftpalsvictoria?mibextid=LQQJ4d>
- Twitter: @CleftpalsV

Bridie Roberts, Social Media - Committee Member.

## ADVOCACY UPDATE

Advocacy is another key role that CleftPALS Victoria plays in the community. To do this we need passionate people to keep fighting for all the rights and needs of the cleft community. The points below provide an overview of some of the progress that we have been making in this area:

- Since 2022, we have been pursuing the inclusion of speech services under the Medicare scheme for cleft-affected people. We have been in discussions with the Department of Health and various Federal MPs with an interest in health issues. Some that have shown support and have allowed us to meet with them include: Ged Kearney, Mike Freeland, Mark Butler, Kate Thwaite, Jordon Steele-John, Aaron Violi and Daniel White. We are still actively working with Federal MPs to gain access to speech services under the Medicare scheme.
- Concurrently, we have been working with Speech Pathology Australia on building awareness of the speech needs of cleft-affected people along with the government relevant decision-makers.
- With many families struggling with the high cost of living, adding the cost of speech services to the family budget can be challenging. CleftPALS has also been supporting families complete NDIS applications. These applications can be confusing and involve many complicated steps. We have helped three people begin the NDIS application process and gain access to NDIS services that holistically support the needs of the person.
- Whilst we pursue our long-term objective of better access to speech services under Medicare, we have also been exploring our role in creating a pipeline of speech pathologists who are trained in treating cleft patients. We have made presentations at Victoria University to grow awareness of the cleft condition amongst final year speech pathology students – with the goal of increasing interest to continue with further specialisation in cleft lip and palate.
- We are looking at all possible avenues to support better access to much needed services. Grants are one avenue that we can access funds if we are successful with our applications. We have been looking into Federal grants like the ILC grant that can provide affordable pathways for speech therapy.
- Speech Space is a new service who have reached out to the cleft community expressing an interest in furthering their support for cleft-affected patients, with the speech services that they provide. We are currently in discussion as to what this may look like in the future.

Looking forward, 2024 will see further meetings booked with Federal MPs to 'keep them honest' with going ahead with recommendations from 2019 MBS Task Force. Further talks with Speech Pathology Australia, Daniel White, Speech Space and pursuing ILC grants. We will also continue to connect with local Universities to speak about sponsored Bursary Awards and ways in which we can pass on vital knowledge in understanding cleft lip and palate.

We play an important part in being the voice of the community and fighting for the rights and needs of cleft affected people when they cannot.

**Jessica Beckman**