

CleftPALS  
VICT♥RIA INC.

CleftPALS VICTORIA Inc.  
AGM & Family Fun Day

Sunday 22nd May, 2022  
Ashburton Bowls Club



## AGENDA

1:00 pm	Welcome - Bridie Roberts, President.
	Introduce Committee Members
	Rina Bowden Vice President
	Tracey Ruse Treasurer
	Melissa Creber Secretary
	Kirsty Pekusic Feed & Equipment
	Cheng Yeo Grants Officer
	Bec de la Bere Social Media
	Kayla Doncon & Fiona Wallace Newsletter Editors
	Maddy Leijen CleftSTARS Mentor
	Mark Banks General Member
	Megan McIntyre General Member
	Jess Beckman General Member
	Phillipa Morris General Member
	Leah McMahon General Member
	Beth Schultz (SA). General Member
1:15 pm	Presentations and Thank You.
1:20 pm	CleftPALS Victoria Inc. AGM 2022

CleftPALS Victoria Inc. acknowledges Aboriginal 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 honor their ongoing culture and spiritual connections to this culture.

We recognise the role and value of culture in our community.



## PRESIDENTS REPORT 2021-2022



It is a privilege to be presenting this report on CleftPALS Victoria's progress from June 2021 to May 2022. This past year was again, a difficult time for so many families, for many businesses, it put an immense strain on our health system, and it produced tough times for not for profit organisations, just like ours. In a year when many organisations have had their plans 'stalled' and 'disrupted' due to the Covid 19 pandemic, I'm proud to say that our organisation stayed strong. We remained connected with our cleft community and financially, we made a considerable profit.

CleftPALS Victoria is fortunate to have such a skilled experienced group of individuals who are passionate and ambitious for CleftPALS Victoria. The initiatives followed through or in progress are testament to a committee that achieves momentum and cohesion. I thank all committee members most sincerely for the support and counsel they give to me as president and to each other.

Despite the many financial difficulties that many individuals faced due to the economic constraints of the Covid 19 pandemic, in 2021/22 many of you, your friends, your family, your work colleagues and the wider community in general 'dug deep' to donate to CleftPALS Victoria. Our fundraising and donations during 2021/22, was driven via our huge social media campaign during Cleft Awareness Week. The PayPal Giving Fund (through the Facebook platform) and our 'donate now' option on our website, also contributed greatly to our overall amount. I am so thrilled to announce that in 2021/22 we raised an incredible amount in donations total of \$10,063.10

At the end of the 2021/2022 financial year, CleftPALS Victoria had total funds of \$67,095.47. This is \$6,503.83 more than the previous financial year end for 2020/2021.

In 2013, I joined this community when I discovered that my daughter Ava was to be born with a cleft lip. The amazing support I received from this community is why I am so passionate in giving support back to CleftPALS. I am so grateful to have the amazing support of my husband and family, and most importantly, the committee members alongside me - we are a team! and a fabulous one at that!

We are a dedicated, hardworking team - and for this, I personally want to thank each and every one of them. This small group of big hearted men and women, with their

families, wives, husbands, and partners, are all here to help. We are passionate about supporting, educating and advancing the cleft cause. We achieved so much this past year and as President for the past 4 year we have continued to operate this organisation in a profitable manner with a record profit. I'm looking forward to what we can achieve in this coming year ahead.

Today I wish to announce that I will be standing down as President, after serving 4 years in this role. I will continue to be a general member on this committee, heading into my 9th year of service to this wonderful community. CleftPALS Victoria is one organisation that I am very passionate about and I hope that my services to CleftPALS Victoria is helping to make a difference.

Thank you all for attending today, all these smiles are just melting my heart.

Bridie Roberts, President.

## Our achievements this year include:

1. Continued improvement to our Website. This is always an ongoing project and we welcome and value your suggestions and input. <https://www.cleftpalsvic.com> is an informative and professional website. It should be everyone's first point of contact, as it contains a wealth of information, Hospital links, feeding and surgery advice and our online shop containing a wide variety of speciality feeding bottles and spare parts. Please jump online and have a browse.

2. New information flyers with updated Logo and Branding. One of our goals this past year was to 'freshen up' and re-design our CleftPALS information flyers and printed materials to include our new logo and branding. These have been updated and are featured in our NewBorn Care Packs, in our Bone Graft Packs and our new information flyers we aim to distribute to the RCH, MCH cleft clinics and Maternal Health Centres. We are thrilled with our new designs, which feature throughout our website, on social media, on our NewBorn and Bone Graft Care Pack bags.

We are always looking to seek a printing company to assist with low cost or donate their services so that we can continue to produce our flyers with a professional look. Please email us with details if you can assist us with our printing needs.

**CleftPALS**  
VICTORIA INC.

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VICTORIA INC.

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VICTORIA INC.

3. Study Prizes and Awards. Like our previous years, we will present four \$500 study prizes this 2022 year. They are awarded to outstanding student midwives at Deakin, Monash, Latrobe and Australian Catholic Universities. In 2021, due to the government guidelines and Covid 19 restrictions, these awards were held virtually. This year these award ceremonies are being held in person which is wonderful news.

4. CleftSTARS Victoria. CleftSTARS is a support group for children and young teens aged 8 – 20+ years. This past year we held a few zoom events and participants played quiz games such as Kahoot! These events are facilitated by the general committee members and with our CleftSTARS mentors who are young adults and were born with a cleft themselves. CleftSTARS is an extremely important youth forum and we are so excited to see the CleftSTARS community grow! We aim to hold 4 in person events per year. If you would like to be involved with CleftSTARS we are seeking general members and mentors to help facilitate this group, please reach out to us via email; Attention CleftSTARS [cleftpalsvic@gmail.com](mailto:cleftpalsvic@gmail.com) FaceBook group click here <https://www.facebook.com/groups/10150096288245134>



5. Social Media - FaceBook and Instagram. The importance of social media and immediate contact with other members of our cleft family cannot be underestimated. Because of this, we are constantly posting information via social media. Our Facebook Support Group is one of our main communication platforms, as well as our Instagram page and we have recently joined Twitter. The committee moderate them most strenuously. Our public Facebook Group is currently sitting at over 1,300 members and Instagram is continually growing with 500 followers. Our Facebook group allows cleft affected families to seek support and knowledge without the need to financially belong. As such our membership has suffered. These valuable dollars are missed. Please think about becoming a financial member and help support CleftPALS Victoria Inc.

**Instagram:** [@cleftpalsvic](https://www.instagram.com/cleftpalsvic)

<https://www.instagram.com/cleftpalsvictoria>

**Facebook Group:** [CleftPALS Victoria Support Group](https://www.facebook.com/groups/26750563559)

<https://www.facebook.com/groups/26750563559>

**Twitter:** [@CleftpalsV](https://twitter.com/CleftpalsV)

**6. Social Events.** Our annual family fun day and AGM for 2021 was held at the Monash Childrens' Hospital. We had a tremendous attendance and managed a successful event just prior to another Covid 19 outbreak and subsequently another lockdown. The feedback we received from many families that attended was, it was a fun-filled afternoon for the children and an opportunity for so many families to meet each other and share their journeys and experiences with one another.

Keep a lookout on our website and on the Facebook group for all our community events. Cleft Awareness Week in Australia is held annually from November 8th through to the 15th. In 2021 we had an enormous donation drive via our Facebook group and our Instagram campaign with the hashtags [#smileforlefts](#) [#cleftpalsvictoria](#) It began with an idea from our Ambassador, Jess Hosking. Cleft Awareness Week is one event in the calendar year, whereby we are able to raise much needed cleft awareness and donations for our organisation. We also held an online fundraiser, 'Paint Your Oscar Cleft Bear Cookies' drive. Many families participated and shared their photos via facebook of them painting and eating their cookies! Much thanks to The Sugar Cookie Box for their support with our Oscar Bear Cookies. I'm thrilled to announce this past year we raided a record amount of \$4400 during Cleft Awareness Week!, our largest amount thus far! We are absolutely thrilled with the generosity from our cleft community, members and the general public.

**7. Ambassador, Jessica Hosking.**

We are thrilled to have Jess continue to be our CleftPALS Victoria Ambassador. Jess is an inspiring woman and mentor to our community. She plays professional football for Richmond in the AFLW league and manages to volunteer her time to 3 charities to which CleftPALS Victoria is one. She was born with a cleft herself, and understands the arduous journey of cleft repairs with over 20 surgeries herself. Jess gives her time generously to supporting and raising cleft awareness with the wider community. The financial support via donations and mentorship she continues to bring to CleftPALS Victoria Inc. is appreciated so very much.

**8. Mr Joel Solomon OAM and Ruth Soloman.**

I wish to make special mention of the continuing support of our founding members Mr. Joel Solomon OAM. and his wife Ruth. I personally would like to thank Joel and Ruth for their continued support and advice. Joel continues to lobby extremely hard for CleftPALS Victoria. Thank you Joel and Ruth so very much for your continued support. We look forward to celebrating CleftPALS Victoria's 50th Anniversary next year in 2023.

## 9. Newborn Care Packages.



In 2020 we were very grateful to be the successful recipient of the Barwon Health Medical Staff Charitable Fund - the very generous \$5000 we received, along with donations received by CleftPALS Victoria has meant we are able to continue to provide cleft-affected families with newborn care packs for the next few years.

These Packs are given to families of newborn cleft affected babies throughout Victoria (and other states if members are financial). We are always seeking financial donations or corporate sponsorship so that we can distribute more of these care packs. This is one project that I am very passionate about and hope to continue for many years to come. We are extremely proud to be able to offer this ongoing initiative.

10. Bone Graft Care Packs. CleftPALS Victoria is pleased to announce that as of June 2021 our Bone Graft Care Packs have been available for you and your child, in preparation for their bone graft surgery.

The contents of this package will contain a \$30 Teen Gift card, a boredom buster toy to keep you occupied during your hospital stay. 1 x CleftPALS Fridge Magnet and Printed Information Booklets & links to some other information you might find helpful, such as recipes and recovery tips. Our packs will contain some practical advice from families who have undergone bone graft surgery, to help answer questions you or your child may have about preparing and recovering from this surgery. To date, we have posted 11 Bone Graft Packs to members of our cleft community, throughout Victoria.



## 11. CleftPALS Victoria Oscar Cleft Bear.

Our mascot Teddy has been redesigned and he is... oh so cuddly!! His name is OSCAR, which means "divine strength". Oscar will be distributed to all new financial members and included in our newborn care packs. Oscar is also available for purchase from our online store – He makes for really cute gifts!

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 organisation and stay viable. Please visit our website [www.cleftpalsvic.com](http://www.cleftpalsvic.com) or scan our QR code.



**12. Newsletters.** I'm so thrilled to announce that our Newsletters are a huge hit! A massive Thank You to our 2021 chief editor, Megan McIntyre who handed her role over to Kayla and Fiona during the year. I wish to thank Kayla and Fiona for their dedication to make these editions happen. These informative issues are distributed quarterly to all financial members.

Our issues contain articles about:

- \* AGM event details including guest speaker details.
- \* CleftSTARS event coming soon
- \* Meet the current President and read her report.
- \* Feeding and equipment - links to shop.
- \* Fundraising.
- \* Pictures of the Family fun days and social events
- \* Interviews with medical professionals
- \* Help and support advice.

If you have any ideas for future editions please don't hesitate to let us know via email to [cleftpalsvic@gmail.com](mailto:cleftpalsvic@gmail.com)

**13. Special Mention - Campaign to lobby the Federal Government to include Speech Therapy in the Cleft Lip & Palate Medicare Scheme.**

What a wild ride the last 6 weeks have been. I think the sub-committee has learnt more about politics and political lobbying in these last 6 weeks, than we have ever learnt in our entire lives. There's a lot of truth in the age-old quote from Socrates below. We need to be the change we want to see. And so it is with this in mind, that the [#cleftwordsmatter](#) began our campaign. From one conversation in the committee, and one request for a re-tweet by the inspirational Yasmin Poole – the campaign began. Grassroots all the way, we engaged the cleft community for the issues that mattered to them, and we took them to the politicians – those in power, and the hopefuls this election.

The subcommittee spoke to any politician who would speak to us. We told them our stories, and we told them how cleft care compared with the rest of the OECD world. We ran our Twitter account tightly and opportunistically – acting as a single voice for the cleft community. I want to acknowledge the hard work of the subcommittee:

- Jess Beckman, who has been relentless in her attempts to reach the media and politicians. Her hard work paid off in a story by Nine News highlighting the plight of cleft-affected children through a lack of accessible and affordable speech therapy.
- Philippa Morris, equally tireless with her efforts to contact speech pathology leaders around the country to understand the state of cleft care in each state system.
- Rina Bowden, who despite feeling unwell with COVID and cold weather ailments, put together the SurveyMonkey survey that gave us the insights we needed to form our proposal to the government.

I want to also acknowledge the collaboration between CleftPALS NSW and CleftPALS Queensland. Jo Myers, Tim Devlin and Belinda Heinze: thank you for gathering the cleft communities in your states, and thank you for sharing your stories with us.

A big thank you to all of you, for opening up to us and entrusting us to tell your stories.

Through this campaign, we have achieved the following outcomes:

- On building awareness, a lot more people are now aware that just because the cleft is 'fixed' as a baby, doesn't mean there does not continue to be structural issues that require surgical intervention.
- On addressing urgent cleft care, CleftPALS Vic have been contacted by Craniofacial Australia, who have offered to fund urgent needs of surgery and speech pathology. Waiting lists are long, and I am thinking of the cleft twins whose parents have been told their surgeries need to be delayed, leading to speech development delay. I am thinking too of the young man who contacted CleftPALS asking if we can help pay for his speech therapy before he goes for invasive surgical intervention.
- On ongoing solutions, we have met with a social enterprise named Umbo, who offer speech therapy via telehealth because they saw the accessibility issues for regional and rural communities. They have one speech pathologist with availability, and she specialises in clefts. For those who can afford it or have managed to get onto NDIS, at least they can get help right away. We are thinking of a little girl (5 years old) who lives north of Melbourne and who just started Prep, who managed to get onto NDIS and needs urgent help with speech.
- On pipeline on speech pathologists trained for cleft, we have made contact with a lecturer at University of Melbourne for the Masters of Speech Pathology about development of course content for future speech pathology graduates. We are also talking to Speech Pathology Australia about the development of this content so that it is accessible to all future speech

pathology students from any Australian university. There are further collaboration opportunities around bursaries and student contact with the cleft community through volunteering at CleftPALS and CleftSTARS events.

The work does not stop here. There is still much work to do. The first order of activity for the new CleftPALS Victoria committee will be to develop a new 3 year strategic plan – which will naturally include the work we need to do to build upon the achievements from this campaign.

Cheng Yeo - Grants Officer



“ How wonderful is it that nobody need wait a single moment before starting to improve the world ”

~ Anne Frank



**With thanks for their products and/or services today;**

**The Sugar Cookie Box** Jun-Ni creates customised fondant sugar cookies for your special occasion. She designed our custom Oscar Cleft Bear Cookies for today's event. Located in Chelsea, Melbourne. Click here to find her on facebook

<https://www.facebook.com/TheSugarCookieBoxAU>

## Amazing Kids Parties

Face Painting & Balloon Twisting ~ Corporate events to parties large and small. Thank you for creating a little 'sparkle fun' for all our children today! Click here to contact them for all your party entertainment.

<https://www.amazingkidsparties.com.au/>

## PROJECTS FOR THE FUTURE.

- \* Continue to produce our Newborn Care Packs, and distribute them to all new cleft affected babies born in Victoria, SA and Tasmania.
- \* Continue to produce Bone Graft Care Packs - to distribute these care packs to young teens and support them through their bone graft journey.
- \* Develop ways to encourage an increase in financial membership.
- \* CleftSTARS increased awareness and participation.
- \* Continue to campaign and lobby the Federal Government to include Speech Therapy in the Medicare Cleft Lip and Palate Scheme and NDIS
- \* Hire a storage facility to stock supplies & equipment of CleftPALS Victoria organisation.



## TREASURER'S REPORT 2020-2021

At the end of the 2021/2022 financial year, CleftPALS Victoria had total funds of \$67,095.47. This is \$6,503.83 more than the previous financial year end for 2020/2021. This is the fourth year in a row that we have made a Profit.

New membership for this financial year totalled \$735. Membership fees continue to cost \$35 for annual membership and \$90 for lifetime family membership. This year we received a total of 7 lifetime memberships and 4 annual memberships. This is \$1,730 below and 20 less lifetime memberships than the previous year.

The addition of the donation option to the Facebook pages and website have allowed for convenient and easy payment options via PayPal. The generosity of our community saw the donation total to be \$10,063.10. The promotion of Cleft Awareness Week in November and End of Year donation opportunities are when the majority of the funds are received.

Feeding equipment income was \$3,975.45, an increase of \$783.45 from the year before. Feeding equipment costs were \$1,020, which was significantly lower than the previous year by \$2,240. The introduction of Dr Brown's bottles have seen a shift in the buying preferences of our members.

This year also saw the closure of Cleft Lip and Palate Australia, whereby funds were distributed across the remaining active state CleftPALS accounts. CleftPALS Vic received a total of \$1551.58. Since 20 January 2014, CleftPALS Vic has been managing CleftPALS Tasmania's funds, which is currently \$3,707.79, with no continued sign of this becoming active again in the near future.

Tracey Ruse, Treasurer - Committee Member.

## STATEMENT OF CASH RECEIPTS AND PAYMENTS

1 April 2021 – 31 March 2022

Income	\$
Clancy Books	30.00
Donations	10,063.10
Event Income	660.00
Feeding Equipment	3,975.45
Fundraising	116.56
Grants	500.00
Interest	59.23
New Membership	735.00
Oscar Bears	160.00
Wonder Books	75.00
<b>Total Income</b>	<b>16,374.34</b>

## Expenses

Awards – Midwife	1,000.00
Event Expenses	2,232.92
Feeding Equipment Purchases	1,020.51
Gifts and Donations	385.50
Insurance	1,426.26
Office Expenses	1,861.80
PayPal Fees	123.54
Postage and Delivery	1,196.80
Printing and Reproduction	62.98
Refund	225.80
Telephone	70.00
Website	264.40
<b>Total Expenses</b>	<b>9,870.51</b>

<b>Net Income</b>	<b>6503.83</b>
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## Opening Accounts

<b>Balance as of 31 March 2021</b>		<b>\$</b>
	PayPal Account	200.00
	Westpac Cash Reserve	10,442.31
	Westpac Community Solutions Cheque Account	16,709.04
	Westpac Term Deposit	33,240.29
	<b>Total</b>	<b>60,591.64</b>

## Closing Accounts

<b>Balance as at 31 March 2022</b>		
	PayPal Account	1,039.77
	Westpac Cash Reserve	10,443.28
	Westpac Community Solutions Cheque Account	22,313.87
	Westpac Term Deposit	33,298.55
	<b>Total</b>	<b>67,095.47</b>

## **SOCIAL MEDIA REPORT 2021-2022**

During 2020 it was decided to have a social media coordinator 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 2021/2022 the Facebook support group has grown to 1.3K members. This group can only be accessed privately with members needing to answer membership questions to be accepted. This group allows members to connect with other members, asking questions and sharing experiences. The committee moderate this content strenuously to ensure it stays as a supportive and safe sharing space. On the support page CleftPALS Victoria is promoted and facilitates a safe sharing space. CleftPALS Victoria's Instagram account has grown from 342 to 500 followers this past year and is able to be viewed publicly. Instagram promotes CleftPALS Victoria; personal stories are shared and general cleft information is posted. Social media allowed Cleft Awareness Week 2021 to still go ahead virtually. The online campaign raised a substantial amount of money purely virtually. With the two platforms it has become apparent that it is difficult to have financial member exclusive information. This will be further investigated in 2022-2023. <https://www.instagram.com/cleftpalsvictoria/>

Rebecca de la Bere, Social Media - Committee Member.

## **FEEDING AND EQUIPMENT REPORT 2020-2021**

Hi, my name is Kirsty and I am the Feeding and Support Committee Member. The feeding and equipment hotline has continued to be an important point of contact for new parents and family members of cleft affected 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 from nil to three or four orders in a week. Newborn care packages produced with grant money from Barwon Health continue to be provided to new babies and their families.

The CleftPALS Victoria Facebook page 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 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. Unfortunately, we are no longer able to source stock of Chu Chu teats. 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 - Committee Member.](#)

## **NEWSLETTER REPORT 2020-2021**

Newsletters have continued to be emailed directly to financial members each quarter and our audience is growing in number each edition.

The newsletter is provided as an added benefit to our financial members and includes latest news and updates, happenings behind the scenes that might not have been communicated via the Facebook support group, and other stories of interest.

Standard articles include: an update from the President or committee; what is happening among our CleftSTARS group; and what's new or available from the CleftPALS store, such as feeding equipment, Newborn or Bone Graft Packs and Oscar the teddy.

Recently, our Cleft Nurse Coordinators at Royal Children's and Monash Children's Hospitals have also kindly come on board to provide a quarterly update. In addition, we have introduced a wellbeing column thanks to one of our CleftPALS mums who is also a certified wellness coach.

A focus for our newsletter editors has also been to include a member's profile or medical story of interest, which is usually based on popular topics or common questions being asked via the online support group. Thank you to our parents and medical professionals who have shared their personal stories or knowledge with our cleft community - we love sharing your stories with our community.

It is important to us to provide topics relevant and important to you so if you would like to contribute a story or idea, please reach out via email at [cleftpalsvic@gmail.com](mailto:cleftpalsvic@gmail.com)

[Kayla Doncon & Fiona Wallace, Newsletter Editors - Committee Members.](#)

## **GRANTS OFFICER REPORT 2021-2022**

This year, we applied for 4 grant applications from VicHealth, Sunsuper, Barwon Health Medical Staff Charitable Fund and Westfield.

We express our gratitude to members and their friends/families who have helped CleftPALS Victoria put in a grant application.

We also want to thank our members who have volunteered their heartfelt stories and experiences, which were included in some of these grant applications. We are very grateful to be the successful recipient of the Barwon Health Medical Staff Charitable Fund - the very generous \$5000 we received, along with donations received by CleftPALS Victoria, has meant we are able to continue to provide cleft-affected families with newborn care packs for the next few years. CleftPALS Victoria is seeking grant funding to be able to support our tween and teenage cleft community. Over the pandemic, we recognised the significance of staying connected and successfully ran virtual meet-ups for our CleftStars community. The grant funding we are seeking will enable us to complement the virtual meet-ups with small group, in-person meet-ups.

[Cheng Yeo, Grants Officer - Committee Member.](#)

## **CleftPALS Victoria Inc. - AGM 2022 AGENDA**

1. Opening of meeting
2. Apologies
3. Presentation of Annual Reports  
by President Bridie Roberts
4. Presentation of Treasurer's Report  
by Treasurer - Tracey Ruse
5. Open forum - question time.
6. Elections
7. Vote of thanks to outgoing committee members.
8. Urgent general business
9. Closure