

## JUNE 2021

Welcome to the June edition of the Kawasaki Disease Foundation Australia newsletter.

We wanted to acknowledge and thank all our KD heroes in our community – our KD kids, parents, siblings and extended family, our volunteers, and all of our fundraising allies.

The strength and courage you each show to support one another is phenomenal! We have seen this time and time again and we know that your contributions reach far beyond our KD community. Thank you for supporting each other and raising KD awareness.

We encourage you to participate in Hero 4 HeartKids day, or share the fundraising venture of KD champion Lane McNeill who is hiking the Bibbulmun Track. We are privileged that Lane has chosen the KD Foundation Australia as the charity of choice for this challenge, and committed to raising KD awareness.

Also featuring in this newsletter is the story of KD hero Rhea and a media article about KD hero Aurora. You can also view our recently launched KD awareness video featuring KD researchers David Burgner and Catherine Chen, and KD heroes Billie-Grace and Quinn, and their families.

We also welcome our new committee member Mel, reflect on KD awareness day/month for 2021, and start planning for 2022. Our first webinar KDAU & You was a great success and we anticipate facilitating further webinars in the future! If you have a KD topic that you would like us to consider, please let us know!

We have joined Shopnate, which is a fundraising platform for online shopping. There are a lot of stores where you can purchase all kinds of products from, so if you are an online shopper, this is a great way to contribute to fundraising for the Foundation.

We are also looking forward to the 13<sup>th</sup> International Kawasaki Disease Symposium in October which is being held as a virtual event for the first time. This a great opportunity to network with other KD communities and hear the latest KD research and developments.

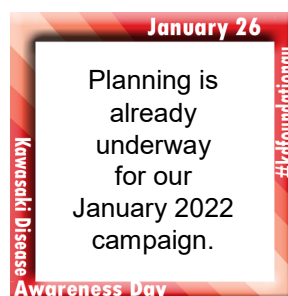


**KD Foundation Australia committee**

## Kawasaki Disease Awareness Day campaign 2022

We would love to share more KD stories in our next campaign and are keen to hear from anyone that would be comfortable sharing their KD story.

Our KD community would also love to hear more stories from adults that have had KD and any challenges you have faced, or even if KD didn't have any long term impact.



Whether you were diagnosed as a child, or didn't find out until later in life following a cardiac event, we'd love to hear from you!

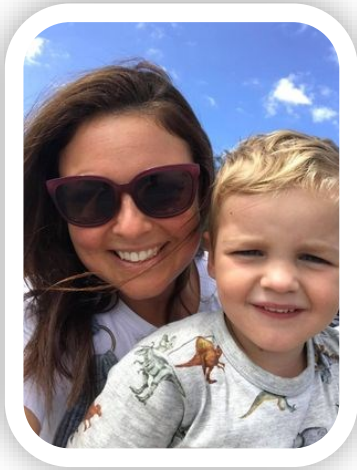
If you would like to share your story, or would like further information, please send us an email, or contact us via message on Facebook or Instagram.

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## OUR COMMITTEE

We welcome Mel Copas, our newest committee member, and NSW State Co-Ordinator.



*Hi KD community, my name is Mel and I am looking forward to working with the committee.*

*I am a Mum of three awesome little people and we live in Wollongong NSW. We were first touched by KD a year ago with our third child Sam, who was two at the time. It was such a whirlwind, and in all honesty, very scary!*

*We are still monitoring his coronary involvement so the journey continues. I decided to get involved as I truly believe communities like this are so important - both to know you are not alone and to get access to quality information.*

Thanks Mel, and we are thrilled to have you join us!

### KDF OFFICE BEARERS

**President** Bec Wilby

**Secretary** Shirley Mates

**Treasurer** Brent Anderson

### State Coordinators

**QLD** Meagan Mitchell

**NSW** Melissa Copas

**TAS** Penny Scott

**SA** Nidal Raslan

**WA** Simone Staadan

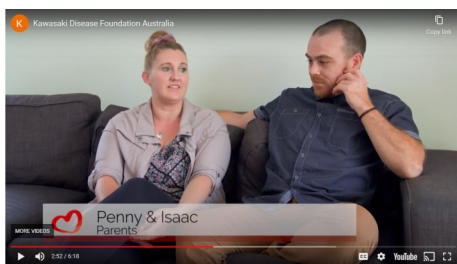
### General Members

Cam Mates

Isaac Long

## VIDEO LAUNCH

Listen to Dr Burgner, Dr Chen, and KD parents talk about the impact of Kawasaki Disease, in our new video. You can view the [video](#) on our website.



Dr David Burgner and Dr Katherine Chen, KD researchers from the Murdoch Children's Research Institute, provide their expertise on Kawasaki Disease including symptoms, treatment, and affects on the coronary arteries and heart.

We also hear from KD parents Rebecca, Penny and Isaac.

Rebecca's son Quinn had Kawasaki disease in 2011 and again in 2012, his second case resulting in coronary artery damage which returned to normal ranges over time.

Penny and Isaac's daughter Billie-Grace had Kawasaki Disease in 2014 resulting in acquired heart disease and a heart bypass.

[Kawasaki Disease Information Video - KD Foundation](#)

## Hero 4 HeartKids Day—Friday 18 June 2021

Is your child a hero? Heroes come in all shapes and sizes!

To support all of our heart kids that have acquired heart disease, you may like to get your child's day care, preschool, kinder, school, or even your workplace involved in Hero 4 HeartKids.



It's a great way to have fun while dressing up in that favourite superhero outfit on Friday 18 June.

For more information on how to get involved visit

[www.hero4heartkids.org.au](http://www.hero4heartkids.org.au)

## KD Awareness Day 2021 reflections

January 2021 was filled with Kawasaki Disease awareness, leading up to KD Day on 26 January.

Our campaign this year focused on sharing statistics of Kawasaki Disease in Australia, sharing stories of children that had been diagnosed with Kawasaki Disease, and our first ever webinar!

We thank you all for liking, sharing or commenting on our social media posts, or adding one of our KD Day frames to your profile picture on Facebook.

Every little bit of your actions has helped to reach thousands of people, generating more and more awareness of Kawasaki Disease each day! Thank you!



Special thanks again to:

- ◆ Belinda Roper
- ◆ Izzy Smith
- ◆ Emma Dudman
- ◆ Katrina Paizis
- ◆ Megan Crisp
- ◆ Veronica Nou
- ◆ Kate Elise

for trusting us to share your KD journeys.

We know that it is not always easy to write about tough times, however your stories have been one of the most talked about elements of KD awareness and have certainly resonated with many others.

## IKDS

13th International Kawasaki Disease Symposium (IKDS) - online event

**Friday 29 to Sunday 31 October 2021**

A fabulous opportunity to hear the latest in Kawasaki Disease advancements around the world.

The Japanese Society of KD are in the process of organising the parents/family session to connect and collaborate with KD support groups across the world. Such sessions have previously been attended by some of our KD community and are highly valuable. This is planned for the second day of the Symposium and via a virtual event rather than face to face so we hope as many of our KD community as possible can join in. More information will be available soon.

Registrations to attend open in July.

<https://site2.convention.co.jp/13ikds/>



*“Kawasaki Disease:  
Studying the Past  
to Create  
the Future”*

## Shopnate—an easy way to fundraise!



Do you love shopping? Online shopping? Well you can now participate in fundraising through the shopping platform Shopnate!

We have recently registered with Shopnate and each time you shop with one of the retailers via

Shopnate, they will make a donation to the KD Foundation!

Stores include ebay, Bonds, Ticketmaster, Cotton On, Catch, Hello Fresh, Kogan, Vistaprint, Boohooman, Millers, Pet Stock, AirBnB, itunes, Uber Eats, MAC, Wiggle, Lorna Jane, Fossil, BCF, Sony, Surf Stitch, asos, Pharmacy Online and hundreds more!!

If you'd like to support us with this fundraising opportunity, sign up to Shopnate to participate, select the KD Foundation as your fundraising recipient, and commence shopping, at no extra cost to you! Too easy!!

[Shopnate—Kawasaki Disease Foundation](#)

## Kawasaki Disease in the media

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During KD Awareness Month, Kidspot featured a story on Aurora Mitchell who developed the first signs of KD at just four weeks old.

[Kawasaki disease: Mum shares the importance of trusting your gut - Kidspot](#)



## Fundraiser by Lane McNeil

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Lane McNeill's niece Chloe is a Kawasaki Kid, having been diagnosed with KD at just 8 months old.

Lane is embarking on an epic fundraising challenge to hike the Bibbulmun Track, one of the world's great walking trails at 1000km long, stretching from Kalamunda in the Perth hills all the way down to Albany!

The Nyoongar people are the traditional owners and custodians of the land of the Bibbulmun track.

The track has breathtaking karri and tingle forests, valleys, giant granite boulders and coastal heathlands.

Lane's goal is to complete the challenge in 6-8 weeks.

We would appreciate your support of Lane's fundraising target and encourage you to share Lane's [Gofundraise](#) page, to support his quest to raise awareness and funds for the Kawasaki Disease Foundation.

We look forward to following Lane's journey!

## Social Media

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Instagram  
256 followers



Facebook page — 544 followers  
Facebook Support Network — 386 members

Our presence on social media continues to increase and we appreciate your support in engaging and sharing our content.

The more people we reach, the more we are raising awareness of Kawasaki Disease!



## KD Kids Corner

**Name:** Rhea

**Diagnosed:** April 2020

**Age:** 9 months old

**Diagnosis:** Kawasaki Disease with dilation which regressed to normal range



Thank you Kate Elise  
for sharing your daughter  
Rhea's KD story.

Rhea became unwell in February 2020 with a cold/flu and had a significant cough that lingered for 6 weeks after she got better. We had taken Rhea to the doctor multiple times who assured us she just had a viral infection and it would take a while to pass.

On 26 March, at 9 months of age, Rhea became very lethargic and had fevers above 39 degrees. We took her to our local hospital that night who thought she may have mild pneumonia. Swabs were taken as this was about the time that COVID-19 first hit Victoria and we were sent home.

The next night we were back in the hospital with Rhea as she was very dehydrated, she was given pain relief and fluids and we were sent home - still with a fever. The next morning Rhea had a few little red dots on her back and chest, and within an hour or so we were back at the hospital with Rhea being covered almost head to toe in a very nasty rash.

Rhea was so dehydrated that the doctors and anaesthetists tried for hours to find a vein to administer fluids and pain relief and were unsuccessful. We were then transferred to a bigger hospital. Rhea was so swollen she was barely recognisable, her eyes were completely bloodshot, and her rash now covered her entire body.

After a few days of lots of tests with no answers we were fortunate enough to meet a doctor that suggested Kawasaki Disease. On day 7 since the beginning of fever, the team decided to treat Rhea with IVIG overnight while she slept. We were so fortunate that this doctor picked up on it sooner rather than later.

Rhea was sent home 4 days after receiving the treatment, only requiring steroids and aspirin for a short period after being released from hospital. After her follow up echocardiogram showing that the slight dilation from the first scan was totally gone, Rhea was discharged with absolutely no lasting effects from Kawasaki Disease.

## Contact Us

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**Kawasaki  
Disease**  
Foundation Aust.

