



**Kawasaki
Disease
Foundation Aust.**

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December 2019 Newsletter

Dear KD Friends and Families,

At this time of the year we find ourselves wondering where the year went. With a blink of an eye, 2019 is almost over and 2020 is fast approaching. We would like to take this opportunity to wish you all a Merry Christmas, and a safe and Happy New Year.

This edition of our newsletter is devoted to a summary of our year and news about our KD Awareness Day (January 26) campaign for 2020. We will be sharing information about how you can help with awareness through this campaign very soon. Every bit of awareness we can generate helps to protect tiny hearts and ensures children are protected for years to come.

In this edition:

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- Vale - Mrs Kawasaki
- KD Awareness Day 26 January 2020
- Meet a KD kid
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We trust you will find this newsletter and the information it contains informative.

Warm regards,

The KD Committee



2018-2019 Achievements (from the President's AGM report)

The Kawasaki Disease Foundation held several strategic meetings this year, including our strategic business planning objectives where our 2018-2019 Business Plan was written, outlining our major goals for the year. We have a number of key focuses for the immediate future such as a brand refresh including our merchandise and carer packs, complete website update and refresh of our fundraising page – Go Fundraise.

In addition to this, the committee has held many events this year and fundraising awareness campaigns such as:

1. Comedy Night: key acts were comedian Bev Killick and magician Tim Ellis
2. HeartFest: run by KD Parent Isaac Long
3. Participation from committee members, their family and friends in fundraisers such as Gold Coast and Melbourne marathons
4. Launch of new Facebook page and relaunch of the Facebook group with a new name and lots of new members to both sites
5. Launch of new Instagram page allowing us to get more likes, followers and social media presence
6. Various awareness days such as Superhero Day at day care centres, and Grilled Burgers campaign
7. Multiple Fundraising tins in various locations in South Australia (managed by our SA Rep, Nidal Raslan)
8. Participation in HeartKids events in WA, VIC, TAS – wearing KD shirts to help raise awareness and carrying Acquired Heart Disease flags

We are excited about what's coming up and the projects we are working on for 2020:

1. Anticipated launch of our new website in January 2020
2. KD Awareness Day campaign – month of January, KD facts, social media push, KD awareness day event 26 January(?)
3. Working with HeartKids to ensure KD information support packs are at all hospitals where a HeartKids representative/office is, and handed to any new KD parents
4. Updating merchandise
5. Continue to work with State Co-ordinators for localised events
6. Social media campaign – hope to engage a Fundraising & Social media volunteer to assist with driving this.

With the relaunch of our website in January 2020 we hope to do a big social media campaign to boost likes and followers to all our sites in order to help raise awareness.

We would like to give a special thank you to the businesses, families and individuals that have supported the Foundation throughout the year, whether it be through donations, fundraising, raising awareness, or engaging through our social media channels. Our Foundation would not be successful without all your support.

We are also very fortunate to be able to continue to work very closely with our Medical Advisor, Professor David Burgner – without him we would not be able to provide the expert knowledge and guidance that our families need in those early days of diagnosis and beyond. Professor Burgner's support, time and dedication to the Foundation is truly valued. He continues to participate in research studies within Australia in the hope that we may find some more answers about the unknowns of Kawasaki Disease.

Vale

The KD Foundation was saddened to hear of the passing of Reiko Kawasaki, the lovely wife of Dr Tomasaku Kawasaki.

Reiko accompanied Dr Kawasaki to all his professional events and was a key supporter of his Kawasaki Disease endeavours. Some of us were privileged to have met Reiko, most recently at the International KD Symposium 2018. Reiko will be remembered for her welcoming smile, endearing qualities, and her support for KD research and awareness.

The KD Foundation sent their love and sympathy to Dr Kawasaki and their family, on behalf of all of the Australian KD Community.



Quinn Bailey with Mr and Mrs Kawasaki at the International KD Symposium in Japan 2018

26 January 2020

10th International Kawasaki Disease Awareness Day

We are all familiar with 26 January being Australia Day, but did you know that 26 January is also celebrated in many countries around the world as Kawasaki Disease Awareness Day? Not only that, but for all of January leading up to the 26th, is a time to promote KD awareness!

What are we doing and how can you participate?

KD QUIZ VIA SOCIAL MEDIA: We will be posting quiz questions, facts and information throughout January on our social media platforms – Instagram and Facebook. We would love EVERYONE to get on board, give it a shot at answering the quiz questions and SHARE, SHARE, SHARE all our posts to your friends, family, and other networks. #getKDonthemap #kdawarenessdayAU2020
There will be a prize for a randomly chosen winner so tune in to our social networks for more info!

If you have not already joined our KD network (a closed group of Australian KD parents) please join us here <https://www.facebook.com/groups/kdforumaustralia/> and if you haven't already liked and shared our new Facebook page please check it out <https://www.facebook.com/kawasakidiseaseau/> or Instagram <https://www.instagram.com/kdfoundationau/>

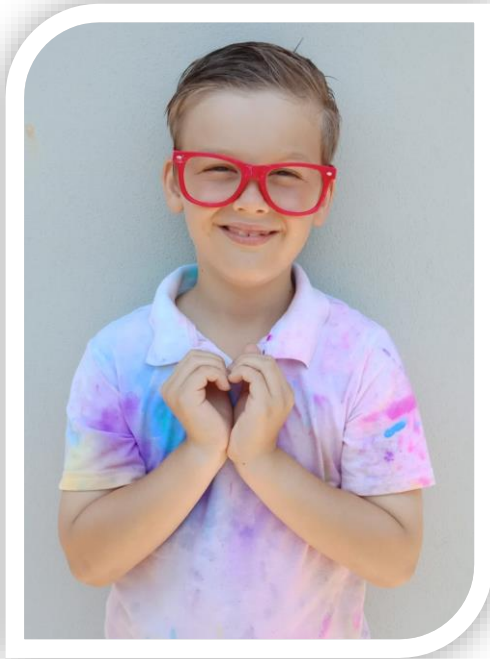
RESEARCH CAMPAIGN FUNDRAISING: We are excited to announce that we have just been advised of a new KD research proposal coming out of the University of Western Australia!! The research focuses on the long term effects of KD, of which little is known. Prof Burgner, our medical advisor, although now based at the Murdoch Children's Research Institute at the RCH in Melbourne, is a co-investigator with this study. This is an amazing opportunity to collaborate with the Uni and our aim is to contribute \$10,000 from the KD Foundation toward the research. We would love your support to fundraise throughout the first half of 2020 for this purpose. The KD Foundation will match community fundraising dollar for dollar, up to a maximum amount of \$5,000. Please keep an eye out for our fundraising details as we need as much support as possible to reach our target!

HEARTWORK COMPETITION: For the young and old creative members of our community, we are having a Heartwork (artwork) competition!! Why Heartwork? We all know that a child's heart can be affected by KD so we are seeking Heartwork to include in our brand-new Parent/Carer information packs that will be distributed to families in hospitals when a child is diagnosed with KD. We would like to include some pages for children to colour in, so we are seeking black and white drawings suitable for young children. Heartworks can be drawings, dot to dot, mazes or other activity sheets, but must have a heart included.

Entry is \$5 per submission via our GoFundraise page to contribute toward our fundraising target for the upcoming KD research campaign. All submissions need to be on A4 paper, clearly scanned and emailed to info@kdfoundation.org.au with the subject heading 'KD Day HeartWork comp'. Please include evidence of your GoFundraise donation with your submission. Closing date for submissions is 26 Jan 2020. Our GoFundraise can be found at <https://www.gofundraise.com.au/beneficiary/KawasakiDiseaseFoundation> just select the 'donate' option to get going. Entries will be shared on social media and there will be two prizes awarded – people's choice, and KD Foundation choice! (Australian residents only eligible for prize).

Your artwork may just make a difference for the next KD kid during their time in hospital.

Kawasaki Kids Corner!



Today we feature one of the KD kids from our KD community. This is young Alexander Dorbek, who suffered from KD at 8 months old. Now 7 years old, Alexander recently had a blast doing the Colour Run at his school. Alexander wanted to pose for the camera with a heart, how adorable!! He has a heart full of love, and judging by the t-shirt, the colour run looks like it was loads of fun!!

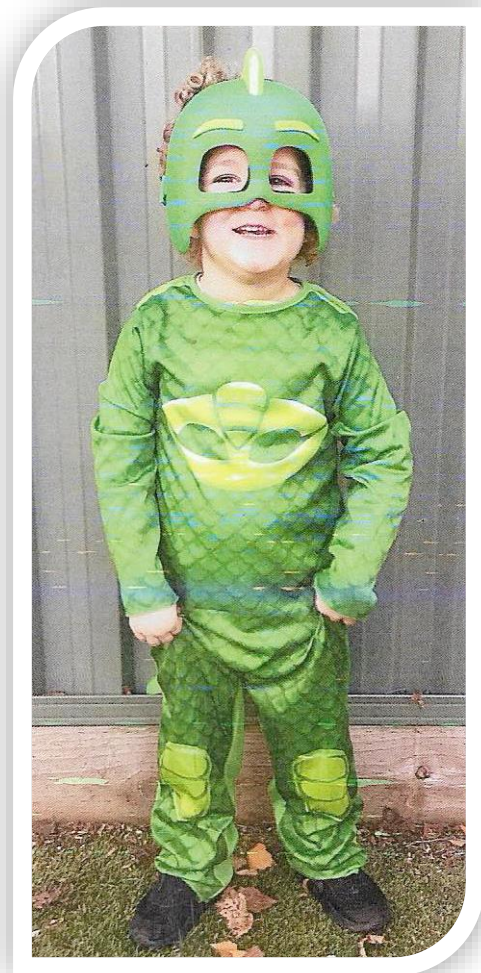
(Photo used with permission)



On 3 July 2019 a child care centre celebrated of SUPERHERO DAY!!! Children all came dressed as their most favourite superhero, young Rafy Mitchell pictured.

This event was organised to help raise awareness of Kawasaki Disease, and information was shared in the child care community that KD is the #1 cause of acquired heart disease in children yet is still so foreign to many of us, including our medical experts.

Children engaged in an event artwork making the Superhero cityscape by pasting paper to create buildings. What a fun day!!
(Photo used with permission)



If you know a KD child that would like to be featured in a future newsletter, please email info@kdfoundation.org.au

HeartKids Two Feet and A Heartbeat Walk

On 8 Sept, some of our KD Community participated in HeartKids Two Feet & A Heartbeat 4 km walks.

This year these were held in around 30 different locations all over Australia in honour of the four lives lost to congenital or acquired heart disease every week, with furry friends welcomed too.

The rain held off in Melbourne till just after the morning's walk and activities finished. In Perth, our WA coordinator Simone Staden and her 2 boys, had beautiful weather!

We hope to see many more of you at one of next year's walks as they provide another opportunity to get Kawasaki Disease more commonly recognised in Australia.



The KD Foundation is excited to announce we are strengthening relationships with HeartKids, to help spread awareness of KD and how it is the leading cause of acquired heart conditions.

They will be assisting us to distribute our new carer packs to families of newly diagnosed KD children while they are in hospital.

This is something we hope to be able to expand to as many hospitals around Australia as possible. If this is something you may be able to assist us with (you may work or have contacts in a hospital) we would love to hear from you.

Societi -UK

We are very aware of the importance of establishing and strengthening as many links as possible with other KD groups and medical researchers so we can all liaise, share ideas and assist each other in our fight to spread awareness of Kawasaki Disease.

We have had a very strong relationship with the US KD Foundation going back a long time, and since 2015, regular contact with the Japanese Parents Association. We also have contacts in the UK, Canada, NZ as well as other countries through the various Forum groups. We appreciate their assistance in directing parents to us when they are the first port of contact.



Facebook post from our fabulous friends at Societi:

WE HAVE MAIL....FROM DOWN UNDER...!!

..And we just LOVE the "Kawasaki" Koala - look at him!

In discussion with Shirley, who is an immense driving force behind Kawasaki Disease Australia, we recently posted a parcel with a Societi GP Pack, a Nursery Pack and a few more bits and pieces - to share our awareness raising approach and a few Societi merchandise items with their organisation.

A HUGE thank you to the lovely Shirley for returning the favour and sending these brilliant awareness raising concepts from the other side of the world! Oh, and some Australia goodies too!! Here are some of the fabulous ideas that are really inspiring us here at Societi HQ today - even a Kawasaki Disease bandanna...!!

Our hope is that in sharing our information, ideas and approach, we can support one another as we all fight just as hard - wherever we are in the world, to combat Kawasaki Disease - TOGETHER we will!

Kawasaki Disease is a GLOBAL concern and working together we can make change happen. We're looking forward to many more conversations and continuing to work together, despite the miles, to protect children's hearts from Kawasaki Disease!

[#TeamSocieti](#) [#Partnership](#) [#ForOurChildren](#)

Recent Fundraisers

On 7 July, our newly appointed President Meagan Mitchell, organised a small team to run in the Gold Coast Marathon to help raise funds and spread awareness of KD. This was Meagan's first marathon, but we know it won't be her last! Then in October, Meagan's husband Ryan, took part in the Melbourne Marathon. We are sure it won't be long before these become family events with the kids taking part as well.

These fundraisers were run through our GoFundraise page which is a great avenue for anyone to create an event of any sort or take part in one of the many events run in all States of



Australia.

We will be posting fundraising opportunities, and events you may wish to participate in throughout the year on our social media pages. Our GoFundraise page also has a list of events which is constantly being added to. GoFundraise allows supporters an increased range of ways to fundraise. These can be direct donations, a personal challenge (in the past we have had supporters compete in marathons/half marathons) or special occasions.

There are a few different groups like GoFundraise that collect donations on behalf of various charities. However, you do not have to go through the particular one that is coordinating the event as you can still raise funds for the KD Foundation by creating a page on our GoFundraise:

<https://www.gofundraise.com.au/beneficiary/KawasakiDiseaseFoundation>

Please contact us if you have any questions about how this works. We are more than happy to assist you with setting up your own page.

This is what Meagan posted on her page set up:

Hi there!

I'm making a difference and running for a cause that's close to my heart.

My Daughter Aurora was diagnosed with Kawasaki Disease at just 7 weeks of age. She was misdiagnosed on a number of occasions and due to this she went into cardiac arrest and we nearly lost her. The damage to her coronary arteries was severe (and still is), she is on Warfarin & Aspirin. I'm running to raise funds and more importantly awareness about Kawasaki Disease. In Australia there are about 400-500 cases a year, but the studies are inconclusive and inaccurate, so I believe there are more and it's on the rise.

It's the #1 cause of acquired heart disease and can affect children of any age. If picked up within a 10 day window it can be completely treated with no damage allowing the child to live a normal life. If not treated within that window aneurysms can form in the coronary arteries and can lead to heart damage or worse, death.

Please support my efforts by making a secure online donation and by posting a message of support.

Donations made through this platform are secure and will be remitted directly through to my charity of choice.

Thanks so much for your support!

The Mitchell Family x

