



JANUARY 2021

Thank you

2020 has been an interesting year to say the least!

The COVID-19 pandemic has seen a worldwide spotlight shine on Kawasaki Disease, one that could never have been anticipated!

Although this was unexpected, we embraced the positives including media opportunities to raise awareness, and collaboration with other Kawasaki support organisations across the globe to provide a consistent global response to concerns that were raised within the KD community.

Our medical advisor, Professor David Burgner, was instrumental in providing prompt information and advice, which helped to ease the

minds of many parents across the nation, regarding any potential impact of COVID-19 among our KD kids and adults.

The spotlight on Kawasaki Disease brought a number of new members to our community network as well as new volunteers. We appreciate everyone's contribution and support to each other throughout the year and into the future!

It always makes it that little bit easier knowing we can reach out to someone that has walked in our shoes, even if each KD story is unique!

Much love and wishes for a fabulous and healthy 2021!

 **KD Foundation
Australia committee**



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Kawasaki Disease Awareness Day campaign

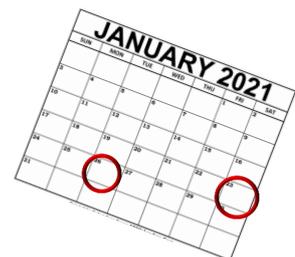
Every January we capture the essence of Kawasaki Disease and promote as much awareness as we can.

Kawasaki Disease Awareness Day (January 26) initially began in the US eleven years ago and has since been embraced by many other countries as an unofficial global recognition of Kawasaki

Disease. The date is significant as it is the date that Dr Kawasaki first saw a patient with symptoms of what is today known as Kawasaki Disease.

Please keep an eye on our social media platforms throughout January in the lead up to KD Day. We will be sharing KD facts, Information, stories and

holding a webinar on January 23! We'd love your participation!



Vale Dr Tomisaku Kawasaki



Dr Kawasaki

25/02/1925 — 05/06/2020

Age 95

Dr Kawasaki was the pioneer of Kawasaki Disease as we know it today. Dr Kawasaki observed a number of patients with a set of symptoms and identified a new illness which was firstly coined Mucotaneous Lymph Node Syndrome. It later became known as Kawasaki Disease, aptly named after Dr Kawasaki due to his scientific discovery.

Dr Kawasaki worked tirelessly throughout his career and beyond, having an unwavering commitment to ongoing research in a hope to find the cause of Kawasaki Disease. Unfortunately this was not to occur in his lifetime, as despite many theories and advances in

the medical field, the cause remains unknown.

However his legacy continues on under the guidance of countless researchers and medical specialists, as well as continual awareness raising of KD globally.

A gentle and compassionate man, he made an impression on all those he met. He leaves many of the KD Foundation Australia members with beautiful memories of his kindness and passion for KD. He will be greatly missed.

You can read tributes to Dr Kawasaki here:

www.jskd.jp/memory/index.html

Vale Mr Man Asai

We were deeply saddened to hear of the sudden passing of Mr Man Asai on 27 September 2020.

Mr Asai was the President of the Japanese Association of Parents with Children with Kawasaki Disease, and had been involved in raising awareness of Kawasaki Disease for 39 years.

Mr Asai is humbly remembered by a number of representatives of the KD Foundation Australia



Mr Asai with Association colleagues and Mr & Mrs Kawasaki

who attended the 12th IKDS in Yokohama 2018 and had the pleasure of meeting Mr Asai. His hospitality and warm welcome was testament to his personality and he will be sadly missed within the KD community.

It is hard when great leaders pass away, however we know that the work of Mr Asai will continue on with the Japanese association and their connections with research and other support organisations.

HeartKids

We continue to strengthen our partnership with HeartKids, who provide a range of services and support to children and adults (and their families) who have been affected by childhood heart disease, including congenital and acquired conditions such as Kawasaki Disease.

Did you know that HeartKids recently updated their website to include information about KD and a link to the KD Foundation Australia website? Take a look, you might also be interested in participating in their upcoming events such as Sweetheart Day on 14 Feb.

www.heartkids.org.au



COVID-19 and Kawasaki Disease



When the first headlines emerged of COVID-19 and a possible link to Kawasaki Disease, we were all shocked and went straight into resourcing as much information as we could!

This included liaising with our medical advisor Dr David Burgner, and other KD experts, as well as working closely with other KD support organisations across the world. This provided us with a wonderful opportunity to strengthen our networks, and we look forward to future opportunities to continue these collaborations.

Although the illness associated with COVID-19 shared similarities with KD symptoms, it

is identified as a separate illness under the label of Paediatric Inflammatory Multisystem Syndrome temporarily associated with SARS-CoV-2 (PIMS-TS).

We contributed to the Shared Statement in response to COVID-19, with the following organisations:

- Rari ma Speciali, Kawasaki Disease Italy
- Kawasaki Disease Canada
- Societi, the UK Foundation for Kawasaki Disease
- Asenkawa, Asociacion
- Enfermedad de Kawasaki Spain

The Shared Statement is available to view on our website.

Our then president, Meagan, also appeared on 9NEWS. This resulted in an influx of contact from people that had either been diagnosed with KD in the past, KD discovered in adulthood following a missed childhood KD diagnosis, and newly diagnosed KD cases. We are grateful to everyone that has connected with us, for the questions that you have raised, for sharing your experiences, and mostly for supporting each other through a challenging time. Thank you!

Please visit our website kdfoundation.org.au to view COVID-19 resources.

IKDS

The 13th International Kawasaki Disease Symposium (IKDS) is to be held over the weekend of Friday 29 to Sunday 31 October 2021. The theme is Kawasaki Disease: Studying the Past to Create the Future.

Originally scheduled to take place in Tokyo, Japan, this has now been moved to a virtual event. This is a fabulous opportunity to make the event

accessible through virtual attendance and is open to medical professionals, researchers, patients and their families around the world.

Registrations to attend will open in July 2021. Keep an eye on the IKDS website for further information.

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



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

Blood Donation



People of all walks of life need donated blood products, and we know all too well the importance of Intravenous Immunoglobulin (IVIg) being the effective treatment in most cases of KD.

IVIg is a byproduct of human plasma donation, containing antibodies that assist the fight of inflammation in KD patients. It takes thousands of donors to make the IVIg needed for our KD kids!

*“The need for blood
doesn’t stop for
the holidays”*

We understand that blood donation is not for everyone, not everyone is eligible, and some of you already undertake this life saving contribution. If you are interested in finding out more, visit the Australian Red Cross Lifeblood website for up to date information:

www.donateblood.com.au

Recap of Kawasaki Disease in the media

If you missed any of the news items throughout the year, head to the resources section of our website for more information where you will find interviews with Meagan Mitchell and Professor David Burgner, including:

- 9NEWS
- Healthed Podcast
- ABC News



Aurora & Meagan Mitchell

www.kdfoundation.org.au/resources/

KD Diagnostic Test

Well it is not here yet but it is on the way!!

SkylineDx has collaborated with Imperial College London and University of California & San Diego (UCSD) to develop a diagnostic test for Kawasaki Disease. This is something the KD community have been waiting on for a long time!

The KD Foundation Australia has been involved in the consultation process with SkylineDX and we are looking forward to following this development with great enthusiasm.

“The test is based on 13 genes that form a “gene signature” in the blood of children, which enables KD to be distinguished from other infectious and inflammatory diseases”

Michael Levin

This could just make a world of difference in the future. A diagnostic test would assist with prompt diagnosis and therefore timely treatment to even further minimize any long term cardiac complications.

More information is available on the SkylineDx website

www.skylinedx.com



Social Media



Instagram

213 followers



Facebook page — 510 followers

Facebook Support Network — 362 members

We've had a positive year in increasing our presence on social media, and we'd love your continued support in engaging and sharing our content on social media during 2021, as well as supporting new members in our wonderful KD community. The more people we can reach, the more people know about Kawasaki Disease!

KD Kids Corner

Name: Blaire

Diagnosed: 6 August 2020

Age: 1 year old

Diagnosis: A-typical Kawasaki Disease

It took at least 6 weeks of sickness and temperatures of 39 for 14 days straight and multiple hospital trips and doctor visits to finally be listened to and have bloods done to be diagnosed with A-typical Kawasaki Disease.

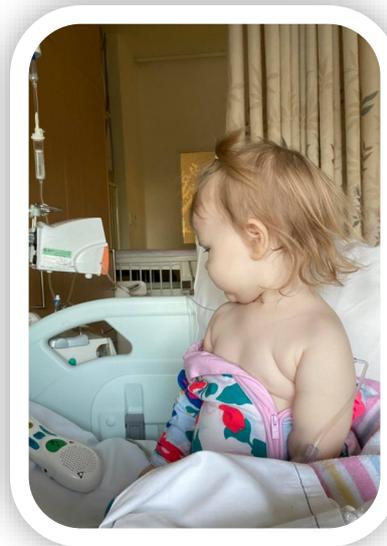
We stayed in hospital for a week getting antibiotics and the IVIG infusion. She had an echocardiogram that showed slightly inflamed coronary arteries but nothing too concerning, just to continue aspirin for 6 weeks and then another echocardiogram and thankfully that was clear!

Being a young mum, I knew about the more common diseases some children get but I had never heard of Kawasaki and was quite shocked and frightened when the paediatricians came in and told her dad and I about it and that our 1 year old baby needed an infusion.

The biggest fear I had was that nobody was listening to me and

thought I was "crazy" and that my daughter just has a normal "virus".

Until that night that I had enough and took her back to the hospital with high fevers and irritability as I knew something wasn't right with my baby.



Blaire Norris

Finally a Doctor listened and did tests to check everything and came in and told me that her levels aren't good and she needed to be admitted.

I was so thankful that someone had listened to me and taken the time to find out why she had these temperatures of 39 for 14 days.

Blaire suffered from sore legs and muscles for a few weeks after being diagnosed. She would struggle to walk far distances and was a bit irritated.

Her hands and feet still to this day become red sometimes but thankfully we've had no other concerns from the disease.

I would definitely like to see more information about Kawasaki Disease and more awareness about the disease as it can be highly dangerous and it's rare but it is scary.

I am very thankful to the Paediatrics team that Blaire had in hospital and all the support of our family to get us through the tough time.

Blaire is now a happy healthy two year old.

"The biggest fear I had was that nobody was listening to me"

Izzy Smith

Thank you Izzy Smith for sharing your daughter Blaire's KD story.

Contact Us

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**Kawasaki
Disease**
Foundation Aust.

