



# Kawasaki Disease Foundation Aust.

**Support Awareness Research**

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

## **Kawasaki Disease Foundation Aust. News December 2016**

Dear KD Friends and Families,

We would like to take this opportunity to wish you all a Merry Christmas and a Happy New Year. As 2016 comes to an end it is again time to reflect on the past year and to plan and look forward to the year ahead.

In this edition, we are pleased to present some reports on what has been happening with some of our fellow KD Foundations overseas – Japan and America. It is heartening to know we are all joined in a common cause.

Since our last newsletter, we are pleased to announce we have been licensed to fundraise in Western Australia. We are now registered to fundraise in all States – Victoria, South Australia, New South Wales, Tasmania, Queensland and Western Australia.

Your efforts in helping us with fundraising and awareness are greatly appreciated. Every little bit helps in our mission to educate the general community about Kawasaki Disease.

If at any time during the year you would like to run a Fundraiser/Awareness Event for the Foundation, please contact us for ideas/assistance on what is required under State Legislation.

We also have our information brochures available if you have somewhere to place them or hand out e.g. Maternal Health Centres, Preschools.

Warm Regards,

Shirley Mates and Aylee Sunstrom  
National Co-ordinators



We really like to correspond with our members via email when we can. Please help us by keeping your email details up to date. Please send updates to [info@kdfoundation.org.au](mailto:info@kdfoundation.org.au) with Email Update as the subject and include your full name and email address details.

## Latest Research

With each year comes more opportunity for researchers to gain more knowledge about Kawasaki Disease, and hopefully have more breakthroughs which can help aid future cases. Dr. Kawasaki himself, at 91, is still such an inspiration and actively involved with the Japan Kawasaki Disease Research Centre. Only last month he applied to the Chan Zuckerberg Initiative in the hope they will fund research. (See below) The US KD Foundation assisted with a petition which collected signatures worldwide, including many of us here in Australia. We hope to be able to let you know in the near future that it was successful.

### 日本川崎病研究センター JAPAN KAWASAKI DISEASE RESEARCH CENTER

〒101-0041 東京都千代田区神田新田町1-1-1  
久保キタビル6階  
電話 03-5256-1121 FAX 03-5256-1124

KUBO BLDG, 1-1-1, KANDA-SUDACHIO  
CHIYODA-KU, TOKYO 101-0041 JAPAN  
TEL 03-5256-1121 FAX 03-5256-1124

#### The Chan Zuckerberg Initiative

Dear Dr. Chan and Mr. Zuckerberg:

Allow me to introduce myself and to thank you for your generous commitment to funding basic research that will solve important diseases. My name is Dr. Tomisaku Kawasaki and I am a pediatrician in Japan. Almost 45 years ago, I saw an infant with a mysterious rash/fever syndrome that I did not recognize. The baby recovered and I filed the case under "GOK," God Only Knows. One year later, I saw a second infant with fever and the same rash, bloodshot eyes, cracked bleeding lips, swollen hands and feet. I knew at that moment that I was seeing something new, something that had not been previously described in my country.

Today, the condition is known as Kawasaki disease and I am humbled by this honor. The disease is now recognized as the most common cause of acquired heart disease in children worldwide, leading to long-term health consequences for children who suffer damage to their coronary arteries resulting from Kawasaki disease. While its cause remains unknown, research groups in Japan and the U.S. are pursuing promising theories. Although the disease responds to a high dose of intravenous immunoglobulin, the standard of treatment in developed countries, this is an expensive resource and most of the world's children who are affected are never treated.

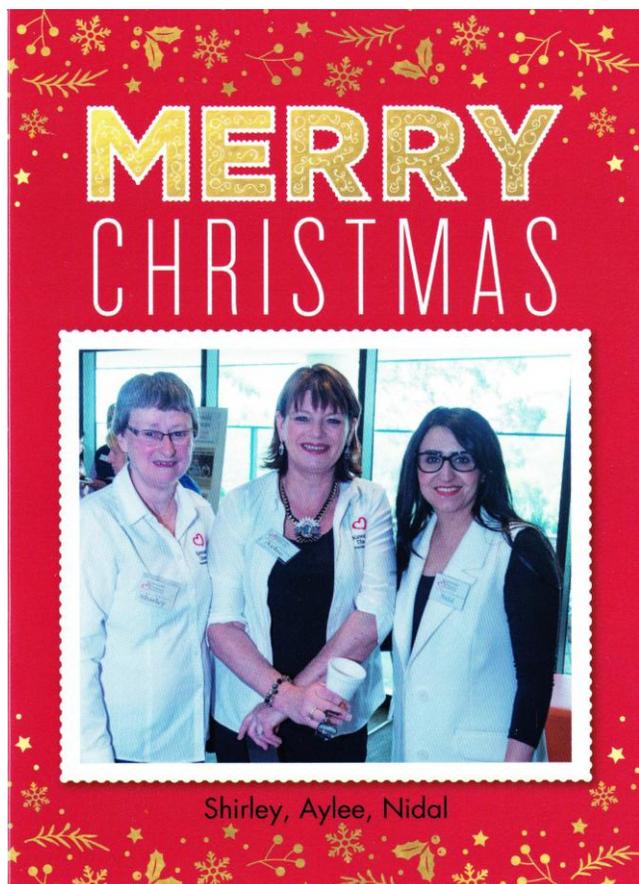
Even at age ninety years, I am dedicated to learning the cause of this disease and to improve outcomes for children worldwide. It would mean so much to me if Kawasaki disease were chosen by your initiative – it is a disease that I believe can be solved in the near future. With the right funding, research teams are poised to make great progress. I am dedicated to solving this disease in my lifetime. You can help make that happen.

Sincerely yours,

  
Tomisaku Kawasaki, M.D.

## Japanese Parents Association

This time last year (we were lucky to meet Dr. Kawasaki and some members of the Japanese Parents Association at the International Symposium); we sent them a Christmas Card. This featured in one of their newsletters this year. The following is a translation –



‘6 people from Australia attended the Kawasaki Disease Symposium. Our Secretary General of meeting, Ogasawara received a Christmas Card. In 2018 the next symposium will be in Yokohama. Please meet again at the next meeting. Australian parents are saving money to attend this meeting. Looking forward to meeting everyone from Australia’.

In their latest newsletter, they cover the 35<sup>th</sup> Annual Meeting of the Japanese Society of Kawasaki Disease. About 50 people from all over Japan attended. The first night they talked and ate and drank till midnight. The following day they held their annual meeting in the morning and in the afternoon about 100 people attended a session where two doctors presented medical lectures. Parents also had a chance to ask questions about their children.



◎シンポジウム I Jane C.Burns先生を囲んで  
川崎病急性期治療の夜明け：インフリキシマブ ◎

Dr Burns (US Researcher)



Dr Kawasaki (91 years old)

## US KD Foundation

In November this year the KD Foundation together with the Kawasaki Disease Research Center UCSD/ Rady Children's Hospital hosted the Parent Symposium in San Diego. This year it was live streamed through Facebook so it was available all around the world. Due to the time difference it was 3am here. However, you can now access it through the following link -

Part 1:

<https://www.facebook.com/TheKDFoundation/videos/1408333759196523/>

Part 2:

<https://www.facebook.com/TheKDFoundation/videos/1408424162520816/>

Some information from this symposium –

\* status of KD in Japan (2014) – over 14,000 new cases. One in every 60 boys and one in every 75 girls in Japan will develop KD during the first 10 years of life. Many will have a parent/adult relative who has also had KD.

- Evidence that KD has a genetic component in Japan
- 4 percent reoccurrence in Japan – less than 1% other nationalities.
- Could be caused by more than one trigger – maybe genetic plus environment trigger
- Most cases are in Winter and early Spring in Northern Hemisphere
- American Heart Association will be publishing new guidelines for follow up treatment in 2017. At the moment there are no set guidelines, even in the US.
- Researchers at the San Diego Rady Children's Hospital USCD are still working on three diagnostic tests
  1. Computer Algorithms – smart phone apps
  2. Blood Test
  3. A Urine Test

Questions they still need to answer

- Why do only certain children get KD?
- Why do only certain KD patients get coronary artery aneurysms?

To quote Dr. Burns “the eye does not see what the mind does not know”

## Website

We regularly update our website and are planning a revamp in the New Year so if you are interested in sharing your family's experience please email your story to -

[info@kdfoundation.org.au](mailto:info@kdfoundation.org.au).

## Database

We are still missing a few details for some people on our database. We hope to be able to finalise our general and State data bases soon. If you have not already done so can you, please take a few minutes to email back us the following details:

- Name
- Postal address
- Email address
- Contact phone number/s
- KD Child's name

We also appreciate receiving questionnaires as your experiences give us valuable information about this disease plus help us establish a database. If you haven't already completed one, it can be accessed on our website on the contact page or [click here](#).

## Facebook

Click on



Check out our Facebook page to see the latest updates on KD events, view photos and more! Click on the button above to go directly to the page (you must be a Facebook member to view). Please like our page and share it with your family.

## **KD Forum**

Bec Bailey a KD parent has set up a closed group Facebook Forum page for Australian parents. This is a great place to share your experiences and ask advice of other parents. If you are interested in joining, search for the group on Facebook and request to join, or email Bec directly at - [mychildhadkd@gmail.com](mailto:mychildhadkd@gmail.com)

There is also a FaceBook aneurysm group that some of you may be interested in if you haven't already joined. It can be found on Facebook under Kawasaki disease support - children with aneurysms.

## **My Heart - for young people 13-22**

HeartKids Victoria/Tasmania have also launched a new resource for young people living with childhood heart disease - [www.myheart.org.au](http://www.myheart.org.au) explores a range of topics relevant to people aged 13-22 and also has some really useful resources for their parents. It also includes a closed forum where young people with Childhood Heart Disease can safely chat online with their peers about topics important to them.

## **KD-Kidz' Corner**

KD Canada Parent Awareness Group set up this closed Facebook page to unite KD kids of all ages by providing them with a safe and secure forum to share their stories, feelings, ask questions and post pictures.

Here is how you can help get your child involved:

[kdcanada.ca](http://kdcanada.ca) or

[www.facebook.com/KDCanadaPA/](http://www.facebook.com/KDCanadaPA/)

Safe Guidelines:

- To be eligible to sign up for Facebook, you must be at least 13 years old
- Parents/guardians of children under 13 years old are permitted to join the closed

KD Kidz' Corner Facebook page and work with their child

- Therefore parents/guardians must supervise their child if they are under the age of 13 years

As this is an International Group and it fills a gap in KD support currently available let's get behind this great initiative and join up your child.

## **GoFundraise**

Just a reminder that we are registered with GoFundraise which 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) special occasions etc. A link to our page is available on our website and we are more than happy to assist you with setting up your own page.

While there are a few different groups like GoFundraise that collect donations on behalf of various charities you do not have to go through the particular one that is coordinating the event you are taking part in. GoFundraise coordinates events like the Melbourne Marathon. If you are taking part in an event which is under another group, you can still raise funds for Kawasaki Disease Foundation by creating a page on the Foundation's GoFundraise page. Please contact us if you have any questions about how this works.