



# Kawasaki Disease Foundation Aust.

**Support Awareness Research**

## Kawasaki Disease Foundation Aust. News April 2015

Dear KD Friends and Families,

In this edition of our newsletter our main feature is a report on the 11th International Kawasaki Disease Symposium held in Hawaii from the 3-6 February. We hope you will find this information very informative. Eight parents travelled from Melbourne, South Australia and New South Wales to attend this amazing event. A summary of a poster presentation by Dr. Katherine Chen is also included. Interim results of this ongoing study which some of you may have participated in were presented. KD participants who have had coronary aneurysms are still being recruited for this study. If you are able to assist please contact Dr. Chen at [katherine.chen@mcri.edu.au](mailto:katherine.chen@mcri.edu.au) or on (03) 9936 6553.

You can also read about recent fundraising events in South Australia, Tasmania and Warrnambool as well as our regular features.

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.

### **Interested in helping with Australian Kawasaki Disease research?**

**You may be able to help if you or your child:**

- **Have had Kawasaki disease**
- **Are they aged between 6 to 30 years**
- **Are able to attend the Murdoch Childrens Research Institute (at the Royal Children's Hospital campus in Melbourne) for a one off study visit (travel costs\* will be reimbursed)**
- **The study visit will involve an ultrasound, blood pressure measurement, eye photographs and a single blood test (with Angel cream to numb the skin)**
- **Please contact Dr Katherine Chen for more information on 9936 6553 or email [katherine.chen@mcri.edu.au](mailto:katherine.chen@mcri.edu.au)**

**\*Parking costs at the Royal Children's Hospital and public transport within Victoria**

## 11<sup>th</sup> International Kawasaki Disease Symposium 2015

Since the historic 1<sup>st</sup> International Kawasaki Disease Symposium in 1984, the international symposium has been held every three years in Japan, the United States and Taiwan, drawing attendees from all continents. This year it was held in Hawaii, so being reasonably close to Australia, 8 parents decided to make the journey. Our medical advisor, Dr. Burgner and Dr. Chen who is working with him with his research, also attended. A summary of their poster presentation can be viewed on our website on the home page.

This 3½ day conference included lectures, discussions and oral/poster presentations focusing on the latest advances in Kawasaki Disease. Kawasaki Disease is well-documented as the major cause of acquired childhood heart disease in developed countries. About 400 clinicians and scientists from around the globe came together to share their common interest and new knowledge of Kawasaki Disease. Eighty-five parents had also registered for the Parent Symposium but unfortunately not all could make it due to the heavy snow in parts of America.

As Adrienne Kovacs, who presented the Alex McCormack memorial lecture at the Parent's Association session said "We were fortunate to be able to attend this symposium. It is an incredible opportunity for health care providers and scientists to work together to improve the medical outcomes of children, teenagers and adults affected by Kawasaki Disease". It was amazing to see the collaboration and cooperation between all the different countries.

Dr. Kawasaki and his wife were present for the whole symposium and it was such a great honour to meet this amazing man. He had to be the most photographed person at the symposium. He turned 90 while in Hawaii so a special celebration was held at the final dinner where he was presented with a cake. As Dr. Burns closed the video summary of the conference –

"Our fearless leader"



(Dr. Kawasaki before the Parent session)

As well as having the opportunity to meet with researchers from around the world this event provided a wonderful opportunity to network with other parents. Parent Support groups from America, Hawaii, Japan, Canada and Australia were represented and each group gave a small presentation about the work of their group. We work very closely with the US Foundation and it was good to meet representatives from there.

This engagement between doctors and families and parents works both ways. In the Science News summary video of this event from the American Heart Association Dr. Newburger said most KD researchers are driven by their interaction with their patients and families so it seems logical to have them present. We stimulate doctors to do their work on this disease. We are their inspiration.

On a personal level it was wonderful to meet a Canadian mother I supported over 6 years ago. Her son Michael is now doing 1<sup>st</sup> year nursing and has been working with the Sick Kids team. His personal experience with KD has led him to help with research into this disease. He is working with his cardiologist Dr. McCrindle.

Vincenzo Tito a young boy who had KD at 5 months, over 10 years ago, was also present selling copies of his book 'Living With The Effects of Kawasaki Disease'. He decided to share his story to help other children to realise they are not alone and to help raise funds for KD research.



Copies of his book can be purchased online.  
Please contact us for further details.

### What did we learn?

- As parents we learnt a lot about KD and how it affects our individual children. For the doctors, as is common, it answered some questions but raised more. While knowing KD has a higher incident rate in Japan than other countries, I was surprised to learn how much. 1 in 85 children in Japan are diagnosed with KD which is more than the 1 in 100 children diagnosed with Congenital Heart Disease in Australia. Rates are much lower in other countries.
- Genetics is very important in Japanese research. Prof. Onnouchi said “Japanese studies are looking at a common agent in Asian groups. In so doing they also hope to find what is different between Asian and European groups”. Dr Burns suggested Europeans may in fact respond differently. Children in Japan today are likely to have a parent who had KD as a child. There has been an increase in the number of cases in Japan and probably other countries.
- It seems there might be more than one trigger that causes Kawasaki Disease.
- It has been 10 years since the American Heart Association guidelines on KD were written. They are currently updating these. In Australia doctors generally use the AHA guidelines.
- Most KD patients and their families want to know their long term prognosis. There is currently no 30-40 year follow up so there is very little knowledge at this stage for children with medium or giant aneurysms.
- Adrienne in her parent address also made us aware that it is important to be mindful that the impact of KD can extend beyond physical well-being. It can also affect psychological and

social well-being of the patient and family. Also, patients are more than their medical diagnosis.

Dr Kawasaki when interviewed said his number one priority is to discover the cause of Kawasaki Disease.

To quote him from a few years ago –  
*“It was in January 1961 that I encountered a child patient, aged 4 years and 3 months, who was to become the first known case of Kawasaki Disease. [Over] fifty years have elapsed since then. At the time, I had no choice but to discharge the patient as “diagnosis unknown”. Fortunately, the child suffered no sequelae, and is currently enjoying a full and active life as an adult. Since then the incidence of Kawasaki Disease has continued to grow. Why? Why can’t we stop this disease? The reason, unfortunately, is that its cause is not known. At the time I first described the disease, I felt we were on the threshold of discovering its cause, since its symptoms were extremely clear-cut. Despite the efforts of numerous researchers, however, we are still searching. It is my strong hope that young researchers will be able to identify the root cause of this disease”.*

At the final dinner a message from this patient, who is now 60, was read out. He thanked Dr. Kawasaki and wished him a Happy Birthday.

Aubry Shackelford, a KD parent is working on the following invention at his company Pegasus Therapeutics. His daughter is the motivation behind what could be a revolutionary way to treat aneurysms in the future. You can find out more on their campaign page -  
<https://www.indiegogo.com/projects/pegasus-therapeutics-healing-kids-with-aneurysms>

The next symposium will be held at Yokohama, Japan in 2018

Shirley Mates

\*Further information and photos can be found on our website on the IKDS page.

## Website

We have just updated our website so if you haven't visited it for a while you can do so at [www.kdfoundation.org.au](http://www.kdfoundation.org.au). We regularly update with the latest in research and upcoming events. New family stories are also added.

## Database

We are currently establishing new databases including one for each State. We sometimes have information about events in a particular State so this will enable us to just send an email to the relevant people. As so much contact today is through emails we actually don't have postal address for everyone. Can you please take a few minutes to email back to us the following details:

- Name
  - Postal address
  - Email address
  - Contact phone number/s
- so we can check our database.

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.

## Facebook



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.

## GaRDN

We were recently invited to join GaRDN (Genetic and Rare Disease Network) in W.A. Our new member profile from their Issue 5 2015 newsletter can be viewed [here](#).

## 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 (last year we 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. We have a list of Fun runs and marathons.

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 coordinate 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.

## Quickbeds

We have recently signed up to this program. Quickbeds is an accommodation search and booking website owned by Flight Centre Travel Group. They have 5500+ properties listed in Australia and New Zealand.

Next time you are booking accommodation go to [www.quickbeds.com](http://www.quickbeds.com)  
Enter our unique Grassroots ID: 1195  
And you'll be helping our Foundation.

If you are interested in fundraising for the Foundation please contact us so we can assist you with making sure it is conducted in accordance with State Legislation. Alternatively you may wish to donate stationery, goods for raffles etc. All donations will greatly assist us.

## Recent Fundraising

### South Australia

Our South Australian coordinator Nidal Raslan was given the opportunity to promote awareness of Kawasaki Disease at an Australia Day BBQ at Rezz, Newtown. How wonderful to be able to do so on what has been declared KD Awareness Day by the US KD Foundation.

### Tasmania

Penny Scott held an awareness BBQ stall at the Made with Love Market Wynyard. Penny has also offered to be a support contact for other parents. She can be contacted by email - [creations647@yahoo.com.au](mailto:creations647@yahoo.com.au)  
Penny's story is also on our website under Our Stories.

### Victoria - Warrnambool

Brooke Dean organised for the Foundation to receive proceeds from a raffle and the jumping castle at the annual Holden Car Show held at Lake Pertobe. A big thank you to the Western Victoria Holden Car Club for their support.



(From the latest edition of the Japanese Parents Association Newsletter)



(Catherine Frank and Greg Chin (left) from the US Foundation with Australian parents)



(Dr Kawasaki being presented with a gift bag from the US KD Foundation)