



# Kawasaki Disease Foundation Aust.

**Support Awareness Research**

## **Kawasaki Disease Foundation Aust. News December 2015**

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 2015 comes to an end it is again time to reflect on the past year and to plan for the year ahead.

In this edition of our newsletter our main feature is a report on our Melbourne Information Session held at the RCH in October. We are also pleased to provide information on our partnership with the CoRDS registry, which we officially launched at this session.

We are pleased to announce that Simone Staaden has offered to be our W.A. coordinator and our rep for GaRDN (Genetic and Rare Disease Network), which is based in W.A. We were invited to join this organisation earlier this year. We are currently applying to become registered to fundraise in W.A, so hopefully early next year we'll be able to announce that we are 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 - as Prof Nigel Curtis said at our information session in Melbourne, there is a lot more awareness of KD today, partly due to the efforts of the Foundation.

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.

## Melbourne Information Session

A very informative session was held at the Royal Children's Hospital Melbourne on the 24th October. We had families attend from - Queensland, New South Wales, South Australia, Tasmania and Western Australia as well as Victoria which was really amazing and there was a lot of networking between parents.

We really appreciate our medical advisor Professor David Burgner arranging this session for us and giving up his Saturday afternoon to share his knowledge of this disease with us. We also wish to acknowledge Prof. Nigel Curtis, Associate Prof Bryn Jones and Dr. Katherine Chen for their contributions to this session.

Their presentations were not only very enlightening but also parent friendly. Dr. Chen has provided an update on the research study she is currently undertaking with Dr. Burgner. (See right side of page). Prof. Curtis and Prof. Burgner have also kindly let us have some of their slides if anyone is interested. We know you will understand these are for personal use only. Please contact us by email if you would like a copy.

For those who were able to attend this session and heard Penny Scott from Tasmania share their KD journey so far, we would like to update you - Billie-Grace is recovering from surgery performed this month at the Children's Hospital in Melbourne. The whole KD community wishes Billie-Grace a speedy recovery and sends our best wishes to Penny and Isaac. Hopefully you will all be back home soon.



4 days after surgery

## What we know and don't know about the long term outlook in Kawasaki disease

First described in 1967, those who had Kawasaki disease (KD) in the 1960s and 1970s are now entering middle-age. Whether KD increases later cardiovascular risk, especially in those with no identified coronary artery changes or with changes, which have resolved, is therefore an increasingly important question.

Non-invasive methods for measuring blood vessel structure and function, initially used in studies of atherosclerosis ('hardening of the arteries'), have been used to estimate future cardiovascular risk in those with previous KD, who are currently asymptomatic. These methods predict risk of future heart attack and stroke in adults, but their significance in children, especially in those who have had KD is much less clear. This uncertainty should be born in mind when we interpret the results of studies of KD.

Overall, those with coronary artery aneurysms following KD have evidence of thickened and stiffer large blood vessels compared to children who did not have KD, although findings are not always consistent; some studies have found these changes and some have not. It is uncertain whether those children whose coronary artery aneurysms have resolved on echocardiography differ from those with persistent aneurysms, as no studies to date are of adequate size to explore this question definitively. KD patients with no history of coronary artery aneurysms, in general, have similar blood vessel thickness compared to controls, but some data indicate minor stiffening of their large blood vessels. The long-term significance of these differences is unclear; this is particularly important as these methods were developed for studying atherosclerosis rather than KD.

Until data is available on the longer-term risk and outcomes, it is prudent to maintain a healthy lifestyle following KD and to minimize traditional modifiable cardiovascular risk factors such as smoking, high blood pressure, high blood sugar and fat levels, and obesity.

## CoRDS registry

We officially launched our partnership with Sanford Coordination of Rare Diseases (CoRDS for short) at our information session in October. The US KD Foundation also partnered with them last year.

### What is the CoRDS Registry?

It is an international, central patient registry for individuals diagnosed with a rare disease. CoRDS was primarily developed to meet an unmet need for patient registries worldwide. Only approximately 20 percent of rare conditions are represented by a registry.

If you or a family member has been diagnosed with KD, you can help researchers see the whole picture. You can play a vital role in finding cures and improving treatments.

This research is separate to research being carried out in Australia. We will continue to ask for your assistance with Australian research studies when they are being conducted.

### How to join CoRDS

Registration is simple and takes approximately 10 minutes of your time. You will be asked to read and complete a consent form and brief questionnaire.

To Enrol:

- Go to [sanfordresearch.org/cords](http://sanfordresearch.org/cords) and click Enrol in CoRDS [or Click Here](#)

An information brochure produced by CoRDS is also available on request from the Foundation.

## Our presenters at our Information Session



Prof. Curtis and Prof. Burgner



Dr. Chen



Associate Prof Bryn Jones

## **Website**

We regularly update our website, especially with the latest in research, so if you haven't visited it for a while you can do so at [www.kdfoundation.org.au](http://www.kdfoundation.org.au). New family stories are also added so if you wish to share your family's experience please email it to [info@kdfoundation.org.au](mailto:info@kdfoundation.org.au).

## **Database**

We are still finalising our 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. If you have not already done so 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**



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 just 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.

## **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 (this 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.

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.

