

Kawasaki Disease Foundation Australia

Kawasaki Disease Foundation Aust. News September 2013

Dear KD Friends and Families,

It has been a while since our last newsletter but in future we hope to email more regularly, even if it is only with reminders about upcoming events. We hope you find this newsletter informative and if you have suggestions for upcoming newsletter articles or would like to contribute a small article – this may be your or your child's KD story – please email us at info@kdfoundation.org.au with the subject heading 'newsletter' In this issue we have two parents who have written about their experiences with KD.

While we are on the subject of emails – please note the email mentioned above is now the one we have in use. Some of you may still have our old address – akfn@optusnet.com.au.

We look forward to hearing from you,
Shirley Mates and Aylee Sunstrom
National Co-ordinators

*11th International Kawasaki Disease
Symposium*

*Feb. 3-6, 2015 Hilton Hawaiian Village,
Honolulu, Hawaii, US*

An afternoon of parents' association activity has
been scheduled for the 4th February

**Interested in helping with
Australian Kawasaki disease
research?**

**Have you or your child had Kawasaki
disease?**

Are they aged 6-30 years?

**Are you able to come to the Royal
Children's Hospital in Melbourne for a
single two hour visit, arranged at your
convenience?**

**Please contact the study coordinator, Dr
Katherine Chen (03 9936 6553 or
katherine.chen@mcri.edu.au) for more
information**

Kawasaki disease research update – Australia and worldwide

Dr David Burgner – medical advisor to KD Foundation

Clinical research around the world: Research into Kawasaki disease continues apace both locally and around the world. There have been almost 200 scientific and medical papers published in 2013 already, and almost 300 published in 2012. Many of these reports highlight the unusual ways that Kawasaki disease can present, which is why it can be so hard to diagnose the condition. Some of the recent highlights include:

- Professor Jane Burns and colleagues from the US have developed a scoring system based on clinical and laboratory features that may help with diagnosis in some (but unfortunately not all) cases.¹ It will be interesting to see how this scoring system and other improvements to diagnosis perform in clinical settings.
- A couple of studies have shown that KD children may be more prone to allergies and infections, confirming an Australian study that we published in 2011.³ This is true both before and after the KD itself, suggesting that children who develop KD may have immune systems that behave differently from other children.
- There was a lot of interest in the use of steroids as an additional treatment in KD following the publication of a Japanese trial in the Lancet in 2012.² Although the Japanese study showed improved outcomes (less coronary artery changes) in those with very severe KD given steroids in addition to immunoglobulin, the scoring systems used to identify the highest risk KD patients in Japan do not work that well in non-Japanese children. Generally KD experts outside Japan still remain cautious about how and when to use steroids. Immunoglobulin and aspirin remain the front line treatments.

Australian KD research:

The major breakthrough we all hope for in KD is a diagnostic test. Therefore much of the research is focussed on trying to understand what makes KD different from other childhood illnesses, so that a diagnosis can be made more quickly and treatment can be started. In Australia, our research is approaching this central problem in two ways.

Firstly we have been looking at the genetic make-up of children with KD. This is a large international collaboration, involving KD researchers from many countries. We have found some genes involved in the immune system that seem to be important and analyses are continuing. The KD genetics group (The International KD Genetics Consortium, to give it its proper title!) is meeting again in October in the US to discuss the latest research and findings. We will also discuss whether we should enrol more KD patients in the genetics study from Australia and elsewhere, so stand by for announcements of how you might be able to help in the months to come.

Secondly, we are starting a smaller study based at the Royal Children's Hospital and the Murdoch Childrens Research Institute in Melbourne, looking in detail at the immune responses and cardiovascular systems of children who have had KD.

We are currently looking for participants for this study, so if you or your child has had KD (with or without coronary artery changes), is aged 6-30 years and are able to visit the Royal Children's Hospital in Melbourne for about 2 hours, we'd love to hear from you. For details please contact the study coordinator, Dr Katherine Chen (T (03) 9936 6553 or katherine.chen@mcri.edu.au)

1. Ling et al. Point-of-Care Differentiation of Kawasaki Disease from Other Febrile Illnesses J Pediatr 2013;162:183-8].
2. (Kobayashi T et al, Efficacy of immunoglobulin plus prednisolone for prevention of coronary artery abnormalities in severe Kawasaki disease (RAISE study): a randomised, open-label, blinded-endpoints trial. Lancet. 2012 Apr 28;379(9826):1613-20.
3. Webster RJ, Carter KW, Warrington NM, Loh AM, Zaloumis S, Kuijpers TW, Palmer LJ, Burgner DP. Hospitalisation with infection, asthma and allergy in Kawasaki disease patients and their families: genealogical analysis using linked population data. PLoS One. 2011;6(11):e28004. (*this article is freely available on-line*)

Website

We regularly update our website with the latest in research and upcoming events. If you haven't visited it for a while you can do so at www.kdfoundation.org.au.

We are always keen to have more family stories.

Facebook



Click on

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

Latest KD published article in Australia

Our medical advisor Dr. Burgner who is based at the Murdoch Childrens Research Institute and Dr. Michael Cheung, who is Director of Cardiology at the Royal Children's Hospital, Melbourne have just had an article on Kawasaki Disease in the Australian Family Physician which is published by the Royal Australian College of General Practitioners. This article stressed the importance of prompt recognition and early referral. It is very easy to read and an excellent resource for any medical professional. A link to this article can be found on our website.

We recently addressed the Maternal Health Nurses at the Geelong Regional meeting and presented them with an awareness package which included this article. This presentation was well received and provided us with another avenue to raise awareness of KD. Please contact us if you know of similar groups that we may be able to address.

Fundraising in Schools

We have been very fortunate to have a few schools in S.A., N.S.W. and Victoria fundraise for the Foundation. The student committees/SRC's have organised these events, usually as one of our KD children attends the school or they know of someone who has had KD. Our KD wristbands at \$2 each are ideal for these fundraisers.

We also received a large donation from the Barcaldine Rodeo Association in Queensland who held a rodeo to raise money for research. A good friend's daughter was diagnosed with KD and like all of us they are keen for a cure or at least a diagnostic test. We are very grateful for all the donations and appreciate the support we get from you in helping raise awareness of Kawasaki Disease.

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 in N.S.W and Melbourne) 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 eg City to Surf just held in Adelaide, 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.

Donations to the Foundation can also be made via Paypal or cheque to our P.O. Box. All donations over \$2 are tax deductible.

KD Family Stories

Bec Bailey

In December 2011 our 13 month old son, Quinn, became seriously ill and was admitted to hospital. This was to become our first experience with Kawasaki Disease. Fast forward 5 months later to when Quinn was 18 months old and we were back in the hospital where he was again diagnosed with KD.

During our journey with KD, we became aware that Quinn would always be at higher risk of heart disease and the best way to combat that was for him to lead a healthy and active life. I decided to step up my game and improve my own health and fitness so I could be a healthy role model. So I started running. It was a pretty lame attempt when I began but I soon found myself enjoying running and progressed from being a non-runner to running 1km, then 3km, then 5km.... I found myself setting some

running goals and one of them was to complete a half marathon! I decided to participate in the half marathon at the Melbourne Marathon Festival. The KD Foundation had set up a fundraising page through "GoFundraise" and this gave me the perfect opportunity to link my half

marathon fundraising opportunity to the KD Foundation, as well as raising awareness of KD and achieving my personal goal.



I have since thought about other ways that I can support the KD Foundation and raise awareness of KD.

I recently lodged a submission to my workplace to consider the KD Foundation as a major charity to support via staff fundraising, facilitated to organise a talk from the KD coordinators to local Maternal and Child Health Nurses, and organised for KD information/leaflets to be displayed at the Maternal and Child Health Centres. Every little bit helps and is one step closer in supporting research, awareness, knowledge, early diagnosis, treatment and the health of many children.

Regards,
Bec

Stacey Kinsmore

Hi my name is Stacey and I am keen to get as much awareness out there in regards to Kawasaki Disease.

Since my son was diagnosed last year - after being misdiagnosed several times I really wanted to make as many people as I can be informed about the disease in the hope that it helps other children get the right diagnosis and treatment.

I contacted our local papers first who have been very willing to run a story in the paper. I also run a fundraising car cruise for Black Saturday and we handed out 600 show bags, which I placed the Kawasaki flyer in. I also wrote a little story of our experience with Jake, printed it out and attached it to the flyer which I handed out to all the parents at Jake's kinder and the other 2 kindergartens in our local area. The parents were very appreciative of this information and asked me a lot of questions which I thought was great. I just make sure I tell them to also let as many other parents as they can know about Kawasaki Disease.

With the help of Shirley I have also placed the poster at our local Doctor's surgery, Maternal Health Centre and other medical centres. I have left flyers at these centres as well. I also hope to place the posters and flyers at all childcare based centres and medical centres in our local area - the Yarra Ranges. It is a BIG area, but I want AS many people as I can reach to know about the symptoms etc. of Kawasaki.