



Kawasaki Disease Foundation Aust.

Support Awareness Research

Kawasaki Disease Foundation Aust. News March 2016

Dear KD Friends and Families,

Welcome to the latest edition of our newsletter. It is hard to believe it is March and Easter already and that's with an extra day this year. It appears the year is 'Leaping Away'. This time last year we had just attended the International Kawasaki Disease Symposium in Hawaii where we were very honoured to meet Dr. Kawasaki. This amazing man has dedicated so much of his life to trying to unravel the mystery of Kawasaki Disease. In this edition you can see photos of him celebrating his 91st birthday last month.

We hope the information we provide in this newsletter is of value to you. Please let us know if there is anything you would like covered in future newsletters.

Warm Regards,

Shirley Mates and Aylee Sunstrom
National Co-ordinators



(Refer to last page)



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 with Email Update as the subject and include your full name and email address details.



Dr Kawasaki celebrating his 91st birthday with the Japanese Parents Association.

Introducing KD-Kidz' Corner

Kawasaki Disease Canada Parent Awareness Group launched this group to coincide with KD Awareness Day – 26th January.

Over the last decade social networking has exploded and thanks to Facebook and Twitter's services we can now create KD awareness and support families anywhere in the world. Social networking is an amazing tool for parents to utilise as a way to gain valuable information and much needed support.

After attending the Alex McCormack Memorial Lecture (Facing & Coping with Uncertainty) at the IKDS in Hawaii last year, we realized that it's also very important to consider the mental health and wellness of children affected by Kawasaki Disease.

Kawasaki Disease Canada Parent Awareness Group (KD Canada PA) has created a closed Facebook page just for KD kids called, KD Kidz' Corner.

- The focus of this closed page is 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. Giving KD kids an opportunity to develop supportive friendships is important for their overall health and wellbeing.

KD-Heroes International is a campaign to introduce KD Kidz' Corner, a closed Facebook page promoting communication among kids with Kawasaki disease. It is our hope that KD-Heroes International will:

- Help your child introduce themselves to other kids that are just like them and to help initiate dialogue

- Get KD kids working with their medical team, so they can start to build personal and positive relationships with their doctors. Our children need to feel comfortable talking about their concerns
- Help reduce anxiety that may be caused by doctors appointments, having blood taken or undergoing clinical tests by creating an interactive and fun distraction
- Give family members or friends a way to support your child as they often want to be a part of their KD journey but don't know how

Here is how you can help get your child involved:

kdcanada.ca or
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.

The Power of Social Media

Those of you on Facebook may have seen a lot of posts from parents in the U.S/Canada and U.K. raising the profile of the KD Awareness Day (as mentioned previously – the 26th January). As this is Australia Day we will never be able to adopt this day but it demonstrated to us the power of Social Media. The following link will take you to information put out by the U.S Foundation – [Click here](#)

It is of course possible to adapt ideas to suit Australia. Bec Bailey posted the following (Australia Day here today but Kawasaki Disease Awareness Day around other parts of the globe. [Click Here](#) to see photo) A couple of other parents posted their stories.

We often get asked how you can help with awareness. Posting your child's story is one way to spread KD awareness far and wide. This can be done around special days e.g. KD Awareness Day or Rare Disease Day – February 28th - but really any day can be KD Awareness Day – the more posts you do throughout the year (maybe sharing KD Foundation posts) the more awareness will be generated – and this is totally free.

The following story from the UK is a perfect example. It resulted in an amazing 75,000 pound donation – a perfect example of the power of Social Media. [Click here](#) to read it.

You may also find the following 2 stories posted by the US Foundation inspiring –

Backstreet Boy Brian Littrell's Son Boylee. Following in his Performing Footsteps [Click Here](#)

and

Dave Harris's Video– [Click Here](#)

Radio Interview by David Burgner

Our medical advisor David Burgner conducted a radio interview for the ABC at the end of last year. It went to air – overseas and here – in January and just happened to coincide with the 26th January. A lot of this information was similar to what he presented at our Information Session last year so if you could not attend here is your chance to hear David – [Click Here](#)

It is also good to see Kawasaki Disease is being mentioned more in T.V. medical shows (even if only briefly). Just a couple of weeks ago a neighbour commented to me that Doc Martin had a story on Kawasaki Disease and it was the first time she had heard it on a T.V. show. Grey's Anatomy last year also featured KD in an episode and a few years ago an episode of House also mentioned KD. These shows reach millions of viewers so it all helps with awareness.

Awareness Posters

We are currently in the process of making our own KD symptoms posters and are sourcing images so if you have high quality photos of your child with KD symptoms e.g. red eyes, swollen lymph node, strawberry tongue & swollen feet and hands you are willing to share we would be very grateful. Your child's identity will not be visible.

These will be in A4 size which will be easy to mail and also a convenient size to display in doctors' surgeries, Kinders, Childcare Centres etc. We will notify you when these are available. In the meantime if you are interested in spreading awareness in this way please contact us at info@kdfoundation.org.au with the subject heading KD posters and indicate approximately how many you would like.

Conference Call – Dr. Jane Burns

Dr. Jane Burns, a U.S. KD expert, recently held a conference call for parent support volunteers. Parents had an opportunity to ask questions as well as gaining up to date information on the latest research. The following is a short summary of what was discussed –

- 1) The American Heart Association should release its updated KD Guidelines within a year. At the moment there is not enough information available to have standardised guidelines.
- 2) Dr. Burn's group are currently working on 3 different diagnostic tests and hope to have success with one in the near future.

They are working on –

- 1) A Urine Test
- 2) Blood Test
- 3) Computer Algorithms – smart phone app

These are all in the early stages of testing but hopefully in the very near future a lot more cases of KD will be diagnosed and treated within the 10 day window.

- 3) They are also conducting an adult study designed to learn about the cardiovascular and general health of individuals who experienced KD in childhood.

We hope to be able to update you on new research findings as they become available.

Dr Katherine Chen has just had a paper published that summarises the data on long term effects of KD. Once this is available we will link to it on our website.

Immunisation Guidelines following Kawasaki Disease

This is one subject that regularly comes up so we are providing the latest recommendations -

The following information on immunisation sourced from The Australian Immunisation Handbook 10th Edition 2013 (updated January 2014)

Patients who have been diagnosed with Kawasaki Disease fall into the groups with special vaccination requirements. Recommended intervals between IVIG and measles-mumps-rubella (MMR), measles-mumps-rubella-varicella (MMRV), or varicella vaccination (chicken pox) is **11 months**. If the vaccines are given sooner they may not be as effective due to antibodies in the IVIG.



Each year the 16 members of the Parent Association invite Dr. Kawasaki, his wife(to Dr. Kawasaki's right), his secretary and Dr. Sonobe (left of Dr. Kawasaki) to a celebration around Dr. Kawasaki's birthday - Feb 7.

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 and click Enrol in CoRDS [or Click Here](#)

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



Another photo from Dr. Kawasaki's birthday celebration.



Photos of Cherry blossom tree at Keiko Ogasawaja's (a member of the Japanese Parents Association) house. Most trees open in late March in Tokyo.



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. New family stories are also added so if you wish to share your family's experience please email it to 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 a 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 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

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 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 (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 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.