



# Kawasaki Disease Foundation Aust.

**Support Awareness Research**

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

## **Kawasaki Disease Foundation Aust. News October 2018**

Dear KD Friends and Families,

Since our last newsletter we have a lot to report from our KD community, here and overseas. It has taken a while to source a lot of this information, so we will be producing another newsletter before Christmas so we can deliver all this information to you.

In This Edition:

- 1: Study Findings: 2015-2016 Murdoch Children's Research Institute
- 2: Current Australian Research Study
- 3: 2017 HeartKids Research Grant – interview by Dr. David Burgner
- 4: US/Canadian Studies looking for participants
- 5: Researchers in US Identify potential Diagnostic test for KD
- 6: Characteristics of Kawasaki disease in older children- author information
- 7: US KD Parent- Aubry Shackelford
- 8: Societi - the UK Foundation for Kawasaki Disease- Racheal McCormack Founder
- 9: Two Recent Fundraisers – members' relatives

We trust you will find this information informative.

Warm Regards,  
Shirley Mates and Aylee Sunstrom  
National Coordinators

## **1. Study Findings from 2015-2016 MCRI Study – Dr. Katherine Chen**

*Some of our families participated in this study and we are glad to report on the findings.*

Thank you for taking part in 2015-2016 MCRI Kawasaki disease study. We appreciate the time and effort that you and your child put into helping us.

As you may recall, the study was looking at how the body fights infection, comparing children who have had Kawasaki disease with a group of children who have not had this illness. We were also looking at changes in blood vessels following Kawasaki disease. A total of 177 children and young adults took part in the study. The study finished in 2016 and we have now analysed the findings.

### Study findings

There were 59 children and young adults who have had Kawasaki disease that took part in the project. We found that in comparison to children and young adults who have never had Kawasaki disease:

- A small difference in the thickness of the inner lining of the abdominal aorta wall in children or young adults who had more severe Kawasaki disease. The aorta is the main blood vessel supplying blood to the body. More severe Kawasaki disease was classified as those with coronary artery aneurysms that had resolved or persisted. These children and young adults had a mildly thicker lining of the aorta wall compared to those who have never had Kawasaki disease. We do not know if this is of any significance for your child's/your future cardiovascular health.
- No difference in the carotid artery, which is the blood vessel supplying blood to the brain, or in the small blood vessels in the eye.
- A larger response in the immune cells, which fight infection, of the children and young adults who have had Kawasaki disease when we mixed their blood with different germs in the laboratory. This finding suggests that children who have had Kawasaki disease may be more prone to inflammation in some circumstances. Again, we are unsure if this is of any clinical significance.

In accordance with the American Heart Association guideline, we recommend that all individuals who have had Kawasaki disease maintain a healthy lifestyle. This includes;

- . avoiding cigarette smoke
- . healthy diet and exercise
- . maintaining healthy weight
- . maintaining normal blood pressure
- . maintaining normal levels of fats in the blood

We will use the study findings to add to the growing work understanding Kawasaki disease. We have published several articles of our findings including one in Atherosclerosis.

Dr Katherine Chen  
General Paediatrician, Dept of General Medicine and Complex Care Hub  
Postdoctoral Research Fellow, Murdoch Children's Research Institute Honorary  
Fellow, The University of Melbourne  
The Royal Children's Hospital

## 2. Current Australian Research Study

In our last newsletter we congratulated Dr. Chen on gaining her PhD. At the recent International KD Symposium in Tokyo, she was awarded *The Young Investigator Award*. - shown here by Dr. Burgner (our Medical Advisor)



Seated here with Dr Kawasaki are Dr David Burgner (left) and Linny Kimly Phuong (right). Linny is currently completing her PhD working with David.

*Dr. Burgner is now working with new doctors undertaking their PhD. The following is a summary of their current study.*

Dr Ryan Lucas, a paediatric doctor in Sydney is undertaking research into Kawasaki Disease for his PhD. He will be conducting a number of studies to help better understand the disease in Australia. A large part of this research will be a 2-year surveillance study at hospitals around Australia. In partnership with the Paediatric Acute Disease Surveillance unit (based at The Children's Hospital at Westmead), Ryan will be recruiting children at the time of diagnosis and following them over time. This study will provide a wealth of information; such as how common Kawasaki Disease is; how common the heart problems are and how they are being treated; and how to identify children who need more specialised treatment.

Kawasaki Disease is an enigmatic condition that can be difficult to diagnose. One of the great difficulties is the lack of a diagnostic test - doctors diagnose the disease based on clinical criteria (such as the presence of a rash, fever, swollen lymph nodes and red eyes). Unfortunately, many other conditions can look just like Kawasaki Disease, making it very difficult to decide which children need to be treated with intravenous immunoglobulin (IVIG). One of the long-term goals of this study is to help develop a diagnostic test so that children with Kawasaki Disease can be diagnosed and treated earlier.

Much of the funding for these studies has been kindly provided by the National Blood Authority. IVIG is a blood product that comes from blood donors. As such, it is a highly valuable and sometimes scarce, resource. It is hoped that this research will help to make more informed decisions about how IVIG is used in the management of Kawasaki Disease.

### **3. 2017 HeartKids Research Grant – Dr. David Burgner**

We congratulated Dr. Burgner in our last newsletter on being granted one of 7 grants for 2017. An informative interview about his study can be found via this link – [Click Here](#)

### **4. US/Canadian Studies looking for participants**

The following studies are currently recruiting more participants – you do not need to live in the US or Canada to take part.

A: On-going Adult KD Study that is the largest effort to date in any country collecting longitudinal data on adults with a history of KD in childhood and adults who present with heart attack and lesions in the coronary arteries consistent with antecedent KD.

Interested individuals can contact us at [adultkd@ucsd.edu](mailto:adultkd@ucsd.edu) They will be sent a consent form and information about the study. For individuals joining remotely (not in San Diego) it involves only an on-line health questionnaire every 2 years through a privacy-protected portal.

For local participants, we also draw blood for biomarker studies. Our adult KD team of cardiologists is available by appointment for individuals who want to come to San Diego and meet with adult cardiologists knowledgeable about and interested in KD.

We also ask our subjects to identify a "best friend" control, someone who is the same sex and never had KD. This individual will also be sent a consent form for participation and will receive the health questionnaire every two years.

B: We also have an on-going study of KD genetics into which we are only enrolling patients with aneurysms. For more information, people may contact us at [kdgenetics@ucsd.edu](mailto:kdgenetics@ucsd.edu)

C: Sick Kids Toronto—Kawasaki Disease with Coronary aneurysms: Educational and Psychosocial Needs Assessment- Parents and Adolescents.

We would like to invite you and your child (10-18) to join an approved research study to explore education/learning needs, feeling and social experiences of living with the long-term effects of Kawasaki disease. The study will be conducted through an online questionnaire.

<http://kdcanada.org/looking-for-online-research-study-partic>

*We will continue to provide you with information of other research study opportunities.*

### **5. Researchers in US Identify Potential Diagnostic Test**

Many researchers, including our own, are working to develop a diagnostic test for KD. Hopefully this will happen in the very near future so this is very exciting news.

For the first time, researchers at University of California San Diego School of Medicine and Imperial College London, with international collaborators, have determined that Kawasaki Disease (KD) can be accurately diagnosed on the basis of the pattern of host gene expression in whole blood. The finding could lead to a diagnostic blood test to distinguish KD from other infectious and inflammatory conditions. As there is no diagnostic test for Kawasaki disease, late diagnosis often results in delayed or missed treatment and an increased risk of coronary artery aneurysms, said Jane C. Burns, MD, pediatrician at Rady Children's Hospital-San Diego and director of the Kawasaki Disease Research Center at UC San Diego School of Medicine.

*The full article can be found here – [Click Here](#)*

## **6. Characteristics of Kawasaki Disease in older children. Author information**

*Although Kawasaki Disease primarily affects young children, 75% are under 5 years; older children and even teenagers can also be affected. It appears older children may be more difficult to diagnose and may be affected differently also. As we are seeing more older children being diagnosed we thought you may find this study interesting.*

### **CHARACTERISTICS OF KAWASAKI DISEASE IN OLDER CHILDREN.**

#### **OBJECTIVES:**

To evaluate characteristics of Kawasaki disease (KD) in older children in comparison with younger patients with the disease and to improve the knowledge of clinicians on KD in older children.

#### **METHODOLOGY:**

All children with a discharge diagnosis of KD at Wuhan Union Hospital from January 2004 to May 2010 were retrospectively reviewed.

#### **RESULTS:**

A total of 113 patients were included in this study; 20 patients (17.7%) were  $\geq 5$  years old at the time of illness and 93 patients (82.3%) were  $< 5$  years old. The older children seemed to have longer total fever duration, pre-IVIG and post-IVIG fever duration than the younger children. The individual clinical criteria appeared later in the course of KD in older children than in the younger ones except cervical lymphadenopathy. The older age group had a higher incidence of cervical lymphadenopathy in comparison with the younger group (85.0% vs 51.6%). ESR was quite different between the older and younger groups (85.92 vs 67.27). Overall the older age group had a higher prevalence of additional IVIG treatment and coronary artery abnormalities (60.0% vs 32.2%) versus the younger age group.

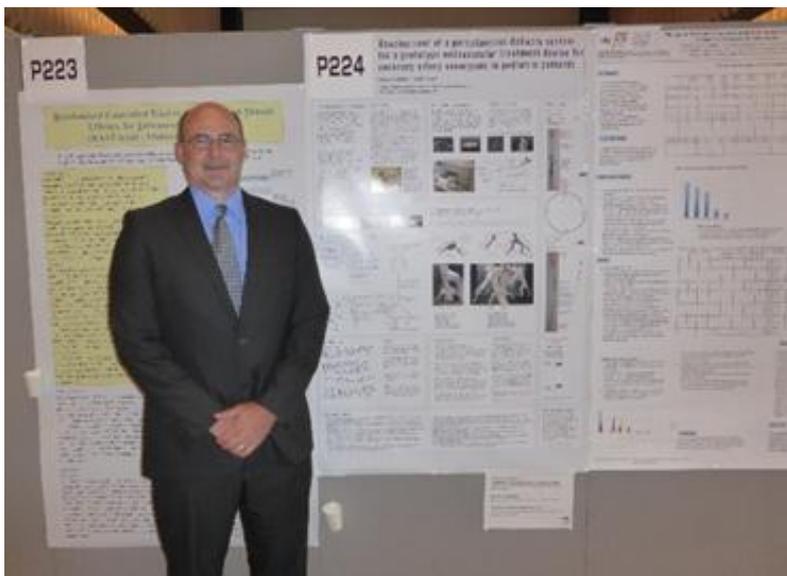
#### **CONCLUSION:**

For some reasons, KD in older children was difficult in early diagnosis and treatment. Also, older children may have a more marked inflammatory response and those treated with IVIG were more likely to require repeated IVIG treatment. And probably because of all these, older patients with KD had a higher prevalence of coronary artery abnormalities than the younger patients.

## 7. US Parent- Aubry Shackelford

*We first met Aubry at the International KD Symposium in 2015. This year he presented a poster presentation at the Symposium in Tokyo. He has kindly written the following background story and given us permission to print photos.*

At the age of five, Allison had KD, and like many others, her mother Jean had to become relentless in her pursuit of a diagnosis when initial visits to various pediatricians came up empty. Luckily, Jean found a pediatrician who had encountered the disease before (her nurse's daughter had KD many years ago), and they ended up at Children's Hospital Boston with KD expert Dr. Jane Newburger. Unfortunately, the diagnosis and initial IVIG treatment came too late, and Allison was left with giant aneurysms. Her parents turned to her uncle Dave, a medical device developer with broad medical knowledge, for help in translating the medical details of what they could expect down the road and what alternatives were available for treatment. While there are medications for controlling blood clotting, there seemed to be nothing available to prevent the likely occurrence of a stenosis - the restriction of the coronary arteries that deliver oxygen to the heart muscle. In this case, the primary treatment currently available is to perform a bypass surgery after the stenosis occurs. Hoping to develop an alternative treatment that heals the aneurysm, Allison's father Aubry (also an engineer) teamed up with Dave to form Pegasus Therapeutics, a company exploring potential technology that could be used. Spring-boarding off of a crowdfunding campaign to pay for equipment and materials, they are working on a medical device that borrows from state-of-the-art brain aneurysm treatment and coronary artery stenting technologies and have received the designation for a humanitarian use device from the Office of Orphan Products Development (OOPD) of the US Federal Drug Administration (FDA). At the recent International Kawasaki Disease Symposium in Yokohama, Japan, Aubry presented the results of their work on the development of the prototype medical device. While there is still a long way to go in development, many pediatric cardiologists and researchers from around the world who attended were encouraged to see the work being done in developing alternative treatments. As parents, we want to help not only our own children, but also others potentially affected by KD to the best of our abilities, and that can take many forms - whether advancing medical technology in treatment and diagnosis, helping parents and children understand and deal with their new situations, or raising awareness of the disease itself, we all can contribute and make a difference.



Here is Aubry Shackelford in front of his poster presentation at the International KD Symposium in Tokyo 2108.



## **8. Societi - the UK Foundation for Kawasaki Disease- Racheal McCormack Founder**

*I recently connected with Rachael Mc Cormack the Founder of the UK Foundation for Kawasaki Disease -Societi.*

*My initial connection with UK parents goes back over 20 years when I came across an article in a magazine from Sue Davidson telling her KD story- the first time I had seen anything since Cameron was diagnosed! Back then I tracked her down by writing an old fashioned airmail letter!!! Sue and Nicky Clements (another KD mum) started offering support to other families. Later, with the assistance of our own medical advisor Dr.Burgner and Dr. Nigel Curtis who were both still living in the UK and who are now both at the Royal Children's Hospital in Melbourne) set up a small support group. Roll forward to 2015 and Societi was formed to work with them. -Shirley Mates*

### **Rachael's story:**

My family experienced Kawasaki Disease in 2009. Frustrated by the lack of progress and no change in either awareness or outcomes for children, I set up Societi in December 2015. I left my job as a Government agency Director and this gave me the time I knew I would need to invest in Societi.

Societi is a small organisation, we have no paid staff (at all) and all our volunteers have full time jobs, myself included - but that doesn't stop us! We have huge ambition - to match the challenge of Kawasaki Disease in the U.K. and we are utterly determined to create change. What we have achieved so far is simply through our passion and desire for change - I've never let the (complete!) absence of external resources stand in our way, and for me, waiting for funding to come just wasn't an option. I decided we needed an organisation to be the catalyst for change - and so Societi began. I don't believe in waiting for anything.... perhaps that's why we've achieved so much in such a short space of time.

With that resolve, we have been able to create some visibility for Kawasaki Disease where before there was very little. But it's by no means just been my efforts that have for us here. Not at all. From the outset I invested heavily in building partnerships and finding people who were similarly minded to drive change. We created a clear identity and narratives which strongly identify WHY our work is so important. And from those foundations we've grown a strong and steadily growing supporter base of people who want to be part of the change - and bring their energy and time to help achieve that. Our incredible supporters see our progress and want to be part of the change we all know we need. Today we're blessed to have a phenomenal team within our charity, every single supporter I hope, recognising themselves as a critical part of Societi - because in every sense, they are. Without our supporters we cannot move forward. They inspire and drive all that we do. Hence #TeamSocieti. Our supporters step up, take action, come up with ideas and deliver them themselves, raise funds, raise awareness, grow their Kawasaki Conversations...and so much more. And we support them EVERY way we can. It's exciting to be part of such a phenomenal team and our active supporters, all leaders in their own communities for Kawasaki Disease, have made that team what it is today.

And we in turn push hard, every day on our portfolio of well over 40 projects and initiatives, with our fabulous expert clinicians guiding our work - and many, many remarkable partners driving forward our shared agenda alongside us. Their support is simply invaluable. They exponentially extend our reach, bring expertise, bring momentum, capacity and new ideas. They too are a critical part of #TeamSocieti.

There's much more we can do, many more opportunities ahead and I'm hugely excited about where we will get to in the next 18 months.

I won't stop, until Kawasaki Disease is known - and I won't stop until we have consistent and high levels of care for our children, young people and adults in the U.K. There's a mountain to climb - but we've set up a fabulous base camp! We're well on our way.

Please feel free to share any and all of our Facebook posts. I purposely created an open page not a closed group for Societi. I write every post (and tweet!) that we post, and I'd be delighted for those to reach an even greater audience with your support. In fact, please share any of the public content we have created. As voluntary organisations, and charities, collaboration is critical to make most impact together. We have a shared set of aims across our organisations and working together will achieve them faster. That's an exciting prospect and it's fabulous to know there's the basis of a partnership here as we move forward. Best regards,

Rachael  
Rachael McCormack MIO D FCMI FILM  
Societi Founder & Trustee

*Here is an interview with Prof Tulloh from Societi's YouTube channel which is very informative.*

[Click here](#)

*As Rachael says, everything we do is a team effort – every little bit of awareness we can get out to the wider community will help save precious children's hearts! Over the next few months we will be looking at ways we can further promote awareness leading up to KD Day on 26 January. We will be liaising further with the US Foundation on this. Unfortunately, this day is also Australia Day, so we are looking into how we can work around this.*

## **9. Two Recent Fundraisers –Members' relatives**

*Following on from Rachael's inspiring piece we are thrilled to report on two recent amazing fundraising/ awareness events by two different uncles of KD kids here. One of these was a swim in the UK. Both were run through our GoFundraise page.*

*The UK swim by Paula Wheaton's brother Kim resulted in over \$2000 raised to support our KD Foundation but would have no doubt also raised more awareness of KD in the UK. Paula wrote the following about their KD kids and how the swim came about.*

### **Kim's UK Swim**

"I have been to a few of the KD Foundation events and seen the good work everyone is doing so when my brother asked me if there was a Kawasaki's organisation he could donate to it was obvious what to recommend

My daughter had Kawasaki's when she was 9 weeks old. It took quite a while to diagnose her and consequently she was left with an aneurysm, although it has resolved significantly. My sister's daughter was also diagnosed with and treated for KD a few years later when she was about four. Fortunately, she was diagnosed more quickly, and treatment prevented any arterial damage. But the fact that we had the two cases in my family makes us all wonder about the genetic influences.....I am grateful for the time and energy you put into the foundation. I hope the donations can be of some help."

Regards Paula Wheaton

## Michael Murray's Run

The motivation behind Michael Murray running the half marathon in the Sydney Blackmore's Running Festival was his nephew who was early this year diagnosed with Kawasaki Disease. He came across the Kawasaki Disease Foundation after trying to find out more information about the disease online. His efforts also resulted in over \$2000 in donations as well as a lot of awareness.



Both these fundraising efforts will greatly help us to fund our awareness video and posters currently in production.