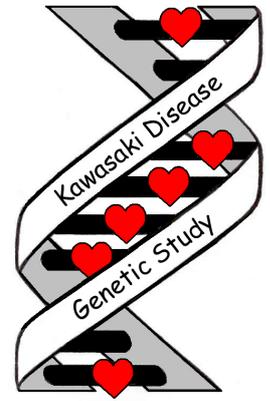


Kawasaki Disease Genetic Study (KDGS) Newsletter 2 July 2005



Welcome back to another year of the Kawasaki Disease Genetic Study...

We now have over **320 families** from Australia participating in this research – that works out to well over **1000** people involved in the study. Genetic studies of this kind rely on a large number of study participants and we are well on the way to achieving an exceptionally strong cohort. Our international collaborations continue in the UK, Singapore and Holland and are being established in Canada, New Zealand, USA, India, Korea and Hong Kong – in total we have over **1000 families** participating worldwide. This study is now considered to be the largest of its kind in the world.

Provisional analysis of the data continues and we are hoping to have some exciting results by the end of this year. The study will continue for a few years to come – so if you know of any families who have experienced Kawasaki disease and might want to take part study we would like to hear from them. We now have ethics approval to recruit from all over Australia.

KDGS - Results to date:

Our preliminary findings have identified a specific region in the genes of our study participants who have had Kawasaki disease which differs from parents and unaffected siblings, allowing us to narrow our search for a more detailed analysis commencing this year. This information opens up enormous research possibilities so this breakthrough, although small, is highly significant at this stage of our research. We hope to identify the genes responsible for making certain people more susceptible to KD and also the genes that determine whether a person goes on to develop ongoing heart problems or not. The preliminary findings will be published in the next few months.

8th International Kawasaki Disease Symposium

The 8th International Kawasaki Disease Symposium was held in San Diego in February of this year. Professor Tomisaku Kawasaki – the man who discovered Kawasaki disease back in 1967 is seen here with Dr David Burgner (KDGS Chief Investigator) and Miranda Odam (KDGS Study coordinator) who both attended from Perth, WA.

The conference ran over 4 days with an international group of researchers, parents, doctors, nurses and supporters. There were sessions for all groups of attendees. The next KD Symposium will be held in 3 years time.

Deservingly, Professor Kawasaki won the 8th International Kawasaki Disease Symposium Lifetime achievement award.



Miranda Odam, Professor Tomisaku Kawasaki & Dr David Burgner

Here are some of the conclusions from researchers presenting at the conference...

In the USA, Hawaii has the highest annual incidence of KD. The incidence of KD in Canada appears to be rising – as we all know the cause remains unknown. New methods of analysing outbreaks of KD suggest an infectious agent as the cause. A Japanese study suggests an environmental trigger for KD. Delayed diagnosis often leads to increased incidence of coronary artery aneurysms. To improve diagnosis it is thought greater suspicion of KD is required in young children presenting with fever/rash illnesses. Preliminary data from one study suggest breast-feeding may be protective against the development of KD in children. Some research groups suggest there is no reason to believe that children who have had KD will go on to develop cardiovascular disease as they get older, other groups suggest there may be; this area is still unclear. Canadian, Japanese and American researchers all suggest that long-term follow up may be beneficial in patients with a history of KD.

Newsflash - The Kawasaki Disease Genetic Study has just been awarded \$400,000 for the first ever genome-wide association study of Kawasaki disease by the Genomic Institute of Singapore (GIS). Those of you who have consented to share your blood samples with other countries participating in this research will be part of this analysis. We are very excited with this prospect and will keep you updated of any results.

Aims of the Kawasaki disease genetic study –

The Kawasaki Disease Genetic Study aims to investigate which genetic factors determine a person's chance of getting Kawasaki Disease (KD) and the genetic factors which influence that person's health outcome thereafter; in KD this relates to the possibility of ongoing problems with the heart such as aneurysm formation. The study requires 1 blood sample from the person that had KD, their biological mother and father, and a brother or sister (if available). We also ask for a questionnaire to be completed. From here on the information gained from the blood samples, questionnaires and medical notes are put onto a database so that the information may be analysed. This information is stored under strict guidelines so that study participant's personal information is kept confidential at all times. Study participants have the freedom to withdraw from the study at any time without having their rights to fair medical treatment affected. The study information collected will be shared with our international collaborating research sites. Some of you will have entered the study already.

Your support is very much appreciated. Thank you.

For more study information please contact Miranda on 08 9340 8749 or 0414 930 248 E-mail mirandao@icmr.uwa.edu.au or Dr Burgner on 08 9340 8222 E-mail dburgner@paed.uwa.edu.au.



Dr David Burgner - Chief Investigator



Miranda Odam - Study Coordinator

KD Info....

Australia: The **Australian Kawasaki Family Network (AKFN)** is a voluntary organisation managed by parents whose children have suffered from KD. If you would like to learn more about this organisation please contact Mrs Shirley Mates on (03) 9894 1257 or email AKFN@optusnet.com.au.

The **new** AKFN website - <http://members.optusnet.com.au/~mateshearts/index2.html>.

UK: The **Kawasaki Disease Support Group** is a parent-led charity that supports families affected by Kawasaki disease and is run by Sue Davidson kssg1sue@discover.co.uk, Tel. 0247 6612178. Sue has a deputy, Janet Smith janetsmith@invernet.zzn.com, Tel. 0161 292 5778.

KD Fact sheet Royal Children's Hospital, Victoria – http://www.rch.org.au/kidsinfo/factsheets.cfm?doc_id=3731.

Diagnosis, Treatment and Long-term Management of Kawasaki Disease

Newburger et al *Circulation* 2004;110:2747-2771 (available on request from study coordinator).

We would like to thank the Genomic Institute of Singapore (GIS), Imperial College London, the London Law Trust and the Sir Samuel Scott of Yews Trust, UK, the University of WA, Princess Margaret Hospital, Telethon Institute for Child Health Research, the Royal Australasian College of Physicians, the Ada Bartholomew Medical Research Foundation, Royal Perth Hospital (DCIBG), the Rebecca L. Cooper Medical Research Foundation and the Raine Medical Research Foundation, Australia, for their ongoing support with this study.



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