

A few extraordinary days – Societi Foundation in Glasgow... 12, 13, 14 March 2018

Why go to Glasgow for Kawasaki Disease?



The Royal College of Paediatrics and Child Health have an annual conference – the largest annual gathering in the UK of paediatricians and those working in medicine with children. This year the RCPCH conference was held in Glasgow and with support from brilliant partners and sponsors we attended – this was too good an opportunity to miss! Last year you may remember we made exceptional headway for **Kawasaki Disease** at this same event, held in 2017 in Birmingham, and our aim was to repeat this. With some of our key partners also Scotland based, we planned to make best use of time north of the border and put together a full schedule for Rachael!!



Persistent fever



Bloodshot eyes



Cracked lips/
strawberry tongue



Swollen glands



Swollen
fingers/toes



Rash

Monday 12 March

4.30am – An Early Start! The alarm went off and the day had begun! Plenty to do before leaving for Glasgow!



11.30am – Meeting Professor Irene McAra McWilliam, Head of School of Design at Glasgow School of Art, and a brilliant lady with many other roles too. We talked about opportunities for truly innovative ways to work together with families, partners and clinicians to identify areas which would make a difference to families already affected by Kawasaki Disease. We discussed the use of technology (and design) in Kawasaki Disease too, and have a list of possible project ideas and funding avenues to explore. I've been invited to spend time with a group looking at innovation in Health – just one of a number of things we will follow up from this meeting.

THE GLASGOW
SCHOOL OF ART

1.30pm – Meeting Professor Mike Danson, Heriot Watt University, Professor of Economics and Statistics. We met to discuss the data we hold since completing our Freedom of Information request for Kawasaki Disease – a request we sent to over 200 NHS Trusts to find out what the incidence of disease had been over the last decade. We will be working with Mike and his team in the coming months to analyse this and get the most comprehensive picture (ever!) of what's happening in the UK, working closely with Professor Robert Tulloh and his recently completed BPSU study data too.

HERIOT
WATT
UNIVERSITY

4.00pm – Meeting Dr Marit Boot, Founder, Children in Hospital charity. We met to discuss potential new collaborations on videos – Dr Boot has already generously given Societi full use of 9 of her charity's videos which we include on our online Family Portal which show the types of procedures children can expect in hospital when facing a Kawasaki Disease journey. We then discussed new opportunities around our "Questions of the Heart" research fundraising campaign and the clear potential for mutual interest and joint working. We'll follow this up in coming weeks.

what? why?
children in hospital

6.00pm – Meeting Gerry Higgins, Chief Executive, CEIS, We met to discuss growth opportunities and the need for Societi Foundation to now look for new capacity – with so much urgent need and many projects to deliver, we need a plan to scale our capacity and in doing that, grow our impact so we can reach bigger audiences more quickly. We identified a series of key next steps and a range of key contacts to pursue.

CEIS

9.30pm – Catching up on emails – the "day job" beckons!

Kawasaki Disease is SERIOUS! Awareness is URGENT!



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 **Tuesday 13 March**



Tuesday started with a quick catch up with **RCPCH colleagues on the Paediatric Care Online** (PCO) stand – PCO have been working on a ‘Persistent Fever’ Key Practice Point on their app – which is available to over 18,000 RCPCH members. The app helps clinicians diagnose children QUICKLY – something we know is essential in Kawasaki Disease. Then off to INOPSU, the **International Conference for Paediatric Surveillance Units**, and **Prof Robert Tulloh** spoke about **Kawasaki Disease**. He highlighted to a packed room – increasing UK incidence, high levels of coronary artery aneurysms in treated children and significantly higher levels of serious heart damage in the very young, even with very few symptoms. Key message? Even with ‘just’ persistent fever, please **THINK Kawasaki Disease**.

Posters on display on Tuesday, led by Ms A George (UH Bristol) were on **Admissions to hospital for Kawasaki Disease & awareness** and **Biomarkers for coronary artery aneurysms** – these were well visited and well photographed!

Dr Laidlaw (UH Bristol) gave a plenary presentation on work to identify the **risk factors for U.K. children** who go on to experience the worst outcomes from Kawasaki Disease. Early findings include being less than one year of age, male and those patients with the highest inflammatory markers are those at greatest risk of serious complications. More research is needed – let’s work to fund that here in the U.K.!


 **Wednesday 14 March**



Wednesday started with a wider group of colleagues from **Paediatric Care Online**, discussing the existing Key Practice Points where Kawasaki Disease is mentioned and where information and links can be added, and planned projects for the next few months.

We met next with **Dr Damian Roland**, UH Leicester, to plan an online learning activity (some of our Societi supporters are helping directly with this!) to improve diagnosis by helping doctors understand that Kawasaki Disease symptoms present so differently in our unique children. That’s why we use our symptoms icons and NEVER pictures!

Then we met with the **British Paediatric Surveillance Unit**, discussing new joint education opportunities for Kawasaki Disease, future events and made plans for possible international comparative papers working across paediatric surveillance units – to raise the profile of the poor outcomes here in the U.K. from Kawasaki Disease. We spoke about a Webinar and a clinical “How to manage” session for doctors on Kawasaki Disease. We’ll take all these ideas forward in coming months.

Then, with Ross from **Pretend Lovers**, our film makers, we made final plans for our next 2 exciting films – 

Reflections from Rachael

Societi
Foundation
Founder



A tremendously valuable and hugely productive few days. All of the above and **the 15 other** actions I have on my ‘to-do’ list which resulted from these brilliant days, were only possible because of the **fantastic support and critical fundraising** we have from so many Societi supporters – and incredible partners – thank you. I’m so grateful. And it’s brilliant to know we have the support of a growing group of doctors. It was fantastic to meet new clinicians who are just as determined as we are to change things around Kawasaki Disease.

Lots to do though. We need the support of our fundraisers and Societi supporters more now than ever, if these opportunities are to be realised. **Are you with us? I do hope so.**



Kawasaki Disease is the #1 cause of acquired heart disease in UK children. It’s time we changed that! ...**Together** we will



societi.org.uk