societi

the UK Foundation for Kawasaki Disease

Kawasaki Disease is the leading cause of acquired coronary artery disease in children in the UK

.....it's time we changed that

Welcome to our Summer 2016 Newsletter. Societi, the UK Foundation for Kawasaki Disease, was only established in December 2015 but in the short time since then we've taken huge strides forward to deliver our organisational aims – and bring a voice to Kawasaki Disease in the UK.

We are a policy shaping and influencing organisation, and we are proud to be working in close partnership with the long established Kawasaki Disease UK Support Group – KSSG. KSSG (www.kssg.org.uk) offers a helpline and email support for families affected by Kawasaki Disease.

Kawasaki Disease is the leading cause of acquired coronary artery disease in children in the UK and we think it's time we changed that.

Who & How Many? Kawasaki Disease at onset primarily affects young children. But because the damage it can cause can be lifelong, thousands of children, young people and adults are affected in the UK today by Kawasaki Disease. So we have been working with pace, through powerful partnerships and with the passion that drives our Board to help transform the future for those affected by Kawasaki Disease. For more about our work go to www.societi.org.uk.

Societi has four organisational aims:

- National awareness raising
- Research
- Clinical supervision
- Support for the Support Group

We have identified a series of 2020 outcomes for Kawasaki Disease, to drive forward change across the UK:

2016 Outcomes – This is where we are today

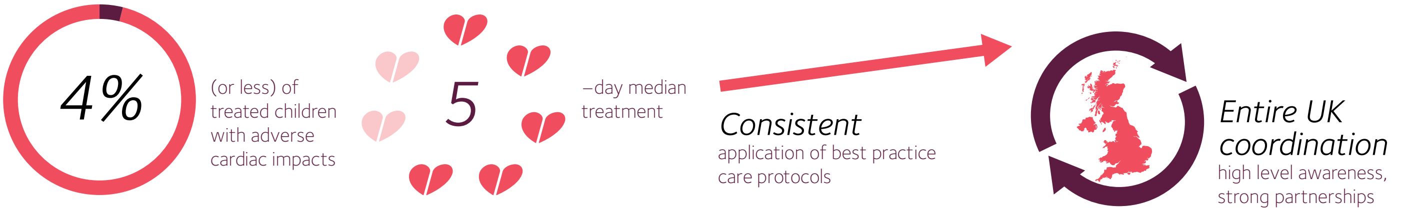
28% of treated children with adverse cardiac impacts

7 –day median treatment

Inconsistent application of care protocols

Partial UK coordination knowledge pockets, poor general awareness

2020 Outcomes – This is where we want to be



4% (or less) of treated children with adverse cardiac impacts

5 –day median treatment

Consistent application of best practice care protocols

Entire UK coordination high level awareness, strong partnerships

From our Scientific Advisory Board – Professor Robert Tulloh:

"Our recent national survey of Kawasaki Disease across the UK and Ireland, with the BPSU and with funding from KSSG, demonstrated a huge unmet need in the management of Kawasaki Disease giving us information on over 600 children with a new diagnosis. Over a quarter of these children, despite having timely diagnosis and treatment, had cardiac involvement, some with long term consequences. Societi is working through partnerships to raise the profile of Kawasaki Disease and improve the outcomes for our children and young people with Kawasaki Disease."

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Our Societi Timeline!

December '15 – June '16

Here's just a quick summary of our recent activity!

We have connected with many national partners, identified and presented the key issues around Kawasaki Disease to be addressed, developed and shared a clear strategy for Kawasaki Disease in the UK - and brought key stakeholders together to drive forward change - with pace. Much has been achieved - but there is much (much!) more to do.

Want to contribute? Contact rachael@societi.co.uk.

December 2015 - Establishing Societi
We set out our organisational concept and aims; describing this in our first publication – Societi, The UK Kawasaki Disease Foundation. In this we undertook a review of the current environment around Kawasaki Disease – what is being done; what is needed – and where opportunities exist. From this understanding we focused our remit into our four Societi aims. We engaged our long term partner for communications and design, O Street, and our Societi brand and house style was created with a focus on high visual impact.

January 2016 – Developing Partnerships We actively engaged with the British Heart Foundation (BHF), meeting with the Chief Executive to raise the profile of Kawasaki Disease and our aims. Since then BHF – who we recognise as a key partner, have been kept closely informed of our work and conversations continue. We held a Skype meeting with Kawasaki Disease Research Center (KDRC), California, to understand international action underway. And O Street finalise the Societi comms strategy.

February 2016 – Establishing Societi's Scientific Advisory Board Recognising the need for Societi to ensure scientific and clinical integrity, with support from the three leading experts in Kawasaki Disease in the UK, we formally established our Scientific Advisory Board (SAB) alongside our Board, comprising Professors Robert Tulloh, Paul Brogan and Mike Levin. Across their multi-disciplinary areas of paediatric expertise – of cardiology, vasculitis/ rheumatology and infectious diseases respectively, Societi is overseen and guided by our SAB. And our promotional pin badges arrived, to support visibility of our Societi brand.

March 2016 – A National Strategy for Kawasaki Disease Shaped by our SAB, we published the first National Strategy for Kawasaki Disease. We met with the Medical Director, BHF, to discuss possible BHF funding for a National Clinical Trial (advancing treatments for acute Kawasaki Disease – a Societi priority), and engaged with the UK Chief Medical Officer to raise the profile of Kawasaki Disease at a national level. We convened the first meeting of a National Clinical Trial group at the Institute for Child Health, preparing for a formal discussion with BHF on long term funding, together with awareness raising support. We become a Charity Partner with printed.com.

April 2016 – Societi is Online Our Website www.societi.org.uk went live (now at >1,600 page views, >20% returning visitors and >150 downloads of the 2013 Kawasaki Disease Management Guidelines). We worked together with KSSG and the NHS Improvement Service to support accompanying information for the Kawasaki Disease National Patient Safety Alert and attend KSSG's fabulous Family Day, Coventry – to launch our KSSG/Societi partnership for our joint work ahead. And our Awareness Raising postcard is published and distribution started.

May 2016 – Our National Agenda O Street assist our publication of an "Infographic", in which we set out what's needed nationally to improve care and management of Kawasaki Disease. This is used in our discussion with Public Health England, shared with the UK Chief Medical Officer and at the Kawasaki Disease Symposium. We took forward discussion on building e-learning modules for Doctors and the development of a national patient registry for Kawasaki Disease – through a working group with BPSU, Bristol Children's Hospital and a software developer. We developed a proposal for corporate sponsorship to support a national awareness raising campaign and our website is updated with more resources including the National Patient Safety Alert.

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....it's time we changed that

June 2016 – A National Steering Group for Kawasaki Disease is Formed

Societi met with the Medical Director, Public Health England, to raise the profile of Kawasaki Disease, discussing the need for NICE protocols for clinical management and a greater focus on better resourcing to prevent long term health damage in children. We spoke with the National Clinical Director (Heart Disease) to raise Kawasaki Disease as a national priority and met with Prof Jane Burns (KDRC) re Societi's agenda to ensure ongoing international connectivity. Societi information was shared at the Kawasaki Disease Symposium at Imperial College and a comprehensive Freedom of Information Request was lodged by Societi with NHS England to follow up actions taken on the May 2016 Patient Safety Alert and gather national data. Regional information sharing is ongoing including QMC, Nottingham and Leeds Children's Hospital. We catalysed a National Steering Group, an expert group with a remit to advance integrated UK clinical management and Kawasaki Disease awareness.

NATIONAL STEERING GROUP FOR KAWASAKI DISEASE: Membership

- Societi Scientific Advisory Board Professors – Robert Tulloh, Paul Brogan, Mike Levin
- National Clinical Director, NHS England (Heart Disease)
- National Clinical Director, NHS England (Children and Young People)
- British Congenital Cardiac Association
- Public Health England
- British Heart Foundation
- Societi Founder

Societi FOI Request 27 June 2016

Issued to Every NHS England Trust – Summary

Following the Patient Safety Alert and in need of definitive, long term data on Kawasaki Disease in the UK, Societi lodged the following FOI Request on 27 June 2016. We asked five questions which are summarised here. For the full text, see our website.

Societi Freedom of Information Request: On 11 May 2016 the NHS Improvement Service issued a Patient Safety Alert regarding Kawasaki Disease which required immediate consideration and subsequent action by all NHS organisations receiving the Alert. The deadline for acting on the Patient Safety Alert was 22 June 2016. We asked the following questions further to the Alert:

Q1 Please can you advise what action has been taken by your Trust in response to the Patient Safety Alert on Kawasaki Disease, issued on 11 May 2016?

Q2 Can you confirm for your Trust, if all current and past patients with giant coronary artery aneurysms resulting from Kawasaki Disease and those with resolved coronary artery aneurysms have been identified and made aware of the Patient Safety Alert?

Q3 Please can you advise what other feedback your Trust, on receiving the Alert, gave?

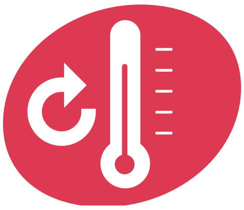
Q4 Are the 2013 Kawasaki Disease Management Guidelines implemented by your Trust?

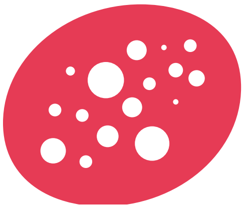
Q5 For your Trust, listing data sets individually, please provide, per calendar year for the period 2006 to 2016 inclusive, information on Kawasaki Disease acute admissions

------UPDATE------ ------UPDATE------ ------UPDATE------

We're already receiving many detailed replies, with over 80 now received at the time of publishing this newsletter. The data we get back will directly inform the work of the National Steering Group and Societi's next steps. We'll publish a full report when we have analysed the replies.

THINK! Kawasaki Disease Symptoms


Persistent fever


Rash


Bloodshot eyes


Cracked lips/
'strawberry' tongue


Swollen fingers/toes


Swollen glands

So – that was our first six months or so.....

What's Societi's plan for the next 6 months?

- The first meeting of the **National Steering Group** will take place, to deliver step-change improvements in UK clinical management of Kawasaki Disease
- A sponsor will be sought to enable delivery of our planned **national campaign to raise awareness**
- Our **National Clinical Trial** discussions with British Heart Foundation will progress, taking the outline to a full application, concurrent with joint work (Societi/BHF/Public Health England) to raise awareness of Kawasaki Disease
- We will maximise impact from **high profile events**, seeking those which present a forum for Kawasaki Disease discussion - getting right to the heart of the medical communities we need to actively engage
- We will progress **e-learning module development**, subject to funding, through a working group
- We will progress discussion on a **national patient registry**, via a dedicated group which we will set up
- We will review progress against the **Societi UK Strategy** for Kawasaki Disease, republishing in 2017
- From our **NHS England FOI** replies we will publish a detailed report on findings, acting on these
- We will continue to promote the need for **clinical protocols**, pursuing these into the NICE work programme
- We will update our **website**, building its reputation as the 'go-to' site for UK Kawasaki Disease, increasing our contact list and responding to repeat visitors
- We will develop a **funding plan jointly with KSSG** to jointly support growth in their work with enhanced resources
- We will continue **our partnerships** and will respond to **information requests** about Kawasaki Disease

From Kawasaki Support Group UK

"The KSSG started in 1994 by mothers of children diagnosed with Kawasaki and we now have **over 1450 families** in the UK within KSSG. We support families affected at all different stages and outcomes. We have a factsheet, parents guide and website **www.kssg.org.uk**

Our group is run voluntarily from our homes - we rely on donations. Over the years we have collated information on the cases we know of to help with research, as well as funding vital research. We are thrilled to be in partnership with Societi, taking on roles we cannot. We continue to concentrate on our main purpose - supporting families."
Sue Davidson & Nicky Clements, KSSG

And Finally - Thank You...

With thanks to and acknowledging the phenomenal support of our partners, and those with whom we have taken forward invaluable disussions over the last six months. Without these conversations, critical support and your investments made to date, our progress would simply not have been possible. Our thanks to:

British Cardiovascular Society
British Congenital Cardiac Association
British Heart Foundation
British Paediatric Surveillance Unit
Bristol Childrens Hospital
Department of Health
Great Ormond Street Hospital
Imperial College London
Institute for Child Health
Kawasaki Support Group - KSSG
Kawasaki Disease Research Center (USA)
Lanarca
Leeds Childrens Hospital
NHS England
NHS Improvement Service
O Street
Public Health England
printed.com
Queens Medical Centre, Nottingham
Royal College of Paediatrics and Child Health
St Marys Hospital, London

Our thanks too, to the remarkable individuals who support us with professional and technical expertise. Without the time you give and your support we cannot make progress.

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Connect with Societi?

Have something you can contribute? Contact us! You can email us or complete the contact form on our website. By filling in the contact form you can join our contact list and receive our updates.

e: rachael@societi.co.uk
www.societi.org.uk