

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

....it's time we changed that

Welcome to our RCPCH 2017 Conference Newsletter!

We're delighted to be at Conference this year with the opportunity to have a **Kawasaki Conversation** with the paediatric community. Kawasaki Disease is the leading cause of acquired heart disease in children in the UK – but is currently little known. By the end of the conference – with your help – we want to change that!

Kawasaki Disease Q & A

What is it? Kawasaki Disease is an acute self-limiting inflammatory disorder, associated with vasculitis, affecting predominantly medium-sized arteries, particularly the coronary arteries. **It is the #1 cause of acquired heart disease in UK children.** The aetiology of Kawasaki Disease remains unknown and it is currently believed that one or more as yet unidentified agents induce an intense inflammatory host response in genetically susceptible individuals. Genetic studies have identified several susceptibility genes for Kawasaki Disease and its sequelae in different ethnic populations, as well as genes influencing response to intravenous immunoglobulin (IVIG) and aneurysm formation.

Treatment? IVIG and aspirin are effective therapeutically and the addition of corticosteroids to IVIG is beneficial for the prevention of coronary artery aneurysms.

How many? Increasingly common, Kawasaki Disease affects hundreds of children in the UK each year. Research by Societì (June 2016) shows hospital admissions for Kawasaki Disease have increased fourfold in the last ten years. Globally Kawasaki Disease is on the rise.

Who it affects? At onset, Kawasaki Disease primarily affects young children with over 75% of those affected being under 5 but it can affect any age group. And 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.

What can I do? Kawasaki Disease is **often misdiagnosed or diagnosed late**, sometimes because a full symptom 'picture' is being awaited. If you see a child with persistent fever and two or more of the symptoms opposite, **THINK Kawasaki Disease.**

What's so critical?



Time!

BPSU research led by Professor Robert Tulloch looking at Kawasaki Disease incidence highlighted a link between cardiac damage and long treatment times. Children in the study with Kawasaki Disease without cardiac damage were treated on average at 6 days. Those with cardiac damage and potential life long heart problems – were treated **later**, on average at 10 days.

EARLY TREATMENT IS KEY

A Symptom Cluster to Know

Because the symptoms of Kawasaki Disease present DIFFERENTLY on our unique children, we created icons.

PERSISTENT FEVER is characteristic of Kawasaki Disease.

ALL SYMPTOMS MAY NOT BE PRESENT IN EVERY CASE.

If you see **PERSISTENT FEVER** with **TWO OR MORE** of these symptoms –

THINK Kawasaki Disease

These organisations and others, help us with expertise, guidance, support and hugely valuable influence. **THANK YOU!**

Kawasaki Disease Symptoms



Persistent fever



Cracked lips / 'strawberry' tongue



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands



WORLD HEART FEDERATION®



University Hospitals Bristol
NHS Foundation Trust



Public Health England



Improvement



RCPCH
Royal College of Paediatrics and Child Health
Leading the way in Children's Health



Great Ormond Street Hospital

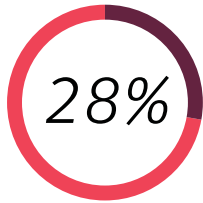
O STREET

Imperial College Healthcare NHS Trust



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2016 Outcomes - Where we are today

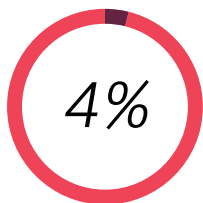


of treated children with adverse cardiac impacts



-day median treatment

2020 Outcomes - Where we want to be



(or less) of treated children with adverse cardiac impacts



-day median treatment

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

Why Societi?

Societi was established in 2015 as an organisation with a specific focus to raise awareness of Kawasaki Disease. We are an influencing and policy shaping organisation, that enables both urgently needed research and pursues changing policy and clinical practice for Kawasaki Disease. Not enough is known about its symptoms or its treatment and long term care for affected families is limited. Many agencies, doctors and parents are unaware of Kawasaki Disease. We want to change this.

An Emerging National Clinical Trial – Acute Treatment

Treatment recommendations in the UK for some time have included treatment with corticosteroids as primary treatment alongside IVIG for acute Kawasaki Disease but practitioners have not commonly implemented these treatment recommendations and this may be one factor in such unacceptably high levels of potentially preventable, lifelong heart damage being experienced here in the UK.

We urgently need a clearly defined evidence base from which to draw a prescriptive mandate for UK-wide clinical care for all Kawasaki Disease patients. A national clinical trial is therefore being proposed to explore the effectiveness of use of steroids, plus intravenous immunoglobulin (IVIG) for prevention of coronary artery complications. Please contact us for more information – we're actively seeking interested centres.

CPD & Learning – Kawasaki Disease

Sharing knowledge about how best to recognise and treat Kawasaki Disease was highlighted as a TOP priority by our UK Steering Group in September 2016. We went on to secure some external funding, and together with our own investment we're currently developing an on-line training module for clinicians. UK Kawasaki Disease expert Prof Robert Tulloh is leading the clinical content development and we have advanced work on the main content areas. The module will be released before the end of 2017 and we'll work with professional bodies and partners to promote it widely.

Parent Resource – Sharing Experiences

When making a diagnosis of Kawasaki Disease, it's often helpful for clinicians to be able to refer parents to a support group and many already refer to the volunteer-run KSSG. Many parents look on-line for information too and with so much – often confused and out of date – information available, much of it is not always relevant to our UK community, KSSG offered Societi funding to develop an online parent resource. We're pressing ahead with this and plan to release it simultaneously with the clinician module.



UK Steering Group for Kawasaki Disease

Newly formed in 2016, this group is supported by the NHS England Clinical Directors for Heart Disease (Professor Huon Gray), and Children and Young People (Dr Jackie Cornish OBE), the Chief Executive of the British Heart Foundation, Simon Gillespie – and leading clinicians. Our work centres on supporting Societi to build national momentum around co-ordinated action to raise awareness of the disease, advocate for much needed UK based research and enhance and standardise clinical practice for Kawasaki Disease.

