



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

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

Kawasaki Disease Symptoms



Persistent fever

What is Kawasaki Disease?

Kawasaki Disease is the leading cause of acquired heart disease in children in the U.K. Raising awareness of the disease is extremely important, as recognising the symptoms and treating early could save a child's heart from life-long damage.

Little known but increasingly common, Kawasaki Disease presents with symptoms, many of which mirror those of other common childhood diseases such as Scarlet Fever. This can lead to misdiagnosis and a delay in treatment severely affecting outcomes. In the UK 28% of treated children have heart damage - which may be avoided if treated early.



Cracked lips / 'strawberry' tongue

Kawasaki Disease has a range of symptoms including a characteristic and distinctively persistent high fever for five days or more, rash, bloodshot eyes, "strawberry" tongue, cracked, dry lips, redness of the fingers and toes and swollen glands in the neck. Kawasaki Disease can be present with some (partial) or all (full) of these symptoms. **A persistent high fever** is the one defining symptom and will always be present. The symptoms of Kawasaki Disease can also appear in series (i.e. not all at once) over a few days.



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands

Societi works in close partnership with KSSG - the support group for families affected by Kawasaki Disease. KSSG have a telephone help line giving parents information and understanding. They currently have over 1600 families in the group and it is growing. To find out more visit kssg.org.uk



KSSG National Family Helpline:

02476 612178

Helpline Email:

helpline@kssg.org.uk



Kawasaki support group UK

Family Resource Portal - Now online at societi.org.uk

We are so pleased to be able to tell you our new online Family Resource is now up and running!! There is so much, often confused and out of date information available on line, and much of it not always relevant to our UK community. KSSG offered Societi funding to drive forward the development of an online family resource. The result is an easy to use, informative and helpful resource available to families when they need it most.

E-Learning Clinical Module - Sharing Knowledge

Educating doctors in recognising and treating Kawasaki Disease was highlighted as a TOP priority by our UK Steering Group for Kawasaki Disease in September 2016. We went on to secure funding from an external partner, and together with our own investment we'll deliver an online training module for doctors. Professor Tulloh, who is on Societi's Scientific Advisory Board, is leading the clinical content development and we are very grateful for his expert leadership - without which this wouldn't be possible. We've employed a software developer, film team and have advanced work on the main content areas.





Societi Is Raising Awareness of **Kawasaki Disease** – Can You Help?

We have 'just' 65 million people to tell about Kawasaki Disease! We work hard to make this happen and have forged strong links with many partners including the World Heart Federation and the British Heart Foundation. We're always looking for new partners to work with. Every year our awareness campaign starts with International Kawasaki Disease Awareness Day (26 January). We work with many families and partners to achieve a high impact start to our year! That sets

us up for the rest of the year, reaching thousands of people to let them know about Kawasaki Disease! **JOIN US? Create a 'Kawasaki Conversation' in your community!** We can help you grow a Kawasaki Conversation in your community. There are lots of downloadable resources on our website to help. Visit societi.org.uk to find out what's available – and if you can't find what you are looking for, get in touch and we'll always try to help. We'd love to hear from you!

2016 Outcomes – Where we are today



2020 Outcomes – Where we want to be



Societi's work programme!

- Awareness Raising** This is our top priority.
- Fundraising** We must source funding to continue working with momentum. Please help if you can.
- E-Learning for Clinicians** We will complete the E-Learning module and to distribute to doctors.
- Family Resource Portal** We will promote our new on-line Family Resource Portal for families affected by Kawasaki Disease.
- FOI Report – Patient Safety Alert** We will publish our FOI report! We're nearly there....
- UK Clinical Guidelines** We are coordinating a writing group to create fully updated, whole of life UK Kawasaki Disease clinical guidelines.
- National Clinical Trial** We will submit a funding application for a National Clinical trial to the British Heart Foundation.
- National Steering Group for Kawasaki Disease** We will continue to lead the UK Steering Group and allow our co-ordinated Kawasaki conversation to grow.
- Partnerships** We will further develop partnerships, locally and internationally to strengthen our voice.



Paediatric Care Online

Paediatric Care Online (PCO UK) is an online decision support system designed for healthcare professionals who see children at the point of care. This innovative tool provides immediate access to clinically assured information to inform decisions and diagnosis. Societi have been working alongside PCO UK to add a new Key Practice Point for 'persistent fever' so that Kawasaki Disease will be more easily recognised by doctors using the app and diagnosed promptly.

What can **YOU** bring?



There are lots of ways you can support Societi in our aim to raise awareness of Kawasaki Disease. We are always in need of funds to help us raise awareness. If you would like to fundraise or donate, please visit societi.org.uk to see how you can help.



societi.org.uk