societi We are the UK Foundation for Kawasaki Disease

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NEW CLINICAL GUIDELINE IN THE MAKING FOR ALL UK CHILDREN AFFECTED BY KAWASAKI DISEASE

On World Heart Day, Societi, the UK Foundation for Kawasaki Disease, announces a major national project to protect children's hearts.

Societi, the UK Foundation for Kawasaki Disease, has launched an ambitious, initiative to create a **national clinical guideline for the acute diagnosis and treatment of Kawasaki Disease**. This expert-led guideline will be designed to ensure that every child across the UK can receive the very best possible care, wherever they live. The guideline is being developed in accordance with Royal College of Paediatrics and Child Health (RCPCH) methods, procedures, and policies, that will enable formal endorsement by the College once complete.

KEY MESSAGES

- **This World Heart Day, Societi Foundation is leading a national project to create the UK's first clinical guideline for the acute care of Kawasaki Disease.** This is a game-changing step to end the postcode lottery of diagnosis and treatment and to protect children's hearts across the UK.
- **Kawasaki Disease is the leading cause of acquired heart disease in children** in the UK.
- **Lifelong, life-threatening heart damage** results in **a quarter** of all affected children, rising to **39%** in babies under 1. (1)
- **Low awareness means Kawasaki Disease is often missed or misdiagnosed**, putting children's hearts at risk of avoidable, permanent damage.
- **Cases are rising worldwide**, making it vital that all health professionals can diagnose and treat Kawasaki Disease quickly.

In the year ahead there will be up to 2,000 hospital admissions of children in the UK facing Kawasaki Disease, which is the leading cause of acquired heart disease in UK children. Worryingly, for such a serious disease, many doctors remain unfamiliar with it.

Families often face what has been described as a "postcode lottery" in diagnosis and treatment, with clinical knowledge and care varying widely. We know too, that for doctors encountering the disease for the first time, it can feel like being in the "wilderness without a map." Confusion and lack of awareness around Kawasaki Disease in GP surgeries and hospitals alike can lead to a delay in diagnosis and treatment, directly increasing the risk of lifelong heart damage for affected children. (1)

This new national guideline will help change that.

Why it matters

It is anticipated that the national guideline will be published in 2026, and will:

- **End the postcode lottery** of care by providing one expert standard for all UK hospitals.
- **Ensure every child receives the best available treatment** as quickly as possible.
- **Save doctors' time**, replacing a patchwork of local guidelines with one authoritative, evidence-based standard.
- **Support families** with clear, up-to-date information and follow-on care tailored to their child's needs.

"Kawasaki Disease is a medical emergency and decisions in the acute phase need to be made quickly and accurately," said **Rachael McCormack, Founder of Societi Foundation**. "On World Heart Day, we're proud to highlight this crucial work. This national guideline will give doctors the expert map they need and will help protect children's hearts across the UK from this very serious disease."

Professor Paul Brogan, of Great Ormond Street Hospital, and Chair of the Guideline Development Group, added: "This is an important opportunity to transform the way Kawasaki Disease is recognised and treated. By bringing together expertise from across the UK, we can create an updated, robust, evidence-based guideline that ensures every child receives the highest standard of care, no matter where they live."

A game-changing project

Societi has convened a **Guideline Development Group (GDG)** of more than **20 leading clinicians and researchers**, supported by over **100 stakeholders** from paediatrics, cardiology, infectious disease, rheumatology and other key specialties across the UK. The group is co-chaired by **Professor Paul Brogan** (Great Ormond Street Hospital) and **Rachael McCormack**, Societi's founder, with leadership from **Professor Rob Tulloh** and **Professor Mike Danson**, all Trustees of Societi.

The project is already well under way with all members of the group driving forward a detailed review of the latest evidence and guiding the development of the guideline to ensure that every recommendation is tested and challenged to the highest standards.

How you can help

Societi Foundation is a small charity leading this major national effort. Public support is crucial to ensure the guideline is completed and implemented.

Donations can be made at: https://www.justgiving.com/charity/societi

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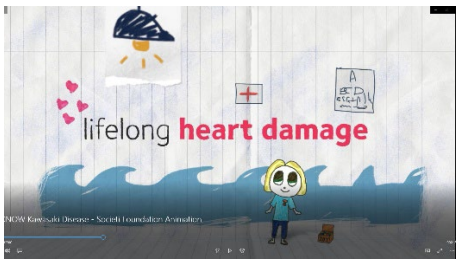
Multi Media Resources:

Our Kawasaki Disease Awareness Animation
Our Kawasaki Disease Awareness Animation can be viewed here.

The QR code below can be scanned to view our Awareness Animation:



Our TEMPERS leaflet

Kawasaki Disease? Remember TEMPERS

Children with **Kawasaki Disease** *are characteristically irritable!*

Temperature – **Persistent high fever**

Erythema – reddened hands and feet with swelling

Mouth – dry, sore mouth, cracked lips, 'strawberry tongue'

Pace – **Treat early** to reduce potential heart damage

Eyes – bloodshot, non-sticky conjunctivitis

Rash

Swollen glands in neck, often just one side

If a child has a **PERSISTENT FEVER** *and two or more of these symptoms* **THINK KAWASAKI DISEASE!**

5 days of fever? THINK Kawasaki Disease

Kawasaki Disease *is the #1 cause of acquired heart disease in children in the UK...*

...help us change this.

Kawasaki Disease – who does it affect?
It is mostly a childhood illness with over 75% of those affected being under 5 years old but it affects older children too.

Kawasaki Disease – what's the issue?
In the UK awareness of Kawasaki Disease is low. Currently UK diagnosis and treatment times are too slow. **39%** of babies (under one year) treated for Kawasaki Disease develop serious heart problems. **28%** of diagnosed children experience heart complications. Overall, **19%** of children treated develop serious heart damage. For a few children every year Kawasaki Disease is fatal ...help us change this. We need everyone to know Kawasaki Disease as early diagnosis and treatment can prevent heart damage. (Data from BPSU Study, Kawasaki Disease UK & Ireland 2013–2015)

Kawasaki Disease – how common is it?
Hospital admissions in England for Kawasaki Disease have increased fourfold in the last ten years. It's more common than some types of meningitis. About 1 in 10,000 children are currently diagnosed each year and very poor levels of awareness mean many more children may be affected.

Kawasaki Disease – what can I do?
Know the symptoms and remember, symptoms may not appear all at once. Not all children present with all symptoms so – if a child has a **PERSISTENT FEVER** for 5 DAYS or more with 2 or more of the symptoms overleaf THINK Kawasaki Disease and seek URGENT medical advice. **You** could save a child's heart.

Kawasaki Disease is serious! Awareness is urgent!
Today, most people haven't heard of Kawasaki Disease. That's one of the biggest challenges we face. Help us get it known because Kawasaki Disease is increasingly common in the UK. Too many children and young people today have lifetime heart damage because of Kawasaki Disease ...help us change this.
For more information visit societi.org.uk

societi
The UK Foundation for Kawasaki Disease
Victoria Court, Holme Lane, Winthorpe, Newark, NG24 2NU
rachael@societi.co.uk

societi.org.uk

societi We are the UK Foundation for **Kawasaki Disease**

A printable versions of TEMPERS, Societi Foundation's information leaflet for Kawasaki Disease, endorsed by the RCPCH can be downloaded at https://www.societi.org.uk/for-families/families-resources-downloads/

The QR code below can be scanned to access our TEMPERS leaflet as a PDF:

References:

1. Professor Robert Tulloh et al. BPSU study: https://www.societi.org.uk/research/kawasaki-disease-a-prospective-population-survey-in-the-uk-and-ireland-from-2013-to-2015/

Notes to Editors:

1. Kawasaki Disease & Societi Foundation – Kawasaki Disease is the leading cause of acquired heart disease in children in the UK. The characteristic symptoms of Kawasaki Disease are a high temperature that lasts for 5 days or more, with a rash, swollen glands in the neck, dry, cracked lips, red fingers or toes and red eyes. Children have improved chances of recovery with rapid diagnosis and treatment. By raising awareness of Kawasaki Disease, Societi aims to enable children to have access to timely diagnosis and treatment – to improve outcomes for children. Wrongly often still described as rare, in the UK Kawasaki Disease incidence in rising – as it is across the globe. No-one knows the cause of Kawasaki Disease, so rapid treatment is currently the best way to stem the growing number of children with heart damage.

Societi Foundation is a registered charity in England & Wales (no 1173755), established in 2015 by a parent of a child who had Kawasaki Disease, Rachael McCormack. We have a specific focus on Kawasaki Disease, helping to raise awareness and supporting affected families. www.societi.org.uk

2. Professor Paul Brogan - Professor of Vasculitis and Honorary Consultant Paediatric Rheumatologist, Great Ormond Street Hospital. Professor Brogan is a Societi Foundation Trustee and member of Societi's Scientific Advisory Board.

3. Professor Robert Tulloh - Professor of Congenital Cardiology and Pulmonary Hypertension (retired). Prof Tulloh is an internationally recognised expert in Kawasaki Disease He is a Societi Foundation Chairman and provides clinical oversight for our organisation.

4. Professor Mike Danson - Professor Emeritus of Enterprise Policy, Heriot-Watt University, is a Societi Foundation Trustee.

Contact Details:

Media enquiries to: Rachael McCormack, UK Foundation for Kawasaki Disease, Victoria Court, Holme Lane, Winthorpe, Newark, Notts, NG24 2NU

w: www.societi.org.uk | e: info@societi.co.uk | X:@Societi_UK_KD | Instagram:@societi_uk_kd | Facebook:@SocietiFoundation