

MEDIA RELEASE 7 April 2024

THINK Kawasaki Disease this World Health Day!

On 7 April, World Health Day, a UK national charity calls for Kawasaki Disease awareness. Severe heart damage is happening to children – now. Low awareness of the **number 1** cause of acquired heart disease in children, **Kawasaki Disease** is the reason. Awareness is KEY to helping protect children’s hearts says Societi, the U.K. Foundation for Kawasaki Disease.

KEY MESSAGES

- = **Lifelong, life-threatening heart damage** results in a quarter of all affected children, rising to 39% in babies under 1. (1)
- = UK Charity calls for **urgent public awareness, worldwide**
- = Kawasaki Disease cases are on the rise globally; it’s a disease **all** parents need to know
- = Kawasaki Disease is the **#1 cause of acquired heart disease in children** in developed countries, including the UK, US and Japan.
- = In Japan more than 1 in 100 children in Japan have had the disease by age 5 (2)
- = Low awareness of Kawasaki Disease means it’s **often initially misdiagnosed**, putting children’s hearts at risk of lifetime damage!

Rachael McCormack, Founder of Societi, the U.K. Foundation for Kawasaki Disease said: ‘We are campaigning to raise awareness of Kawasaki Disease – to help ensure fewer children suffer lifelong, life-threatening heart damage because of this serious children’s disease. Despite Kawasaki Disease being increasingly common, low public awareness means it’s often initially misdiagnosed, putting children’s hearts at risk. We must change this and stop Kawasaki Disease having the devastating effect it has on far too many children, and their families, today’.

Children’s heart health is a hugely important consideration for their lifelong wellbeing - and their ability to contribute to society, no matter their country of residence. With Kawasaki Disease overtaking Rheumatic Fever as the leading cause of acquired heart disease in children in many countries, such as India for example, it’s a matter of grave concern that awareness is so low. Priority must be placed on building knowledge about Kawasaki Disease for paediatric clinicians worldwide to stem this serious risk to children’s heart health. (3)

Professor Robert Tulloh, Chair of Societi Foundation and an expert in Kawasaki Disease said “We know that early diagnosis and rapid treatment are the most important things we can do right now to change outcomes for children around the world affected by Kawasaki Disease. We need more people to know about Kawasaki Disease and for doctors to THINK Kawasaki Disease as a possible diagnosis in any child with a persistent, unexplained high fever - and to treat it urgently.” (4)

Incidence of Kawasaki Disease is rapidly rising globally, and it is now increasingly common. Kawasaki Disease is now believed to be the most common vasculitic disorder of children.(5)

Incidence is much higher in Northeast Asian countries including Japan, South Korea, China, and Taiwan, 10–30 times higher than that of Kawasaki Disease in North America and Europe. In Japan almost 1 in 100 children in Japan have had the disease by age 5.(6)

It’s the leading cause of acquired heart disease in children, in developed countries and is increasingly reported from many rapidly industrialising developing countries.(6)

The characteristic symptoms of Kawasaki Disease include a high temperature that lasts for 5 days or more that that can come and go, but may persist even with children’s paracetamol or

ibuprofen. Children sometimes develop a rash, swollen glands in the neck often on one side, dry, cracked lips, and a sore mouth, red fingers or toes and red, bloodshot eyes. Children with Kawasaki Disease are characteristically irritable too. Often, children do not develop all the symptoms.


Lack of awareness of Kawasaki Disease means that an ever-growing number of children, young adults and adults are facing the prospect of lifelong heart disease and serious heart problems in later life which needs specialist management (7). Around a quarter of all children affected by Kawasaki disease will suffer long term heart damage (1). Studies show links between treatment delay and increased risk of such life threatening and life limiting heart damage (1).

By getting Kawasaki Disease known Societi Foundation is working to protect children's hearts from this devastating lifelong damage. Please know Kawasaki Disease!

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Multi Media Resources:

Our TEMPERS leaflet




Kawasaki Disease is predominantly a childhood illness though it can affect people of any age. Its cause is unknown. **Kawasaki Disease is the leading cause of acquired heart disease in children.** Awareness of Kawasaki Disease is currently low and it is often mistaken for other common childhood illnesses, leading to misdiagnosis and delayed treatment. Children who go untreated or who are treated later face higher risks of developing complications including life long heart damage.

Early diagnosis and treatment are key to better outcomes
...for our children





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

5 days of fever?
THINK Kawasaki Disease



If a child has a **PERSISTENT FEVER** and two or more of these symptoms **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

Endorsed by

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

Printable versions of TEMPERS, Societi Foundations 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:



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:



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/>
2. Rowley, A.H. Shulman, S.T. The epidemiology and pathogenesis of Kawasaki disease. *Paediatric Infectious Diseases* (2018) 6: 00374
3. Jiao, F. Jindal, A.K. The emergence of Kawasaki disease in India and China. *Global Cardiology Science and Practice* (2017) 3: e201721
4. Singh, S. Kawasaki, T. Kawasaki Disease – An Indian perspective. *Indian Paediatrics* (2009), 46 (7): 563 – 71
5. Eleftheriou, Levin, M et. al. Management of Kawasaki disease. *Archives of disease in childhood* (2014), 99 (1) 74-83
6. Elakabawi, K. Lin, J, et. al. Kawasaki disease: global burden and genetic background. *Cardiology Research*, 11 (2020), 9-14
7. Brogan P, Burns JC, Cornish J Kawasaki Disease Writing Group, on behalf of the Royal College of Paediatrics and Child Health, and the British Cardiovascular Society, et al Lifetime cardiovascular management of patients with previous Kawasaki disease *Heart* 2020;106:411-420

Notes to Editors:

1. Kawasaki Disease & Societi – 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, sometimes 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. In the UK, Kawasaki Disease incidence is rising – as it is across the globe. No-one knows the cause of Kawasaki Disease. Societi Foundation is a registered charity in England & Wales (no 1173755), established in 2015 we have a specific focus on Kawasaki Disease. More information at www.societi.org.uk

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

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