

MEDIA RELEASE 26 January 2024

## National charity calls for everyone with children in their world to **THINK Kawasaki Disease!**

26 January is **International Kawasaki Disease Awareness Day!** Awareness is KEY as severe heart damage for children is happening now, because of low awareness of Kawasaki Disease - the leading cause of acquired heart disease in UK children, says Societi, the U.K. Foundation for Kawasaki Disease.

### KEY MESSAGES

- ≡ Kawasaki Disease cases are on the rise – worldwide; it's a disease **all** parents need to know
- ≡ Kawasaki Disease is the **#1 cause of acquired heart disease in children** in the UK
- ≡ Low awareness of Kawasaki Disease means it's **often initially misdiagnosed**, putting children's hearts at risk of lifetime damage!
- ≡ **Lifelong, life-threatening heart damage** results in a quarter of children affected
- ≡ UK Charity calls for **urgent public awareness**

Rachael McCormack, Founder of Societi said: 'We're campaigning throughout January 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'.

Professor Robert Tulloh, Chair of Societi Foundation and an expert in Kawasaki Disease said "We know that early diagnosis and rapid treatment are the single biggest things we can do right now to change outcomes for children in the UK. To achieve this, we need more people to know Kawasaki Disease and for doctors to THINK Kawasaki Disease as a possible diagnosis in any child with a persistent, unexplained high fever."

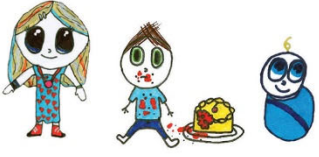
Kawasaki Disease is very serious – it can be fatal in up to 3% of cases if not treated and about a **quarter of all children** affected will go on to have lifelong heart damage, despite treatment. Societi research indicates about 1,000 UK hospital admissions for Kawasaki Disease will happen this year. Once considered a rare disease, incidence is rapidly rising globally and it is now increasingly common. More common than some forms of meningitis, and with more children hospitalized for Kawasaki Disease than measles, it is an illness EVERY parent should know.

The characteristic symptoms of Kawasaki Disease include a high temperature that lasts for 5 days or more and often won't come down, even with children's paracetamol or ibuprofen. Children sometimes develop a rash, swollen glands in the neck, dry, cracked lips, red fingers or toes and red, bloodshot eyes. Children with Kawasaki Disease are characteristically irritable too. Not all symptoms develop in all children.

Poor Kawasaki Disease awareness is leading to delays in diagnosis leaving an ever-growing number of children, young adults and adults living with lifelong heart disease. That means a heightened risk of serious heart problems in later life and needing specialist care for life. Experts have linked these high levels of heart damage in the UK to lack of awareness amongst doctors and the general public. Studies show links between treatment delay and a higher risk of life threatening heart damage. **By getting Kawasaki Disease known** Societi Foundation is working to protect children's hearts from this 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!




**T**emperature - Persistent high fever




**E**rythema - reddened hands and feet with swelling




**M**outh - dry, sore mouth, cracked lips, 'strawberry tongue'




**P**ace - **Treat early** to reduce potential heart damage



**E**yes - bloodshot, non-sticky conjunctivitis




**R**ash



**S**wollen 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](http://societi.org.uk)



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:



## **BPSU study**

With the kind permission of the BMJ, the full BPSU study - Kawasaki Disease: a prospective population survey in the UK and Ireland from 2013 to 2015, Professor Robert Tulloh et al can be found here: <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 & Societì** – 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, Societì 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. Societì 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](http://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 Societì Foundation Chairman and provides clinical oversight for our organisation.

## **Contact Details:**

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