

Kawasaki Disease is the leading cause of acquired heart disease in children in the UK. It's time we changed that....

...**TOGETHER** we will.



TICK TOCK, Tick Tock – We don't have Time!

"Slow treatment times for Kawasaki Disease continue to put children's hearts at risk" - says Societi, the U.K. Foundation for Kawasaki Disease

KEY MESSAGES

- ≡ **Unacceptably high levels of heart damage in children are occurring from Kawasaki Disease in the UK.**
- ≡ **Poor awareness means UK Treatment times for Kawasaki Disease remain too slow**
- ≡ **Watch Kate's story and hear the devastating consequences of a delayed Kawasaki Disease diagnosis on Societi's Family Portal, launched today: www.societi.org.uk**

Today - **International Kawasaki Disease Awareness Day** – sees the start of a campaign for every doctor and every parent in the UK to know the symptoms of Kawasaki Disease, the leading cause of acquired heart disease in children. Societi, The UK Foundation for Kawasaki Disease is stepping up efforts to grow awareness and encourage urgent action when treating this increasingly common, serious disease.

Kawasaki Disease is the leading cause of acquired heart disease in UK children - and research shows **U.K. outcomes remain amongst the poorest in the western world - with about a third of treated children still having heart damage.** This is often due to slow detection rates and delayed treatment.

Kawasaki Disease can affect people of any age, but the under 5 age group is most vulnerable. A recent UK and Ireland study showed that on average, **children waited over 7 days for treatment** between 2013 and 2015. The study showed a link between later treatment and poorer outcomes with those **children treated at 10 days of illness having a significantly greater risk of serious, lifelong heart damage.** Slow treatment and low levels of awareness of Kawasaki Disease is putting hundreds of children's hearts at risk every year.

Professor Neena Modi, President of the Royal College of Paediatrics and Child Health said: "Spotting the signs early and getting treatment quickly is key to limiting the potentially devastating effects of Kawasaki Disease. With better awareness by medical professionals and parents, the condition is more likely to be recognised early. The sooner treatment starts the more likely a better outcome".

Professor Robert Tulloh, the U.K's leading Paediatric Cardiologist in Kawasaki Disease, Bristol Royal Hospital for Children said: "GPs and Paediatricians need to be able to recognise Kawasaki Disease early and aim to start treatment as soon as possible. We are not serving our children well by late diagnosis. Kawasaki Disease is not that rare, with hundreds of children affected each year - we are missing far too many cases who may have preventable coronary artery aneurysms and hence long term consequences. The most seriously affected are young infants with an unexplained fever and few other signs – we need clinicians to THINK Kawasaki Disease."

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Simon Gillespie, Chief Executive of the British Heart Foundation, said: "Kawasaki Disease remains the most common cause of acquired heart disease in children in the western world. It can leave a legacy of permanent damage, which may be prevented through higher levels of awareness, early diagnosis and timely treatment.

"Low levels of awareness about Kawasaki Disease across the UK mean more and more children each year are affected and have long term heart problems. We know that with increased awareness and early diagnosis, we can reduce the chances of lifelong heart damage in young children. International Kawasaki Disease Awareness Day is incredibly important for heightening awareness about this dangerous condition."

Rachael McCormack, Founder of Societi Foundation said "For everyone affected by Kawasaki Disease, TIME is critical. UK treatment times are too slow and put children's hearts at risk. We need **much, much earlier consideration** of Kawasaki Disease in any case where a persistent fever is present - especially the very young. Too often it's just not thought of soon enough - and we now know this is directly affecting outcomes, with late treatment hugely increasing the likelihood of heart damage in our children. Kate's story is typical of a delayed diagnosis – one where everything possible was considered before Kawasaki Disease – the consequences for her son and her family are devastating - watch Kate's story on our website www.societi.org.uk – and hear the impact of delayed diagnosis and late treatment."

"We're working in partnership with key agencies to urgently create a focus on Kawasaki Disease – raising awareness with our TEMPERS mnemonic. Only with earlier treatment will the shocking level of heart damage in children in the U.K. be improved. We want every doctor and every parent to know Kawasaki Disease."

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Notes to Editors

1. Kawasaki Disease & Societi – Kawasaki Disease is the leading cause of acquired heart disease in children in the UK. Children have good chances of recovery with timely diagnosis and the correct treatment. By raising awareness of Kawasaki Disease, Societi aims to enable children to have access to timely diagnosis and correct treatment – to improve health outcomes for our children. In the UK, Kawasaki Disease incidence is increasing – as it is across the globe. This is why it is our main priority to raise awareness of the symptoms of Kawasaki Disease - we urgently need everyone to be able to recognise the symptoms so diagnosis can be made early and early treatment given. Societi Foundation is a registered charity in England and Wales (no 1173755), established in 2015 as an organisation with a specific focus on Kawasaki Disease.
28% of treated children with Kawasaki Disease in the UK had heart damage
24% had coronary artery aneurysms. (Data from BPSU Kawasaki Disease incidence study 2013-15)
In over 20 years, there has been no improvement in outcomes for Kawasaki Disease in the UK

2. Professor Neena Modi – President of the Royal College of Paediatrics and Child Health and Professor of neonatal medicine at Imperial College London. She qualified in Edinburgh and trained in London and Liverpool. She has campaigned for greater investment in research into childhood health, and the college recently announced a plan to raise £10m to train a new generation of child health research leaders. A failure to tackle children's poor start in life is not only unfair to them, Modi argues: it has implications for adult health and longevity. She chaired *The BMJ's* ethics committee from 2009 to 2015.

3. Professor Robert Tulloh - Professor of Congenital Cardiology and Clinical Lead for Paediatric Cardiology, Bristol, is an internationally recognised expert in Kawasaki Disease. Prof Tulloh runs the largest Kawasaki Disease clinic in the UK and the only UK Adult Kawasaki Disease clinic, he is an active researcher and collaborator. He is a Societi Trustee and leads the work of the Societi Scientific Advisory Board, providing clinical oversight for our organisation.

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The UK Foundation for Kawasaki Disease

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Printable versions of TEMPERS, Societi Foundations information leaflet for Kawasaki Disease, endorsed by the RCPCH can be downloaded at www.societi.org.uk/awarenessraising



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

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The UK Foundation for Kawasaki Disease

Kawasaki Disease? Remember TEMPERS

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



T Temperature - Persistent high fever



E Erythema - reddened hands and feet with swelling



M Mouth - dry, sore mouth, cracked lips, 'strawberry tongue'



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



E Eyes - bloodshot, non-sticky conjunctivitis



R Rash



S Swollen glands in neck, often just one side



societi.org.uk
www.justgiving.com/societi

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 does affect older children too and can affect people of any age.

Kawasaki Disease - what's the issue?

In the U.K. awareness of Kawasaki Disease is low. If treated late or untreated, affected children have a significantly increased chance of heart damage. Currently U.K. diagnosis and treatment times are too slow. 28% of diagnosed children experience heart complications. 24% of children diagnosed have coronary artery aneurysms. For a few children every year Kawasaki Disease is fatal...help us change this. Early diagnosis and treatment is key to improving outcomes for our children.

Kawasaki Disease - how common is it?

U.K. hospital admissions for Kawasaki Disease have increased fourfold in the last ten years. It's more common than some forms of bacterial meningitis. About 1 in 10,000 children are currently diagnosed each year and very poor levels of awareness mean even 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** paediatric review. **You** could save a child's heart.

Kawasaki Disease - why haven't I heard about this before?

Kawasaki Disease is increasingly common in the U.K. globally cases are rising fast - but it remains little known by doctors and the general public alike. We want to change this! Too many children and young people today have heart damage because of Kawasaki Disease. The consequences of this can be **very serious** and can be life long

For more information visit societi.org.uk *...help us change this.*

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