

## Societi Foundation Statement: World Heart Day 2023

### Mrs Hinch urges EVERY parent to know Kawasaki Disease: the leading cause of acquired heart disease in children in the western world

#### Key messages:

- ≡ Kawasaki Disease is the #1 cause of acquired heart disease in children across Europe – increasingly common but little known
- ≡ Why is awareness urgent? Delayed treatment for Kawasaki Disease dramatically increases risk of heart damage
- ≡ Serious heart damage from Kawasaki Disease carries heightened risk of major heart attack at a young age

**This World Heart Day, 29 September 2023, Societi Foundation, the UK Foundation for Kawasaki Disease, is campaigning to get this disease known.** Throughout the UK and Europe, a growing number of children's lives each year are being devastated by **Kawasaki Disease – the leading cause of acquired heart disease in children in the western world**, yet this disease remains little known and poorly understood [1].

#### **Kawasaki Disease poses a grave threat to the health of children's hearts**

Recent studies in Europe and North America have found alarmingly high rates of heart complications in affected children, despite treatment. A 2013-15 UK survey showed 19% of children with Kawasaki Disease developed the most serious heart damage – coronary artery aneurysms, even with treatment. More worrying still, 39% of babies under 1 year old had life threatening heart damage [2]. Findings from studies in Germany showed rates of heart damage of 22% and a shocking 42% of younger children suffering the most serious heart damage [3]– and with similar findings in Sweden, where 16% of all children and 45% under the age of 1 year developing coronary artery aneurysms [4] – the need for action couldn't be more urgent.

#### **Parents absolutely must get to know this disease**

**Sophie Hinchliffe**, better known as "Mrs Hinch" spoke about her family's experience "Ronnie got so poorly, so quickly with Kawasaki Disease in June – it was a real-life nightmare. His temperature was spiking to 40 degrees and I rang an ambulance. Wonderful doctors and nurses started treating him with IV antibiotics and took blood tests for everything imaginable – but nothing was working. In fact, he deteriorated.

"We've never felt so fearful or desperate – no-one seemed to know what was wrong, and we waited days for an answer as more and more symptoms kept emerging. I now know that's really typical for Kawasaki Disease – and doctors eventually diagnosed it. With treatment, his recovery was fast and we're lucky, so lucky, that his little heart wasn't damaged by the disease.

"I'm still so shocked that this disease – which is increasingly common – is one we'd never heard of. So many families who have experienced this say the same. It's such a serious disease, and with about 1,000 children affected in the UK this year alone – we just must get it known. Early treatment can be a gamechanger and helps lower the risk of heart damage. We were so lucky; our little Ronnie is smiling again. But it could have been very different. If you've got children in your world – please get to know the symptoms of Kawasaki Disease. It's always a medical emergency and needs urgent hospital treatment."

#### **Quick diagnosis and urgent treatment is key**

Dr Filip Kucera, Societi Scientific Advisory Board member and Consultant Paediatric Cardiologist is a specialist in Kawasaki Disease and said "Studies show a direct link between treatment delay and the most significant heart complications. Early recognition of this

serious disease is key - early treatment of Kawasaki Disease can reduce the risk of a lifetime with heart damage.

“We need both parents and doctors to be able to recognise Kawasaki Disease, it’s a medical emergency – just as they recognise meningitis. Quick diagnosis and urgent treatment, is currently the best way we have to protect the thousands of children who will be affected this year by Kawasaki Disease across Europe, from these grave risks.

“We need better treatments too – and the KD-CAAP clinical trial is urgently exploring additional treatments for Kawasaki Disease. This groundbreaking research is ongoing across Europe led by University College London, with funding from Conect4Children and is focused on reducing the severe heart problems far too many children go on to face, after this illness. These children will need specialist care – for life.”

### **Impact into adulthood – this isn’t ‘just’ a childhood disease**

Dr Tom Johnson, Societi Scientific Advisory Board member and Associate Professor of Cardiology said “With ever-more children being affected by Kawasaki Disease, there’s an increasing number of patients growing into adulthood who will need specialist, lifelong cardiology care.

“We need more adult cardiologists to be familiar with the distinctive legacy Kawasaki Disease can leave and the clinical approach needed. They need to be ready to consider it as a possible cause of cardiac complications, when seeing younger patients even where a history of Kawasaki is perhaps uncertain. The disease has likely been under-diagnosed over time, so Kawasaki Disease just must be on the radar for all adult cardiologists.”

### **Let’s stop needless damage to too many tiny hearts**

Rachael McCormack, Founder of Societi Foundation, the UK Foundation for Kawasaki Disease said “Poor awareness and delays in treatment for affected children mean that heart damage from Kawasaki Disease in the UK is among the worst in Europe. We’re letting children down, as too many suffer devastating heart damage when this sinister disease goes unrecognised for days, sometimes weeks.

“The most serious heart damage can happen in babies under one year, where assumptions are made that an illness in such a young baby ‘can’t be Kawasaki Disease’. That’s an outdated, wrong perception – and we want all doctors to THINK Kawasaki Disease if they see any child with a persistent high fever of uncertain cause. We’ll continue our work until everyone in the UK knows Kawasaki Disease – we just must get it known.”

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### **Notes to Editors:**

**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 is 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](http://www.societi.org.uk)

**World Heart Day** - World Heart Day, now an annual event on 29 September each year, was

established by the World Heart Federation in 2000, in partnership with the World Health Organisation to create a day that would raise awareness and mobilize international action against cardiovascular disease (CVD). The aim is to bring people together to increase awareness, engage communities and advocate for universal access to CVD prevention, detection and treatment. <https://world-heart-federation.org/world-heart-day/about-whd/>

### Multi Media Resources:

- a) With the kind permission of the BMJ, the full British Paediatric Surveillance Unit 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/>
- b) Printable versions of TEMPERs, Societi Foundations information leaflet for Kawasaki Disease, endorsed by the Royal College of Paediatrics and Child Health (RCPCH) can be downloaded at <https://www.societi.org.uk/for-families/families-resources-downloads/>
- c) SoundCloud Podcast <https://on.soundcloud.com/C9qba>  
Released for World Heart Day, Dr Tom Johnson, Associate Professor of Cardiology and Prof Robert Tulloh (Paediatric Cardiologist and Chair of the Board of Trustees for Societi Foundation) talk about the need for greater awareness by adult cardiologists of Kawasaki Disease as the adult patient population grows, for this increasingly common disease.

### References:

1. Editorial – Kawasaki Disease: a need for earlier diagnosis and treatment - Gray H, Cornish J. Arch Dis Child Epub ahead of print doi:10.1136/ archdischild-2018-316379
2. Professor Robert Tulloh et al Kawasaki Disease: a prospective population survey in the UK and Ireland from 2013 to 2015, doi: 10.1136/archdischild-2018-316379
3. Jakob A, Whelan J, Kordecki M, Berner R, Stiller B, Arnold R, et al. Kawasaki disease in Germany: a prospective, population-based study adjusted for underreporting. Pediatr Infect Dis J. 2016;35(2):129–134. doi: 10.1097/INF.0000000000000953. [PubMed] [CrossRef] [Google Scholar]
4. Mossberg M, Segelmark M, Kahn R, Englund M, Mohammad AJ. Epidemiology of primary systemic vasculitis in children: a population-based study from southern Sweden. Scand J Rheumatol. 2018;47(4):295–302. doi: 10.1080/03009742.2017.1412497. [PubMed] [CrossRef] [Google Scholar]

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