

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

...**TOGETHER** we will.

MEDIA RELEASE Embargoed to 29/09/2017

Children's hearts at risk because of lack of knowledge of Kawasaki Disease

...telling the world about our **TEMPERS** on World Heart Day!

TEMPERS is a mnemonic created by Societi to make Kawasaki Disease memorable.

A legacy of permanent heart damage which we must change - together

Simon Gillespie, Chief Executive of the British Heart Foundation, said: "Kawasaki Disease is the most common cause of acquired heart disease in children in the western world and can leave a legacy of permanent damage. However, this doesn't have to be the case. With higher levels of awareness, early diagnosis and timely treatment, we can save and improve the lives of children affected by this disease. We are fully behind Societi's mission to ensure every doctor and every parent in the UK is able to recognise the symptoms and act quickly to treat this deadly disease."

Kawasaki Disease – a little known risk to children's hearts

Kawasaki Disease is the leading cause of acquired heart disease in children in the western world. Across the globe, Kawasaki Disease incidence is doubling every ten years and despite many research efforts, the cause of Kawasaki Disease is still not known.

Here in the UK we're focusing hard on raising awareness of the disease. Our UK-based research (BPSU study 2013 - 2015¹) clearly demonstrates that early diagnosis is linked to better outcomes - and that for some, early treatment can reduce the likelihood of lifetime heart damage. Despite this, awareness in the UK is low and we lag behind many countries in terms of public awareness of Kawasaki Disease. We need

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

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

5 days of fever?
THINK Kawasaki Disease



www.justgiving.com/societi

societi.org.uk



The UK Foundation for
Kawasaki Disease

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much greater levels of Kawasaki Disease awareness in our medical community too.

So, on **World Heart Day** we want everyone to know about our **TEMPERS!**

Kawasaki Disease is increasingly common

Professor Robert Tulloh, the UK's leading paediatric cardiologist in Kawasaki Disease said: "Kawasaki Disease is increasingly common in the UK and we urgently need much earlier consideration of it as a possibility when patients present with persistent fever. The **TEMPERS** mnemonic will help both parents and medics remember Kawasaki Disease and we hope – increase accurate, rapid diagnosis so children can get early treatment."

Making it memorable

Rachael McCormack, Founder of Societi, the UK Foundation for Kawasaki Disease said "We created our **TEMPERS** mnemonic because we want to make Kawasaki Disease memorable. We want every doctor and every parent to know Kawasaki Disease and be able to recognise the symptoms – it is increasingly common. We know that children with Kawasaki Disease are really irritable – which is where the idea for **TEMPERS** came from. One of the most critical words in this mnemonic though is PACE – we need awareness because we need doctors to EXPECT to see Kawasaki Disease and be READY to treat it. Early treatment is key."

Improving lives through awareness

Richard Lynn, Scientific Co-ordinator at the British Paediatric Surveillance Unit (BPSU) said: "Societi's **TEMPERS** campaign will go a long way to raising the profile of Kawasaki Disease amongst clinicians, health workers and the public alike – which can only be to the benefit of children. As a unit, we are pleased to support Societi in their important work to raise awareness of Kawasaki Disease."

Raising Kawasaki Disease awareness every day

Throughout September Societi supporters have been raising Kawasaki Disease awareness across the UK; in Somerset at craft fairs; in Hitchin, Herts, where an Osteopathy clinic have worked though the month fundraising too and we've had marathon runners, running miles and miles in Rutland and Hatfield. All raising awareness of **the leading cause of acquired heart disease in children!** Today, on World Heart Day, Societi supporters at SKY in London – are having Kawasaki conversations – and sharing knowledge with 'Wear Red' days, heart-healthy activities and Kawasaki Disease information for everyone.

-ends-

Notes to Editors

1. Kawasaki Disease & Societi – **Kawasaki Disease is the leading cause of acquired heart disease in children in the western world.** Children affected by Kawasaki Disease have good chances of recovery with timely diagnosis and the correct treatment. By raising awareness of Kawasaki Disease across policy makers and funders, the medical community and the general public, Societi aims to enable children to have access to timely diagnosis and correct treatment – so that together we can 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

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Societi Foundation is a registered charity in England and Wales (no. 1173755)
The UK Foundation for Kawasaki Disease
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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.

28% of treated children with Kawasaki Disease in the UK (BPSU study 2013-15¹) had heart damage

24% had coronary artery aneurysms.

In 20 years, there has been no improvement in outcomes for Kawasaki Disease

Societi Foundation is working to change this.

2. About World Heart Day - World Heart Day is celebrated on 29 September each year. In May 2012, world leaders committed to reducing global mortality from non-communicable diseases (NCDs) by 25% by 2025. Cardiovascular disease (CVD) is accountable for nearly half of all NCD deaths making it the world's number one killer. World Heart Day unites the CVD community in the fight against CVD and reduce the global disease burden. Created by the World Heart Federation, World Heart Day informs people around the globe that CVD, including heart disease and stroke, is the world's leading cause of death claiming 17.5 million lives each year, and highlights the actions that individuals can take to prevent and control CVD.

World Heart Day is a global campaign during which individuals, families, communities and governments around the world participate in activities to take charge of their heart health and that of others. Through this campaign, the World Heart Federation unites people from all countries and backgrounds in the fight against the CVD burden, and inspires and drives international action to encourage heart-healthy living across the world.

3. Societi Foundation - Societi Foundation is a registered charity, established in 2015 as an organisation with a specific focus to raise awareness of Kawasaki Disease. We are an influencing and policy shaping organisation. We don't provide advice or support directly to families - our partner KSSG UK does that. Not enough is known about Kawasaki Disease, its symptoms or its treatment. Long term care for affected families is limited. Many agencies, doctors and parents are unaware of the disease. We want to change this. Visit www.societi.org.uk

4. 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.

5. BPSU - The British Paediatric Surveillance Unit (BPSU) enables doctors and researchers to find out how many children in the UK and Republic of Ireland are affected by particular rare diseases or conditions each year. The Unit was set up in 1986. It is a joint initiative of the Royal College of Paediatrics and Child Health, Public Health England and the UCL Great Ormond Street Institute of Child Health with support from GOSH Children's Charity to facilitate research into rare childhood disorders.

6. Societi Kids - The TEMPERS mnemonic is illustrated with drawings created by Societi's junior artist - who has created over 100 'Societi Kids' which we use in our awareness raising material, avoiding the need to use images of children and thereby protecting their privacy.

References

BPSU survey <https://www.researchgate.net/publication/301748132> Kawasaki_Disease_Results_of_the_BPSU_survey_in_UK_and_Ireland

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Image: This is the reverse side of the TEMPERS
leaflet, the front of which is included on p1.

Printable versions of TEMPERS can be downloaded at
www.societi.org.uk/awarenessraising

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is the **#1** cause of
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...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. If a child has a **PERSISTENT FEVER** for **FIVE DAYS** or more with two 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...**help us change this.**

For more information visit societi.org.uk



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