

MEDIA RELEASE 29 September 2018 – World Heart Day

“39% of babies diagnosed with Kawasaki Disease develop serious heart damage” - new U.K. & Ireland study finds.

“Awareness of Kawasaki Disease is URGENT” - says Societi, the U.K. Foundation for Kawasaki Disease

KEY MESSAGES

- ≡ Kawasaki Disease is the #1 cause of acquired heart disease in children in most continents
- ≡ In the UK & Ireland, research shows 39% of infants with Kawasaki Disease develop coronary artery aneurysms, even when treated
- ≡ Children's risk of heart damage from Kawasaki Disease in the UK & Ireland is currently among the highest recorded globally
- ≡ UK treatment times for Kawasaki Disease are still too slow, study finds
- ≡ Outcomes from Kawasaki Disease in the UK remain unchanged since the 1990s

Children at Risk

On World Heart Day, Societi Foundation, the UK Foundation for Kawasaki Disease is highlighting shocking findings from the newly published British Paediatric Surveillance Unit (BPSU) study, following two years of detailed research into Kawasaki Disease in the UK and Ireland. The study found that children's risk of heart damage from Kawasaki Disease is currently among the highest recorded globally – putting our children at risk.

Worrying Findings

A shocking 39% of infants (babies under one) affected by Kawasaki Disease had serious heart damage – and up to 20% of all children developed coronary artery aneurysms. These children now need specialist care – for life.

Time to act!

Dr Jacqueline Cornish OBE, NHS England Clinical Director for Children, Young People and Transition to Adulthood said “Kawasaki Disease is increasingly common, yet this research shows no improvement in outcomes for children since the last study in the 1990's. This serious disease presents a real threat to children's heart health. Doctors need to be alert to Kawasaki Disease and treat rapidly if it's suspected.”

Urgent change needed

Study author Professor Robert Tulloh said “We found children treated after 7 days from disease onset to be at significantly increased risk of serious heart damage - this risk increases with any further delay. The Kawasaki Disease therapeutic adage of ‘treatment within 10 days’ is no longer fit for purpose - our response to this disease must urgently change.”

Richard Lynn, Scientific Officer for the BPSU said “25 years after the first BPSU Kawasaki Disease study, it is concerning to see a continued increase in cases and still delays in diagnosing and treating children. Investment for raising awareness and continued research into this potentially fatal condition is urgently needed.”

Kawasaki Disease – Must be on everyone's radar

Rachael McCormack, Founder of Societi said “Awareness is key – Societi Foundation is working to build knowledge so that all clinicians treating children can recognise Kawasaki Disease - and know to treat it urgently. For too long Kawasaki Disease has been described as something doctors “won't see”. It's now increasingly common - it's got to be on everyone's radar, if doctors are to recognise it – in time.”

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Multi Media Resources:

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/>

Kate's story is typical of the delayed diagnosis journey happening to children affected by Kawasaki Disease – the consequences for her son and her family are devastating. Watch Kate's story and hear the impact of delayed diagnosis and late treatment here <https://www.youtube.com/watch?v=gZalnGhiDfM> [May change this to another film – late Dx which resulted in a heart transplant]

Printable versions of TEMPERS, Societi Foundations information leaflet for Kawasaki Disease, endorsed by the RCPCH can be downloaded at <https://www.societi.org.uk/families/families-resources-downloads/>

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, 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. 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. The internationally respected British Paediatric Surveillance Unit (www.bpsu.org.uk) was founded in 1986 with the aim to facilitate and investigate the epidemiology of rare paediatric disease and events. Through the circulation of a monthly e-card to clinician's cards cases can be identified nationally. The information gathered by the BPSU has had a major impact on child health policy and management. Kawasaki Disease was first investigated in 1986-89 by the unit.

4. Dr Jacqueline Cornish was appointed to the post of National Clinical Director Children, Young People and Transition to Adulthood in NHS England in April 2013. She is a practicing clinician, having only recently stepped down as Director of Paediatric Stem Cell Transplant (SCT) at the Bristol Royal Hospital for Children. Dr Cornish has over 20 years' experience of Medical Management in the NHS, having been Head of Division of Women's and Children's Services at University Hospitals Bristol NHS Foundation Trust for 10 years before taking up the National post.

5. 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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