

MEDIA RELEASE 26 January 2021

Nottingham's iconic Council House lights up red for Children's hearts.

Nottingham's Council House will be illuminated red tonight (January 26th) for International Kawasaki Disease awareness day.

Severe heart damage in 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 is the #1 cause of acquired heart disease in children in most continents
- ≡ Low awareness of Kawasaki Disease means it's often initially misdiagnosed, putting children's hearts at risk of lifetime damage!
- ≡ A quarter of children affected develop serious lifelong heart damage
- ≡ UK Charity calls for urgent investment in public awareness and accelerated UK-led research

Rachael McCormack, Founder of Societi said: 'The Council House in Nottingham is an iconic regional landmark and we are thrilled that bright red beams will be shining a light on Kawasaki Disease tonight – thanks to the City Council. Despite Kawasaki Disease being increasingly common, low public awareness means it's often initially misdiagnosed, putting children's hearts at risk of lifetime damage. We must change this and stop Kawasaki Disease having the devastating effect it has on far too many children today'.

Professor Robert Tulloh, Bristol Heart Institute and a expert in Kawasaki Disease said "We know 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 consider it as a possible diagnosis in any child with a persistent, unexplained high fever."

Kawasaki Disease is very serious - it's 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. 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. 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.

In the UK today, children's risk of heart damage from Kawasaki Disease is among the highest in the world. Experts have linked these high levels of heart damage to lack of awareness amongst doctors and the general public. Studies show the later children are treated after first becoming ill, the higher their risk of serious, life threatening heart damage. Rapid diagnosis and treatment is key to lowering the currently unacceptable chances of heart damage - so getting Kawasaki Disease known is key.

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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/>

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/>

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, 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, 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. Professor Robert Tulloh - Professor of Congenital Cardiology and Pulmonary Hypertension, Bristol Heart Institute. Prof Tulloh is an internationally recognised expert in Kawasaki Disease. 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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