



MEDIA RELEASE

26 January 2019 is International Kawasaki Disease Awareness Day

## **Kawasaki Disease is increasingly common. Expect to see it. Be ready to treat it.**

On International Kawasaki Disease Awareness Day, Societi Foundation calls for awareness and action to combat this, the leading cause of acquired heart disease in children.

### **KEY MESSAGES**

- ≡ Doctors need to EXPECT to see and be READY to treat Kawasaki Disease
- ≡ Kawasaki Disease is increasingly common, more common than some forms of bacterial meningitis and seen more often than measles<sup>1</sup>
- ≡ UK treatment times are too slow. Lack of awareness of Kawasaki Disease delays diagnosis and treatment, significantly increasing risk of heart damage
- ≡ In the UK & Ireland, research shows 39% of infants with Kawasaki Disease develop coronary artery aneurysms. This is too high!
- ≡ Kawasaki Disease is the #1 cause of acquired heart disease in UK children

### **Children's hearts at risk**

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 clinicians and the general public. Studies show children treated after 7 days from disease onset are at **significantly increasing risk** of serious heart damage<sup>1</sup>. If diagnosed and treated early the risk of heart damage is reduced.

### **Kawasaki Disease is a medical emergency**

Dr Jacqueline Cornish OBE, NHS England Clinical Director for Children, Young People and Transition to Adulthood said "Kawasaki Disease incidence is rising globally. We must now make a conscious change and **expect to see Kawasaki Disease and be ready to treat it**. We urgently need greater understanding of the seriousness of the impact of Kawasaki Disease when treatment is delayed."

A shocking 39% of infants (babies under one) affected by Kawasaki Disease have serious heart damage – and up to 20% of all children develop coronary artery aneurysms. These children need specialist care – for life<sup>2</sup>.

### **Significantly increasing risk**

Professor Robert Tulloh, leading Paediatric Cardiologist and specialist in Kawasaki Disease said "Serious heart damage is a proven risk for children who are treated late and we know this risk significantly increases with any delay beyond 5 days from the start of fever. We must immediately abandon the outdated idea that treatment at 10 days is acceptable - our response to this disease has to urgently change."

RCPCH President Professor Russell Viner said "As Kawasaki Disease is a growing problem with potentially fatal consequences, it is an area that our members take seriously. We know that early diagnosis is key, and so we are looking at ways to improve education and raise awareness so that our members can identify and treat cases as swiftly as possible."

### **Families fighting Kawasaki Disease - let's get it known!**

Rachael McCormack, Founder of Societi said "Kawasaki Disease is a medical emergency. Too many families have experienced the devastating impact of this serious disease – and to highlight the consequences of a delay in diagnosis, on Awareness Day, the Page Family have shared their inspirational journey with Kawasaki Disease. **Please watch** our film <https://youtu.be/Z0zgDeZrWL4> and hear just how serious this disease can be. And then please, let's work together to get Kawasaki Disease known – for all our children."



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### Multi Media Resources:

With the kind permission of the BMJ, the Editorial by Dr Jackie Cornish OBE Clinical Director NHS England for Children, Young People and Transition and Professor Huon Gray, Clinical Director NHS England for Heart Disease can be found here Gray H, Cornish J. Arch Dis Child Epub ahead of print: <https://adc.bmj.com/content/early/2018/12/16/archdischild-2018-316379.full?ijkey=xrnW2e9DorNNI&keytype=ref&siteid=bmjournals>

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/>

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/>

With grateful thanks to the extraordinary Page Family for sharing their Kawasaki Disease journey, please find a link to their film here <https://youtu.be/Z0zgDeZrWL4>

### Notes to Editors:

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

**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.

**Professor Russell Viner** is Professor of Adolescent Health at the UCL Institute of Child Health in London, a paediatrician and adolescent physician working with young people with diabetes at University College Hospital and he directs the Department of Health Obesity Policy Research Unit. He assumed presidency of the RCPCH in March 2018. He set up the first Adolescent Medicine service in the UK and went on to become the UK's first Professor of Adolescent Health, helping lead a new focus on adolescent healthcare in the UK and Europe. He has acted as an advisor on adolescent health and obesity for the Departments of Health and for Education in England and for the World Health Organisation and Unicef internationally.

**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 a Societi Trustee and leads the work of the Societi Scientific Advisory Board, which provides clinical oversight.

### 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. Research article - Kawasaki Disease: a prospective population survey in the UK and Ireland from 2013 to 2015, Professor Robert Tulloh et al doi: 10.1136/archdischild-2018-316379

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