

MEDIA RELEASE 26 January 2021

Thousands of young people in the UK live with acquired heart disease from Kawasaki Disease.

Societi Foundation has created "My Societi", a dedicated online channel, designed by young people for young people with Kawasaki Disease.

Kawasaki Disease is the leading cause of acquired heart disease in UK children - and growing up with a long term, serious condition can be challenging.

Launched today, International Kawasaki Disease Awareness Day – this powerful online resource aims to answer the questions young people affected by Kawasaki Disease might have.

It's full of up to date, reliable information – backed by leading doctors and experts in Kawasaki Disease.

Rachael McCormack, Founder of Societi said: "Young people affected by Kawasaki Disease face many issues, lifelong heightened risks and a fair bit of uncertainty - as it's a disease we urgently need to know much more about. For those most seriously affected with lasting heart damage, young people live with the risk of a major cardiac event - like a heart attack. As a teenager, that can be a lot to cope with.

"With much outdated and often wrong information out there - and far too much that's just frightening written about Kawasaki Disease, as a mum I wanted to create an online place where young people could find doctor-backed answers to questions, as well as support - by knowing they're not alone.

"We've built My Societi working with young people and with doctors - it's a source of trusted information - designed in a way that's really relevant for young people.

Professor Robert Tulloh, Paediatric Cardiologist and U.K. leading specialist in Kawasaki Disease said: "With fast rising incidence, there's a growing number of young people now living with Kawasaki Disease. Reasonably, young people have questions! 'My Societi' will play a really important role here. It's packed with information for its target 13-18yr age group, with personal experiences and age-appropriate content that gives young people living with Kawasaki Disease an understanding of their diagnosis – and what it means for them. They can get to know more about key issues and risks which they might face - and make informed judgements about their own health and lifestyle going forward into adulthood. Importantly too, My Societi will help build confidence in young people to raise issues with their doctors - as well as be reassured that they are not facing Kawasaki Disease alone."

Societi research has revealed that there will be up to 1,000 UK hospital admissions for Kawasaki Disease this year. Once considered a rare disease, incidence is rapidly rising, and it is now increasingly common.

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 that delay in treating children with Kawasaki Disease increases the risk of serious, permanent heart damage. This is why Societi Foundation is working to get Kawasaki Disease known.

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Multi Media Resources:

"My Societì" – Young People's Portal <https://mysocieti.org.uk/>

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 & Societì – 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, Societì 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. Societì 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 Societì Trustee and leads the work of the Societì Scientific Advisory Board, providing clinical oversight for our organisation.

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