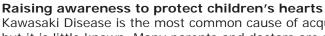
SOCIETÍ the UK Foundation for Kawasaki Disease

MEDIA RELEASE: Issue: 26 June 2017 12 Noon The SKY is the limit for Kawasaki Disease awareness raising! Powerful partnerships to protect children's hearts

Release Purpose:

- Launch Societi's new animated video for Kawasaki Disease awareness
- Early diagnosis is key to preventing life-long heart damage
- Kawasaki Disease is the #1 cause of acquired heart disease in children in the UK

Kawasaki Disease Symptoms

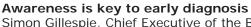


Kawasaki Disease is the most common cause of acquired heart disease in children in the UK but it is little known. Many parents and doctors are unaware of the disease and how serious it can be. Societi is building partnerships across the UK to share knowledge and raise much needed awareness.

fingers/toes

Cracked lips/ Strawberry tonque

Societi launches its animated video in London today to raise awareness of Kawasaki Disease with Sky UK & Ireland Chief Operating Officer Chris Stylianou. Mr Stylianou said "We are delighted that we are able to help raise awareness of Kawasaki Disease, as we know that early detection in children is so critical in sucessfully treating a disease of this type."



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. It can leave a legacy of permanent damage, which is why awareness and early diagnosis are so important in helping to reduce the chance of lifelong heart damage in children.









Swollen glands

'Kawasaki conversations'

Rachael McCormack, Founder of Societi, is excited to be launching the new video from Sky HQ today. "We created our video to spread knowledge about Kawasaki Disease. We want all parents and all doctors to be able to recognise the disease - it's just so important. We'll only do that with the support of powerful partners helping us make 'Kawasaki Conversations' happen - just as Sky have done today."

Kawasaki Disease - poor outcomes

Professor Paul Brogan, the UK's leading paediatric rheumatologist in Kawasaki Disease and Scientific Advisor to Societi said "The shocking issue is that outcomes for treatment of this disease in the UK are worse than they should be. We believe that early diagnosis and appropriate treatment can reduce cardiac complication rates which are unacceptably high at the moment in the UK."

Improving lives through research

Richard Lynn, Scientific Co-ordinator at the British Paediatric Surveillance Unit (BPSU) said "Since its inception, the BPSU has helped to facilitate research aimed at improving the lives of those children affected by this disease. As a unit, we are pleased to support Societi in their important work to raise awareness of Kawasaki Disease." -ENDS-

OUTCOMES:

In the UK **28%** of treated children with Kawasaki Disease have some heart damage, **24%** have coronary artery aneurysms.

IMPROVING OUTCOMES:

Early diagnosis and treatment is directly linked to improved outcomes. Know the symptoms

& TREAT EARLY!

Kawasaki Disease is the #1 cause of acquired heart disease in children. It's time we changed that...

...TOGETHER we will



Watch Societi's new video at Societi.org.uk

Please share the video and the link we want everyone to know Kawasaki Disease!

Notes to Editors:

1. Kawasaki Disease & Societi – Kawasaki Disease is the leading cause of acquired heart disease in children in the western world. The cause of Kawasaki Disease is still not known, despite the disease having been identified 50 years ago in 1967, in Japan. Kawasaki Disease presents with a range of symptoms similar to many other childhood illnesses, and as such it is often diagnosed late or misdiagnosed. The consequences for affected children are very serious indeed as Kawasaki Disease can cause heart damage. In the UK 28% of treated children have some heart damage, 24% have coronary artery aneurysms. Children affected by Kawasaki Disease have much improved chances of a good recovery with timely diagnosis and the correct treatment.

At Societi we recognise timely diagnosis, followed by correct treatment as a transformational opportunity to prevent what can be devastating effects from Kawasaki Disease. 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, correct treatment and appropriate long term support.

Societi was 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 – because our partner Kawasaki Support UK (KSSG) does that. Visit societi.org.uk for more information.

- 2. Mr Chris Stylianou is the Chief Operating Officer UK and Ireland for Sky. Please contact Sky directly for additional information.
- 3. Mr Simon Gillespie is the Chief Executive of the British Heart Foundation. Please contact BHF directly for additional information.
- 4. Professor Paul Brogan is Professor of Vasculitis and Honorary Consultant Paediatric Rheumatologist, UCL Institute of Child Health and Great Ormond Street Hospital. He is an internationally recognised expert in Kawasaki Disease and is an active researcher and collaborator. He has supported Societi since before its formal establishment and sits on our Scientific Advisory Board, providing clinical oversight for our organisation.
- 5. Richard Lynn is the Scientific Coordinator of the 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.

Contact Details: Media enquiries to: Rachael McCormack, Founder, Societi, UK Foundation for Kawasaki Disease, Victoria Court, Holme Lane, Winthorpe, Newark, Notts, NG24 2NU

e: rachael@societi.co.uk w: societi.org.uk twitter: @Societi_UK_KD Twitter tag #Kawasaki_Disease