

MEDIA RELEASE 20 March 2024

TALKING PLASMA IN PARLIAMENT

Today (March 20th) MPs will be talking about the importance of plasma donation in parliament. Plasma is needed to make important medicines like IVIG, which is used to treat Kawasaki Disease.

Plasma is part of your blood. It is rich in antibodies, which can be concentrated into immunoglobulin medicines. These medicines are used to treat more than 50 different conditions, saving or improving the lives of around 17,000 people in England each year. One of the top 10 uses for plasma is treatment of Kawasaki Disease, which is a serious but little known illness that can cause severe heart damage in children. Kawasaki Disease is the leading cause of acquired heart disease in UK children, says Societi, the U.K. Foundation for Kawasaki Disease.

KEY MESSAGES

- E Kawasaki Disease cases are on the rise worldwide; it's a disease all parents need to know
- Kawasaki Disease is the #1 cause of acquired heart disease in children in the UK
- The main treatment is IVIG, made from plasma, given alongside aspirin
- Kawasaki Disease is one of the top ten most common uses for IVIG
- Plasma donation is straight forward and most people aged 17-65 can donate.
- There are donation centers in Birmingham, Reading and Twickenham

NHS Blood and Transplant (NHSBT) are creating a new supply of plasma to reduce the reliance on plasma imported from Europe. With global rises in demand for immunoglobulins, both plasma and immunoglobulin treatments have experienced ongoing pressures on supply in the UK so having our own supply is really important. Currently there are donation centers in Birmingham, Reading and Twickenham with plans to expand the number in the future. NHSBT is also now recovering plasma for medicines from blood donations at a small number of sessions, with that number due to greatly expand.

NHS Blood and Transplant are partnering with Societi, The UK Foundation for Kawasaki Disease to highlight the importance of plasma donation to MPs. An exciting agenda is planned with speakers including Andrea Leadsom; Under-Secretary of State for Public Health & Primary Care.

Rachael McCormack, Founder of Societi said: 'We are thrilled to be working with NHS Blood and Transplant to talk *plasma in parliament*. Plasma is vital for the production of medicines, such as IVIG, one of the main treatments, along with aspirin, for Kawasaki Disease. Without this essential treatment many more children affected by Kawasaki Disease would suffer severe heart damage. We need more people to donate plasma and, to support this, we also need more options for plasma donation."

Kawasaki Disease is very serious – it can be 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, despite treatment. 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**. More common than some forms of meningitis, and with more children hospitalized for Kawasaki Disease than measles, it is an illness EVERY parent should know.

The characteristic symptoms of Kawasaki Disease include a high temperature that lasts for 5 days or more and often won't come down, even with children's paracetamol or ibuprofen.





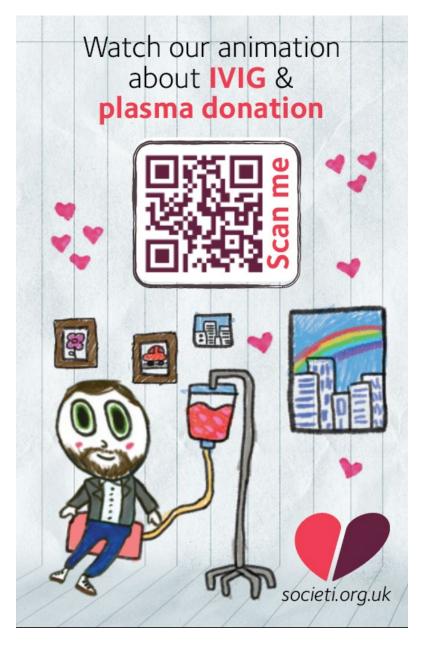
Children sometimes develop a rash, swollen glands in the neck, dry, cracked lips, red fingers or toes and red, bloodshot eyes. Children with Kawasaki Disease are characteristically irritable too. Not all symptoms develop in all children.

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Multi Media Resources:

IVIG animation

We have produced a short video about IVIG use in Kawasaki Disease. You can access the video via the QR code below or <u>click here</u>:







Our TEMPERS leaflet





Kawasaki Disease is predominantly a childhood illness though it can affect people of any age. Its cause is unknown. Kawasaki Disease is the leading cause of acquired heart disease in children. Awareness of Kawasaki Disease is currently low and it is often mistaken for other common childhood illnesses, leading to misdiagnosis and delayed treatment. Children who go untreated or who are treated later face higher risks of developing complications including life long heart damage.

Early diagnosis and treatment are key to better outcomes

for our children





Kawasaki Disease?





swelling



PERSISTENT DISEASE!





Eyes -

non-sticky

conjunctivitis

dry, sore mouth, cracked lips, 'strawberry tongue'







Discose



Kawasaki Disease is the #1 cause of acquired heart disease in children

in the UK...

...help us change this.

Kawasaki Disease - who does it affect? It is mostly a childhood illness with over 75% of those affected being under 5 years old but it affects older children too.

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Kawasaki Disease - what's the issue?

In the UK awareness of Kawasaki Disease is low. Currently UK diagnosis and treatment times are too slow. 39% of bables (under one year) treated for Kawasaki Disease develop serious heart problems 28% of diagnosed children experience heart complications. Overall, 19% of children treated develop serious heart damage. For a few children every year Kawasaki Disease is fatal. I-elpu schange this. We need every prote to know Kawasaki Disease as early diagnosis and treatment can prevent heart damage. (Data from BPSU Study, Kawasaki Disease UK & Ireland 2013-2015)

Kawasaki Disease - how common is it? Hospital admissions in England for Kawasaki Disease have increased fourfold in the last ten years. It's more common than some types of meningits. About 1 in 10,000 children are currently diagnosed each year and very poor levels of awareness mean many more children may be affected.

Kawasaki Disease - what can I do?
Know the symptoms and remember, symptoms may not
appear all at once. Not all children present with all symptoms
so - if a child has a PERSISTENT FEVER for 5 DAYS or more
with 2 or more of the symptoms overleaf THINK Kawasaki
Disease and seek URGENT medical advice. You could save a
child's heart.

Kawasaki Disease is serious! Awareness is urgent! Today, most people haven't heard of Kawasaki Disease. That one of the biggest challenges we face. Help us get it known because Kawasaki Disease is increasingly common in the UK. because Kawasaki Disease is increasingly common in the UK. Too many children and young people today have lifetime heart damage because of Kawasaki Disease "help us change this. For more information visit societi.org.uk



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/familiesresources-downloads/

The QR code below can be scanned to access our TEMPERS leaflet as a PDF and can also be downloaded here:



Our Kawasaki Disease Awareness Animation

Our Kawasaki Disease Awareness Animation can be viewed here.

The QR code below can be scanned to view our Awareness Animation:





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, 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 in 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

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