

societì



the UK Foundation for Kawasaki Disease

Kawasaki Disease is the leading cause of acquired heart disease in children in the UK

Autumn/Winter 2017

.....it's time we changed that

Kawasaki Disease Symptoms



Persistent fever



Cracked lips /
'strawberry' tongue



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands



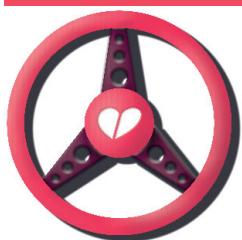
International
Kawasaki Disease
Awareness Day
26 January 2018

Happy Birthday Societì!



It's unbelievable to think that Societì will be 2 years old in December! We have achieved so much in such a short space of time but there is still lots to do and so many exciting projects ahead of us.

When setting up Societì to give Kawasaki Disease in the UK a voice, almost two years ago now, it was our hope that we would be able to connect with like minded people who wanted to create the change we must have around Kawasaki Disease - if we are to have impact. The support we have received from Societì supporters has been incredible. We are privileged now to know some truly remarkable people, who share a passion to act and achieve real change - together.



A National Steering Group for Kawasaki Disease

Societì has formed and chairs the National Kawasaki Disease Steering Group. Meeting at regular intervals, the group includes leading UK Kawasaki Disease specialists from University Hospitals Bristol, St Mary's London and Great Ormond Street Hospital - as well as two NHS England National Clinical Directors, Prof Huon Gray (NCD Heart Disease) and Dr Jackie Cornish OBE (NCD Children, Young People and Transition). We are also immensely pleased to have the Chief Executive of the British Heart

Foundation on our Steering Group and colleagues from Public Health England. Through this group, we are addressing the need to build our Kawasaki Conversation and collaborate across medical disciplines and agencies to improve outcomes for our children.

One recent outcome from this group is the establishing of a Writing Group. Societì has pushed hard the need for 'whole of life' guidance for clinicians - for Kawasaki Disease. Our current guidance deals primarily with the acute disease. We must share and grow knowledge so our children can have the expert lifetime care they need. Our Writing Group met for the first time in October and we will not stop until we have a fully updated, UK disseminated guideline for Kawasaki Disease - for the whole of our children's lives.

Raising Awareness - Can you help?

Of course, one of Societì's main objectives is to raise awareness across the UK general public and within the medical community too. We have 'just' 65 million people to tell about Kawasaki Disease! We continue to work hard to make this happen and have forged strong links with both the World Heart Federation and British Heart Foundation. For World Heart Day 29 September this year, we ran an awareness campaign online with both these

major partners and support from the British Paediatric Surveillance Unit, the RCPCH and others. We reached thousands of people who now know about Kawasaki Disease!

We are now looking forward to building a new campaign for international Kawasaki Disease Awareness Day (26 January each year) and growing public knowledge again. There is so much you can do to help raise awareness, so please visit societi.org.uk to find out more, or get in touch at info@societi.co.uk. Please help us raise awareness!

societì



the UK Foundation for Kawasaki Disease

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

...Together we will

Updating Our Digital Space

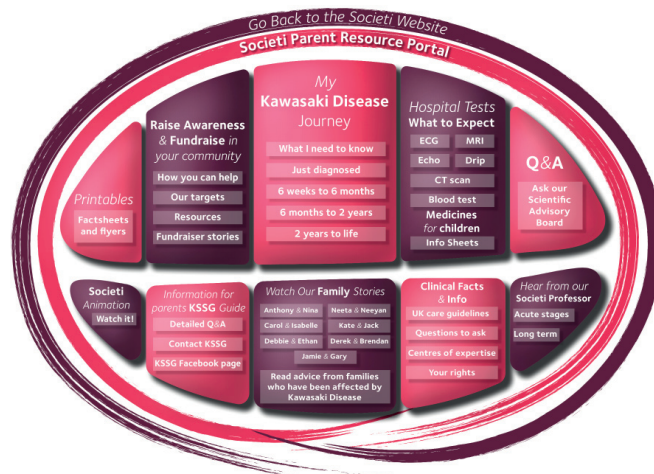
It is so easy for families that have been affected by Kawasaki Disease to feel isolated and in the dark about their child's condition.

Generally, there is a lack of information available and a lot of the information that can be found, is incorrect or not relevant to UK families.

We think it is so important for parents to have easily accessible, relevant and up-to-date information available to them at a time when they need it most. That is why we are really excited to be updating our website, making it even easier to navigate and simpler to find information.

Not only that, but we are very nearly ready to unveil our new Parent Resource Portal. A unique online space, which will be accessed through our website – especially for parents of children that have received a diagnosis of Kawasaki Disease. The portal will be useful to newly affected families and families that have lived with Kawasaki Disease for some time.

It will include many new multi media resources including Family Story films, advice on acute and long term stages



from our Societì Professor, advice from other parents, clinical facts and information, a 'questions and answers' page from our Scientific Advisory Board, help to understand what might happen when your child is in hospital for tests, links to medicine information sheets, a parent guide from our partners, the Kawasaki Support Group and more besides. We really hope that the portal is useful and can be a help to families when they need it most.

Visit Societì's JustGiving page!

We have been absolutely amazed by the support we have received on our JustGiving page since we launched it in September this year. Helped by nearly 200 people already, we have had some remarkable individuals creating their own JustGiving pages for us and raising money in incredible ways from holding table top sales to running half marathons. The effort put into raising awareness and funds has inspired us and we are astounded by the tenacity and passion shown by everyone. We can't thank our supporters enough – we know that together we will achieve our aims.



If you would like to raise money for Societì and raise awareness too, it is simple to create your own JustGiving page. Just go to www.justgiving.com/societì, create your fundraising page and share it with your family, friends and colleagues.



Paediatric Care Online

Paediatric Care Online (PCO UK) is an online decision support system designed for healthcare professionals who see children at the point of care. This innovative tool provides immediate access to clinically assured information to inform decisions and diagnosis. Societì have been working alongside PCO UK to add a new Key Practice Point for 'persistent fever' so that, with the help of their online app, Kawasaki Disease will be more easily recognised and diagnosed promptly.

Societì's on NHS Choices!

NHS Choices (www.nhs.uk) is the official website of the National Health Service in England. With over 48 million visits per month, it is the UK's biggest health website, so we are delighted to let you know that the Societì website is now included on NHS Choices Kawasaki Disease pages as an external resource.



societì.org.uk

societì.org.uk