



# societi 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

### Welcome to our Summer Newsletter 2019!



So much has happened since our December newsletter and there's so much more in store for the next six months too. Hopefully we've managed to squeeze enough of it in these pages to let you know how much of a difference we are making! We're always so busy at Societi and so far 2019 is no exception. We continue working with pace to get Kawasaki Disease known and we are achieving an immense amount, but there's such a lot that still needs to be done and that's where YOU, our Societi Supporters are so important. #TeamSocieti is the heart of Societi Foundation - raising awareness, directing our project work by letting us know what is important to you and raising funds to enable us to complete our project work. #TeamSocieti is steadily growing and has allowed us to achieve so much. I'd like to say a huge THANK YOU to every single member of #TeamSocieti! Your valuable support drives us with our work, as we grow Kawasaki Disease awareness. Please, continue your amazing support and we WILL get Kawasaki Disease known and we WILL make a difference for our children! *Best Wishes, Rachael, Societi Founder*

### Massive Impact at RCPCH 19

We attended the Royal College of Paediatrics and Child Health (RCPCH) annual conference in May, securing HUGE visibility for Kawasaki Disease - with HUNDREDS of clinicians. We had so many in depth Kawasaki conversations and spent time with hundreds of different people over the 3 days! We GRABBED centre stage visually from our excellent stand position, together with our striking visuals and superb #SocietiKids who simply demanded everyone's attention!



Our Societi Exhibition Stand

Professor Tulloh led our training workshop which was oversubscribed! There was fantastic participation and so much engagement - a hugely successful workshop.



Our Kawasaki Disease workshop

Literally thousands of items of Societi awareness information left the conference with the estimated 1,500 doctors and health care professionals who attended. Well over 1,000 fridge magnets alone are now in hospitals, wards and clinics all over the UK (all over the world in fact!) and it was just brilliant to see Societi wristbands on doctors wrists as they made their way round the conference! YOUR support makes this possible!

### Significant Investment Secured for European Clinical Trial



We can't hide our excitement - funding from Conect4Children for a pan Europe clinical trial into Kawasaki Disease has been secured! As Societi kicked off the process leading to this major trial, we're now part of the team for this globally significant research project. MASSIVE thanks to the funder for recognising the need!

The trial, led by Dr Eleftheriou and Prof Brogan from Great Ormond Street NHS Trust, will assess the effectiveness of adding steroids to standard treatment in children with Kawasaki Disease to prevent heart complications. Treatment recommendations in the UK have for some time included giving steroids alongside IVIG, particularly for high risk patients. Doctors have not often acted on this though - this may be one factor in such terribly high levels of potentially preventable, lifelong heart damage being experienced by our children. This project, a MAJOR milestone as we combat Kawasaki Disease, will study whether the use of steroids can help reduce heart damage.



innovative medicines initiative

### Kawasaki Disease Symptoms



Persistent fever



Cracked lips / 'strawberry' tongue



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands



## Celebrating #TeamSocieti - and YOUR amazing achievements! Read on.....!



### Ladies Circle Supports Societi!

We attended the Ladies Circle AGM in May after Lindsay Pickard, Ladies Circle President for 2019/20, chose Societi as her presidential charity of the year. Ladies Circle has a massive network of members with over 100 clubs across Great Britain and Ireland, so we are absolutely thrilled to have the HUGE energy and enthusiasm of tens of thousands of Circlers behind us this year. What a REMARKABLE opportunity, from a REMARKABLE organisation - to get Kawasaki Disease known!

### Running for Societi

We've had such success through amazing Societi runners this spring. Hayley ran London Marathon - a first for her and Societi! Tlou ran Brighton Marathon supported by Jade and her AMAZING cake sale fundraiser! A special mention must go to Cat who has completed a whopping 12 marathons this past year, dedicating 3 of them to Societi - what an incredible feat! **All** our runners are amazing, raising massive awareness and valuable funds for Societi. Their sheer dedication never ceases to amaze us! Check out our Societi Virtual Run if you've been inspired by these incredible achievements!



### The sky really is the limit for Kawasaki Disease awareness!

That's what BRILLIANT Societi Supporter Heather proved when she left from a plane, thousands of feet up in the sky over Scotland - with just a parachute. She was determined to raise awareness and much needed funds with this - the FIRST ever Societi Skydive - so we can tell more doctors, healthcare workers and more people about Kawasaki Disease. Having lost her beautiful son Jaime to Kawasaki Disease at just a few months old, she is a mum on a mission and we're deeply grateful for all she does and continues to do!

### Growing corporate support

Our BRILLIANT supporters have been busy, securing support for Societi from businesses. We're delighted to be working with INCREDIBLE companies like Total Security Installations, The Flavourworks, Lexington Communications, Roche Diagnostics and Alford Timber - receiving simply invaluable support. This includes corporate donations, staff fundraising and FABULOUS joint social media to raise awareness! We've had pro bono support from a number of professionals that we otherwise wouldn't be able to access. If you work for, or know an organisation that could help us - please do put them in touch with us!



### Unstoppable Team Thomas

No less than NINE runners, in Societi tops, made the most AMAZING impact at the Swansea Half Marathon earlier this year. We think you'll agree - a team of NINE and a SEA of Societi RED - would make an incredible impact! But actually, it was MUCH MUCH more than this - with more than DOUBLE the number of supporters too there on the day to cheer, wave banners and fundraise - making sure that many THOUSANDS of people got to know Kawasaki Disease. Incredible impact Team Thomas! We're proud to have your simply unstoppable support, to help protect tiny hearts!

### Team Kiwi - What a team!

With over a dozen team members, led by wonderful Vikki and Anna, Team Kiwi have made an incredible impact in 2019 with a whole host of fundraiser events and activities (and there are more planned!) They are DETERMINED to get Kawasaki Disease known and have completed sponsored walks in challenging weather, ran a fab summer fete again and continue to send Kiwi Bear on his travels to raise awareness! Go Team Kiwi! You're just AMAZING!



### Supporters bag £1,000 for Societi Foundation!

We were just DELIGHTED to win £1,000 from Ecclesiastical Movement for Good, thanks to nominations from Team Societi! Members of the public were invited to nominate causes close to their hearts, with 500 gifts of £1,000 being donated. Societi was one of more than 7,000 charities nominated and the award will fund over 200 GP packs! WOW! Thanks to always brilliant Societi Supporter Vikki for making sure we knew about this opportunity!

### Societi Shopping - THANK YOU for your support!

Our Societi shoppers are growing in numbers each month - and EVERY purchase helps us raise awareness. Not shopped recently? Take a look at what's 'in store'! There's hoodies, Loveheart sweets, boot bags, even fridge magnets! Buying from Societi shop is a great way to support us as not only does it raise valuable funds, but you'll be raising loads of Kawasaki Disease awareness with your new shopping bag, hoodie, running vest or pen! Visit our shop at [www.societi.org.uk](http://www.societi.org.uk) to see the great range of Societi products!



## Know Kawasaki Disease!

Kawasaki Disease is the leading cause of acquired heart disease in children in the UK. It's important to know Kawasaki Disease as early diagnosis and treatment could save a child's heart from being damaged. Symptoms include a persistent high fever for five days or more, rash, bloodshot eyes, "strawberry" tongue, cracked, dry lips, redness of the fingers and toes and swollen glands in the neck, often just on one side. **Kawasaki Disease can occur with some or all of these symptoms. A persistent fever is the one defining symptom and will always be present.** The symptoms can also appear one after the other, over a few days. If a child has a persistent fever plus two or more of these other symptoms, please **THINK Kawasaki Disease!**



## Kawasaki Disease - Myths and Facts!

There's so much dangerous misinformation out there about Kawasaki Disease, it's often difficult to know what's true and what's not! Below, you'll find some of the common myths around Kawasaki Disease that can hamper care and delay diagnosis. Why are we worried about these myths? Because they **SERIOUSLY** affect outcomes for children. We've given you the facts here so you really can 'Know Kawasaki Disease'!

### Symptoms & Treatment

**Myth:** A characteristic symptom of Kawasaki Disease essential for diagnosis is peeling of fingers/soles of feet

**Fact:** Skin peeling only affects some patients and happens later! **If** it occurs it'll be 10-21 days after start of fever.

**Myth:** There is a treatment window for IVIG of 10 days

**Fact: There is no "window" for IVIG.** This is a really damaging myth! It's essential that doctors do not delay IVIG assuming a 10 day window for effective treatment. Current treatment times are too slow. Doctors should aim to treat at 5 days (ASAP) after fever starts - early treatment is key to reduce risk of heart damage!

**Myth:** Kawasaki Disease has no characteristic symptoms

**Fact:** The symptom which should always trigger suspicion of Kawasaki Disease is a persistent, high, unremitting fever for 5 days.

**Myth:** IVIG reduces heart damage from 25% to 5%

**Fact:** 19% of all children develop permanent damage and 39% infants develop coronary artery aneurysms despite IVIG - linked to delayed treatment. Early treatment is critical! This is a most damaging myth!

### Heart Damage

**Myth:** Kawasaki Disease rarely causes heart damage

**Fact:** In the UK, 28% of affected children have some heart damage, 19% have lasting coronary artery aneurysms. 39% of infants (babies under 1 year) develop serious heart damage.

### Diagnosis

**Myth:** Echocardiograms are a useful way to confirm a Kawasaki Disease diagnosis

**Fact:** Echo is very useful to confirm heart damage but Kawasaki Disease if treated early, does not always lead to heart damage!

**Myth:** Persistent fever plus at least 4 other symptoms must all be present for a diagnosis of Kawasaki Disease

**Fact:** 47% of UK/Ireland cases in babies under 1 yr and 25% cases overall are incomplete i.e. **do not have all symptoms.** Kawasaki Disease can be diagnosed with fewer symptoms - not all patients have all symptoms and symptoms can appear over time on different days. If a child has a persistent fever and 2 or more Kawasaki Disease symptoms, always THINK Kawasaki Disease!

### Who & How Many?

**Myth:** Child is too young / too old for Kawasaki Disease

**Fact:** Kawasaki Disease can occur in very young and older children. It can be most severe in infants (under one year) and about 25% of those affected are older than five years.

**Myth:** Kawasaki Disease is very rare, you'll never see it

**Fact:** Kawasaki Disease is increasingly common. Cases are doubling globally every 10 years. In England, hospital admissions for Kawasaki Disease increased fourfold in the last decade. Kawasaki Disease is more common than bacterial meningitis.

### Impacts

**Myth:** The only lasting damage from Kawasaki Disease is to the heart

**Fact:** Kawasaki Disease is a disease which affects all the blood vessels and effects can be wide ranging. In a few children it can affect hearing, sight, kidneys and joints. It can also cause behavioural issues, which almost always resolve in a couple of years. See our Long Term Effects leaflet on our website.

### Long-Term Care

**Myth:** After coronary artery aneurysms have 'resolved', patients can be fully discharged from care

**Fact:** All patients with heart damage which persists beyond the acute phase (even if it 'resolves' later) require lifelong specialist care and are at increased risk of major cardiac events (see NHS Improvement Service Patient Safety Alert May 2016 on our website).

**Myth:** There are no known future health risks for patients with heart damage following Kawasaki Disease

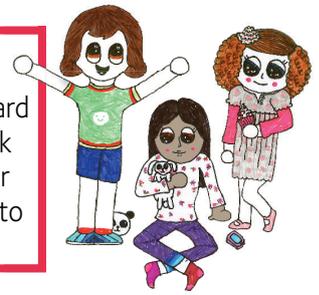
**Fact:** Patients with lasting cardiac damage are known to be at higher risk of major cardiac events in later life. Lifetime specialist care is essential.

**Myth:** A past patient history of Kawasaki Disease is an irrelevant medical consideration later in life

**Fact:** Adverse cardiac events with an unusual presentation can occur in patients with a history of Kawasaki Disease - this should always inform medical care (see NHS Improvement Service Patient Safety Alert May 2016 on our website).

## Our HUGE THANK YOU to #TeamSocieti - that's YOU!

We rely solely on fundraising and donations to fund the work we do. Our Supporters work so hard to raise funds and we'd like to thank every single member of #TeamSocieti for all your hard work and dedication. **THANK YOU** so much for all that you do! There's NEVER enough space in our Newsletters to mention all our volunteers, fundraisers or donors - but we are HUGELY grateful to YOU - and without YOU we can't protect tiny hearts! TOGETHER, we will! **THANK YOU!**



## What's coming up?

We're always super busy here at Societi and this year is no exception. Take a look at some of the projects that we're working towards and just some of the events our FABULOUS supporters have planned too. If you'd like to plan your own event to raise awareness of Kawasaki Disease or raise funds for Societi Foundation, please get in touch and we'll do everything we can to support you.

### Societi's Virtual Run



Kicking off World Heart Day on 29 September, we've launched our Virtual Run. With a successful debut in 2018, our FAB Running Committee have grown the 2019 event - and you don't have to be a super-runner to take part! Choose your distance - anything from a Fun mile to a half marathon, so everyone from 1 to 101 can take part! Check out our website for all you need to know to take part!

### Julie's Craft Fundraiser

Julie is on the case for Societi yet again and she and all of her "crafty" friends and family are busy knitting and sewing in preparation for their fundraiser in October. Julie's 'Yorkshire Campaign' has gone from strength to strength and we're always extremely grateful to Julie for all the support she provides to Societi. We're really looking forward to seeing what types of crafty things will be available at this year's fundraiser!



### Parliamentary Engagement



We've been working with Lexington Health to actively engage with Parliament with a mission to build political understanding of the critical issue that is Kawasaki Disease! We have started the process, having spoken to MPs about major issues around Kawasaki Disease. There's still much more to be done in this area but with the help of Lexington, we will get Kawasaki Disease on the political agenda.

### Coast to Coast

Later this year, fabulous supporters Victoria and Rob will take part in a cycle ride with family and friends to raise money for Societi. The event is a coast to coast challenge of 143 gruelling miles from Ayr to Berwick-upon-Tweed, which means the pair will be raising awareness of Kawasaki Disease right across the country!



### Map of Societi Packs



Building awareness through info to doctors across the UK is a top priority for us. We've now launched an INTERACTIVE map to let our supporters know where info has been sent, thanks to YOUR support! This is live on our website, take a look and see if your GP/hospital has had one of our packs. Plus - find out how to get a pack to your local GP surgery or hospital!

### Lisa's Bounceathon!

We'd never heard of a bounceathon before Lisa got in touch to let us know that's what she's doing to raise money for Societi! We think it's an absolutely fabulous idea and we're really looking forward to seeing some pics of the event. Lisa has already smashed her fundraising target with this brilliant idea. Good luck for your brilliant event Lisa!



### Revisit to FOI

In 2016 we requested Kawasaki Disease data relating to incidence from all hospitals in England under the Freedom of Information Act. The data we collected was powerful and gave us a unique insight into Kawasaki Disease in the UK. We felt it was time to request more data to update our work, so we can continue to track incidence here in the UK. A BIG project for a small charity - we think it's worth it!



### Veswas Grand Gala

Fabulous Veswas Ltd have selected Societi as one of 2 charities to support at their November Grand Gala dinner. Veswas are organising a simply wonderful evening of entertainment and gourmet food - whilst raising money for great causes. Thanks to always amazing Supporter Neeta for this incredible connection - we will be attending to raise awareness of Kawasaki Disease. What an phenomenal opportunity!



### RCGP E-Learning!

Partnering with the Royal College of General Practitioners (RCGP) to produce a Kawasaki Disease online course, we're excited as it will be published very soon. Authored by our Societi GP Trustee, the course will be available to all RCGP members, truly growing knowledge of Kawasaki Disease within the UK GP community! Thank you to EVERYONE who has donated to enable this critical project!

