



societi the UK Foundation for Kawasaki Disease

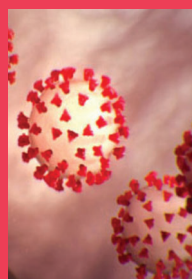
Kawasaki Disease is the leading cause of acquired heart disease in children in the UK

...it's time we changed that



Welcome to our Summer Newsletter 2020!

The world is a very different place since we wrote our last newsletter! Everyone's life has been impacted by the extraordinary events of 2020 and life at Societi is no exception... But in these times of real adversity, I have been inspired by the dedication, commitment and energy of so many of our supporters who, despite the toughest of times, have been unrelenting in their work to get Kawasaki Disease known. I am so proud of our Societi community, and I've been taken aback by YOUR response to our **Emergency Appeal**. We've received so many brilliant and generous donations, totalling over £10,000 now – but also films made for free, UK wide advertising and phenomenal expert support from professional teams, all without charge to help us get through – just to mention a few of your AMAZING offers of support. And as I look ahead, with World Heart Day just around the corner, I am excited for what I know will be a stunning awareness campaign, our biggest yet – and I'm looking forward to getting Kawasaki Disease even more firmly on the map! With your help – we can, we will – and you know what – we ARE protecting tiny hearts. Thank you – for all you do. *Best Wishes, Rachael, Societi Founder*



Societi, COVID-19 & Kawasaki Disease

Due to the COVID-19 pandemic, Kawasaki Disease has hit the headlines like never before – but also with much confusing misinformation being circulated. We've been flooded with questions and concerns from worried families and worked hard to respond to media enquiries. This HUGE increase in enquiries has meant we've had to work ultra hard to respond. We've collaborated with Kawasaki Disease organisations from around the world and worked closely with our Scientific Advisory Board to create detailed statements to give you the FACTS we know you need.

Special thanks must go to **Lexington Communications** for all their amazing help and expert advice, responding to media at the peak of enquiries. A huge thank you too, to all those at NHS England including **Prof Simon Kenny**, whose support has been just brilliant.

We're now accelerating our work to raise awareness far and wide, to reach families who will be unfortunate enough to be affected by Kawasaki Disease – with our aim of helping them get rapid diagnosis and early treatment.

As a small charity with no Government funding, we are reliant on YOUR donations and fundraisers. And our work to protect children from Kawasaki Disease, the **LEADING** cause of acquired heart disease in children, has NEVER been more important. We're concerned that the hundreds of children who, based on our research, we know will be affected by Kawasaki Disease in the next few months, whilst the pandemic continues — may not get the urgent help they need. We simply can't do this alone. **WE NEED YOUR HELP NOW!** We've launched an EMERGENCY funding appeal and you can donate [here](#). THANK YOU to all the phenomenal people across #TeamSocieti who made the launch of our Emergency Appeal possible and to those who have already donated and created fundraisers to help us carry on with our work.



Kawasaki Disease Symptoms



Persistent fever



Cracked lips / 'strawberry' tongue



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands

A huge WELCOME to our fabulous new people!

At Societi we are incredibly fortunate to be supported by so many amazing people – all dedicated to getting Kawasaki Disease known. So we're delighted to be able to welcome some 'new' people into our team – Professor Paul Brogan, Dr Filip Kucera and Lucy Patterson.



When we say 'new', that's not exactly the word we are looking for! Professor Paul Brogan, Professor of Vasculitis and Honorary Consultant Paediatric Rheumatologist at Great Ormond Street Hospital is a fabulous, long standing supporter of Societi. He is a member of the UK Kawasaki Disease Steering Group and also sits on Societi's Scientific Advisory Board. Professor Brogan now joins us in capacity of Trustee where his skills and expertise will help guide and direct the work of Societi.



We are excited to let you know that Dr Filip Kucera, a paediatric cardiologist, has joined our Scientific Advisory Board. He is the cardiology lead for Kawasaki Disease at Great Ormond Street Hospital and is responsible for cardiac management in patients with Kawasaki Disease. With his firm focus on Kawasaki Disease, immense energy and extensive clinical knowledge – we know you'll share our excitement that Dr Kucera has joined Societi!



Lucy is a long term supporter of Societi who has volunteered her time and media skills over the last few years. An immense fundraiser too, Lucy is, quite simply, **BRILLIANT** at what she does! Lucy brings a wealth of knowledge – she is a communications and public relations expert in developing effective and innovative comms strategies within the charity sector. We are so excited to have her to join our small staff team, to lead us in all things marketing and digital!

We are absolutely thrilled to welcome all these remarkable individuals to our team and are just delighted that Societi will benefit from their overwhelming experience and enthusiasm for getting Kawasaki Disease known!

THANK YOU #TeamSocieti - you are AMAZING!

Times are tougher than they've been in a long time. Changes...restrictions... have all been part of our lives. It's been hard! And at Societi, we've had to dig deep too. Yet we've been so completely overwhelmed with the response from our amazing community - from YOU - to our ask for help during these difficult times. The frequent cake sales and wear red days had become impossible during lockdown but our community have found ingenious ways to carry on supporting us. Virtual quizzes, silent auctions, running, walking and much more! There's been no end to the ingenuity and effort, despite the difficult times. We're so grateful to EVERYONE who has carried on supporting us through these exceptional months. YOUR support is VITAL to our work, protecting children's hearts - and it's never been more important! THANK YOU!

HUGE THANKS

to our **REGULAR DONORS!** Because you're our....



REGULAR HEROES!



888 Lockdown Community Challenge

Our 888 Community Lockdown Challenge challenged our network of amazing supporters to get active, and reach a target of 888 miles - running, cycling, swimming and walking. We were blown away by the contribution that every single participant made and YOU achieved a staggering total of 3,631 miles - equivalent to the distance between Societi HQ and Washington USA - WOW!! Fundraising for the challenge reached a BRILLIANT total - over £500! THANK YOU SO VERY MUCH to EVERYONE that took part, donating their time, money and miles.

A HUGE THANK YOU to two of Societi's youngest supporters!

Ethan's 24 hour gaming

Super-gamer & super-supporter Ethan completed a brilliant challenge of 24 hours non-stop gaming to raise funds for Societi! He raised an impressive total of £219, just BRILLIANT! Ethan - we think you're INCREDIBLE! Thank you for gaming so hard...for so long!! And thank you to Debbie and Darren too - for keeping Ethan fed and watered whilst he played and played and played!



Gemma's Two Castles

BRILLIANT supporter Gemma had planned to take part in the Two Castles event in June before it was unfortunately cancelled. The race is run between two of England's most beautiful castles, Warwick and Kenilworth. Utterly unstoppable Gemma made the decision to run the challenging distance of 10km *anyway* and raised an AMAZING amount of money - £590! Gemma is an absolute SUPERSTAR! We're so grateful for her determination and her HUGE 10km success, helping to protect tiny hearts.



#TwoPointSixChallenge

Our newest member of the Societi Active Committee, Gayle Harvey, led Societi's 2.6 Challenge - a nationwide initiative brought about in response to the postponement of many charity fundraisers due to be held on London Marathon weekend. Gayle, who was due to run the London Marathon for Societi, was not disheartened - and instead led Societi Supporters in the 2.6 challenge raising over £1,200! Thank you Gayle for all your energy and determination in leading such an incredible event! Massive thanks too, to everyone who took part - there were some absolutely stunning achievements from right across Team Societi!



Societi Virtual Quizzes

Thank you so much to Societi Supporters Andrew, Vikki and Haley for hosting their Virtual Quiz nights to raise money for Societi. A HUGE THANK YOU too, of course, to everyone that took part and supported our charity! The quizzes were brilliant events, full of giggles - and some tough questions too! Both evenings were AMAZING successes thanks to long standing, dedicated supporters putting the FUN into FUNDRAISING! HUNDREDS & HUNDREDS of pounds have been raised towards our Emergency Funding Appeal too - THANK YOU!

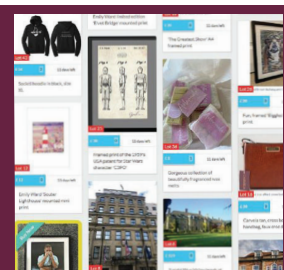


Zara's 2020km in 2020

2020km in 2020 raising £2020 is the aim for Societi Supporter Zara - or Wonder Woman, as we also refer to her! An incredible fundraising challenge - Zara is aiming to run this staggering distance during the year and raise a HUGE sum for Societi in the process. That averages out at more than 5.5km per day - for the WHOLE YEAR! It's also £1 for every km run - JUST BRILLIANT! We're wishing Zara the very best of luck for this incredible challenge, inspired by her best friend, Liz, who sadly passed away last year. You can support Zara's incredible efforts [here](#) and help her reach her amazing target!

Societi Silent Auction AND a 300km walking challenge!

We've been so inspired with the response from #TeamSocieti to our Emergency Appeal! Thank you to the always fabulous Carol for her brilliant initiative - a silent auction. And thank you too, to her amazing network of friends and family for making this all possible. There were no fees to pay, and funds raised above the reserve price were donated to our Emergency Funding Appeal! Even better, on donated items, all funds raised came directly to Societi! But Carol didn't stop there! This amazing lady also walked 300km in 30 days throughout July to raise even more for Societi! We think that is just astounding! You can support Carol in her fundraising efforts [here](#). Carol - you're INCREDIBLE!





Societi Active has arrived!

Are you a cyclist, runner, walker, swimmer, skier, or all-round ACTIVE individual? Or maybe you're ready to get a bit more active and do a bit more – get in shape, increase your fitness. Would you like to have fun, share ideas, raise awareness of Kawasaki Disease – and be supported by a team of wonderful Societi volunteers? Then JOIN our new SOCIETI ACTIVE Facebook page and be part of a NEW and EXCITING community!



Over the last 3 years, the Societi virtual running group has grown from strength to strength. This community, that we are SO PROUD of, is not just for runners – but for ANYONE wanting to take part in ANY activity for Societi – from running to biking, trekking, climbing, swimming, duathlons, triathlons, golf, ANYTHING! And even if you're "brand new" to the whole fitness thing – this community is for you!

A HUGE THANK YOU to our amazing volunteers Hayley, Vikki, (pictured left) Lucy, and most recently Gayle too (pictured right), for ALL their hard work and commitment in making Societi Active happen! This WONDERFUL group of lovely ladies do so much for Kawasaki Disease awareness – and we are so grateful to them!



Feast your eyes on our NEW SOCIETI MERCHANDISE!

We're always thinking about new ways to raise awareness of Kawasaki Disease and our merchandise is no exception to this. We love designing new Societi goodies to put up for sale on our online shop! When you buy from the Societi shop, as well as supporting us by generating valuable funds – whether you're popping to the shops, out for your daily exercise or working in the office – your gorgeous Societi 'stuff' will help you to raise awareness of Kawasaki Disease wherever you go!

Recent additions to our shop include the limited edition BLACK Societi jute bags. Our red jute bags have been hugely popular – they are great quality, really durable, a great size and have lovely comfy handles. And, of course, they are an INCREDIBLE way to raise awareness of Kawasaki Disease – every time you leave the house! Our NEW stock is just the same! Only...BLACK!

Talking about bags, we've also released our brand new Societi Active drawstring bags. Our nylon drawstring bags are lightweight and brilliantly practical with a huge range of uses and are perfect for school, trainer bags or sport bags.

Just as effective at raising awareness are our new reusable Societi face coverings in red or black – available now! Made with Silvadur930 antimicrobial finish which inhibits growth of microbes for protection and durability and with a Zelan R3/Teflon Ecolite water repellent finish on the outer layer fabric, our washable face coverings are both essential gear these days *and* guaranteed to make an impact!

Something that caused a stir recently was the arrival of our new stationery – A5 note pads and sticky post-it notes, complete with Kawasaki Disease awareness raising messages and the perfect partner to our lovely Societi pens!! Our stationery was originally just intended to be used with our GP and hospital packs, to help clinicians remember Kawasaki Disease. However, we received so much amazing feedback that we've made them available to buy at our shop too! Well, who doesn't love a bit of stationery!

And, if you're looking for a bargain, check our new 'Active', 'Awareness' and 'At Home' bundles which will save you £££s when buying all your favourite Societi merchandise in one go. Take a look at our online shop [here!](#)



THANK YOU Clear Channel UK: Scaling up Kawasaki Disease Awareness!



During July, Societi was given a simply extraordinary opportunity – no-cost, UK wide advertising space to support our mission to protect children's hearts. We're hugely grateful to Clear Channel UK for donating very valuable space for a Kawasaki Disease campaign on their digital screens – across the Malls Live network in the UK's leading shopping malls nationwide.

We were able to reach a whole new audience with our Kawasaki Disease awareness raising message – something that, without the generosity of Clear Channel, we just could not have done. Originally planned for one week, Clear Channel then generously extended our campaign for a further 7 days, meaning many MORE people were able to LEARN about Kawasaki Disease – just FANTASTIC! The team at Clear Channel were just incredible, providing all the help and advice we needed to create an effective campaign. And it really was effective with an almost 400% increase in traffic on our website during the campaign! Oh my!!

A huge THANK YOU to Eva at Clear Channel and Richard, the MD, for such terrific support! And a huge THANK YOU too, to wonderful supporter Andrew Patterson who made this happen! By raising awareness in such prominent spaces, we WILL get Kawasaki Disease known FASTER – and help combat the #1 cause of acquired heart disease in U.K. children!



Outstanding Support, Incredible Ladies!

We need to say an *enormous* THANK YOU to Ladies Circle – we are so grateful for their dedication, hard work, ingenious fundraising and tremendous support over the last year. We are extremely lucky to have been chosen by fabulous Lindsey Pickard, President of the Ladies Circle, to be her Presidential Charity of the Year. Ladies Circle is a phenomenal organisation – and one of scale. They have brought so much energy, real passion and determination to our cause, thanks to **phenomenal** leadership from Lindsey and Michelle. THANK YOU!

THOUSANDS of amazing Circlers have worked tirelessly to raise awareness of Kawasaki Disease and are constantly coming up with new, exciting ideas to raise funds for us too. We absolutely love you, ladies! And with the disruption caused by the pandemic, this meant that Lindsey's presidency, due to end in May, will now carry on until September 2020 – and so too will their support for Societi – just amazing! Ladies – we CAN'T thank you enough for all you've done!

Thank you Flavourworks!

Each year, The Flavourworks select charities to fundraise for – and we were absolutely delighted to be chosen last year! Their BRILLIANT team have been so busy getting Kawasaki Disease known, and were planning to run in the Yeovil Half Marathon in March too. The event was cancelled of course, as so many have been in recent times, but the Half Marathon team will still be completing the run as soon as restrictions allow – and this didn't stop them from getting creative raising funds in lots of other ways too! We are so VERY fortunate to have their help protecting tiny hearts! Thank you Flavourworks!



Our New Young People's Portal

We're progressing well with our exciting NEW information service for children and young people affected by Kawasaki Disease! If you're a parent or grandparent, you'll know young people often have tonnes of questions! We want to provide **trusted** answers to their questions about Kawasaki Disease. Some youngsters worry about their future too, having had this disease – so we're stepping in and creating a dedicated online information service JUST for them! Watch this space for updates!



Conect4Children European Clinical Trial

September marks the start of recruitment into our European clinical trial, investigating improved treatments for acute Kawasaki Disease (at the start of the illness). The trial will explore whether treatment with steroids can reduce the risk of coronary artery aneurysms. Societi is a co-investigator and patient involvement lead in this potentially transformational trial!

PLUS -- Societi Supporting UK Research

As well as undertaking our own research, Societi has been engaged by doctors to support their research work – providing input from a family perspective and helping with research design, which is patient focussed. We are currently working with the British Paediatric Surveillance Unit (part of the Royal College of Paediatrics and Child Health) on a UK-wide study looking at all Kawasaki Disease and PIMS-TS cases during 2020. These are separate diseases but share some features. We're also supporting an application for research as the patient and family input provider with a leading children's hospital in England – watch this space for more on that! Exciting times for UK based and UK-led research into Kawasaki Disease!



Clinician Heart-to-Heart

Societi has organised a virtual discussion event with our Scientific Advisory Board to answer the questions YOU have about Kawasaki Disease. The event will take place in September, bringing YOU the incredible and exciting opportunity to hear directly from leading UK experts as they take YOUR questions and discuss Kawasaki Disease. If you are UK based and have a question about Kawasaki Disease for our experts, please let us know by completing our contact form [here](#).



Help us to do more!

Your fundraising is at the heart of EVERYTHING WE DO – from raising much needed awareness of Kawasaki Disease, to making trusted online information available like our exciting Young People's Portal – and much more besides! All this work, now more than ever, is vital to help protect children's hearts from Kawasaki Disease and IT IS FUNDED BY YOU! Societi receives no Government or major grant funding, and so we rely on YOUR donations and fundraising to deliver our work. We know that it isn't always easy to fundraise, so we'll always support our fundraisers where we can. If you'd like to fundraise for Societi, why not take a look at the fundraising pages on our website. [Here](#) you'll find loads of ideas and resources to help. And please get in touch! We'd love to hear about your plans and help make your event a huge success! Don't forget World Heart Day is just around the corner – and if that's too soon, why not raise funds for International Kawasaki Disease Awareness Day on 26th January 2021. There's so much more we need to do, but we need YOUR help to do it! Thank you #TeamSocieti!



**WORLD
HEART
DAY** 29 SEP

World Heart Day – FACTS not Fear! And Our Virtual Run too!

29 September is World Heart Day, the second biggest date in our calendar (after International Kawasaki Disease Awareness Day!) We can't wait!! Help us make plans, take part and let's make World Heart Day a HUGE success for Kawasaki Disease awareness! This year our campaign theme is **FACTS not Fear!** If you'd like to raise awareness and fundraise for World Heart Day or anytime in fact, let us know what you have planned, get in touch – we'll help where we can! **[Check out our fundraising pages here too!](#)**

Responding to the confusing and worrying reporting of Kawasaki Disease and Covid-19, we are working NOW to urgently increase awareness and highlight the need to act to combat Kawasaki Disease – with FACT based information being shared across the UK. We will also be sharing a recording of our Heart-to-Heart discussion with our brilliant Scientific Advisory Board, answering YOUR questions on Kawasaki Disease!

And, of course, our flagship annual Virtual Run event is back for 2020 – BIGGER and better than ever (thanks to our brand new Societi Active Committee). A HUGE THANK YOU to everybody that has already signed up! JUST BRILLIANT! Run or walk your chosen distance – a Family Fun Mile or 10km, on your chosen day, from 22 August. **[Sign up here](#)**. Both races finish on 29 September – WORLD HEART DAY!

