



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 2022!

We love to be busy and WOW we've been very busy! From the RCPCH conference, to Societi research, to creating a new parent booklet – this summer newsletter is just bursting with updates about our work and future plans – although, there's never enough room! We have been extremely lucky to gain some amazing new partners recently who have really helped to accelerate our work to get Kawasaki Disease known. It has allowed us to get started (and finished!) on many projects that would otherwise have stayed on our wish-list – I am extremely grateful! #TeamSocieti (you!!) remain absolutely prolific – supporters are rapidly growing in numbers, and you're raising precious funds by ever more ingenious ways... backing our work and inventing more and more wonderful ways to raise awareness of Kawasaki Disease – we really couldn't do what we do without YOU – our work is YOUR work! We all know so well that Kawasaki Disease is the #1 cause of acquired heart disease in U.K. children. It's INCREASINGLY COMMON and because of our work TOGETHER, it's at last becoming known. We really are making a difference – and helping to protect tiny hearts! For all you continue to do – thank you. *Rachael, Societi Founder*



Works begins on strategic partnerships with children's hospitals across the UK and Europe

On the eve of the biggest day in our Societi Foundation calendar, International Kawasaki Disease Awareness Day, we announced a transformational partnership with the exceptional Randal Charitable Foundation – investing in Societi so that we can build partnerships with every children's hospital in the U.K. Every single one!

Getting Kawasaki Disease known so that doctors can diagnose it rapidly and urgently administer life saving and heart protecting treatment is a game changer. There's simply no two ways about that. By connecting directly with hospital teams we can get this sinister disease known.

With this huge injection of support we've been able to rapidly accelerate knowledge building among children's doctors, to ensure timely diagnosis and better care for affected children. Kawasaki Disease is increasingly common but still gets initially misdiagnosed too often. Through our work, we expect to achieve a reduction in both loss of life from Kawasaki Disease and lower the rate of heart damage in children. Amazing goals, we hope you agree.

About a quarter of all children affected by Kawasaki Disease today will have heart damage – that's hundreds of U.K. children every year. We want to change that and this remarkable support from the Randal Charitable Foundation marks the next, truly significant steps in that change.

We are deeply grateful for the Randal Charitable Foundation's faith in us – and their incredible commitment to our goal: to protect children's hearts.

Societi hits record at Chemical Business Association annual luncheon

Societi was extremely grateful to be nominated by Kate Mingay, Chair of the Chemical Business Association as the chosen charity, at their annual luncheon – a legendary event that hasn't been possible for 2 years due to the pandemic.

Societi benefited from hundreds of generous donations from CBA members. A CBA record amount of £16,068.01 was raised – the largest donation ever recorded in the association's 99 years! This transformational amount of money is now helping fund our life saving work – to protect children's hearts.

We were able to share knowledge of Kawasaki Disease to over 900 guests and show the work we do to protect tiny hearts from the devastation it can cause. We shared our new awareness animation, a proud moment for us that was greeted with applause. And when we showed our parent film, 'Know Kawasaki Disease' where so many of you spoke about the impact Kawasaki Disease has on our families, parents, children.... you could have heard a pin drop! And we are in no doubt, your support ensured this level of impact.



Kawasaki Disease Symptoms



Persistent fever



Cracked lips /
'strawberry' tongue



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands



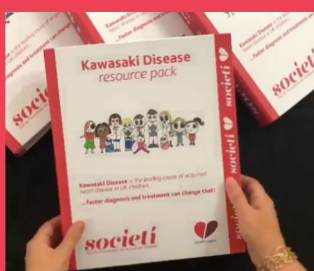
Societi returns to RCPCH

It was just fantastic to finally be back at the Royal College of Paediatrics and Child Health annual conference in June.

We had some fabulous conversations with doctors who had HUGE appetite for learning resources and hungrily “hoovered up” EVERYTHING we had on offer. The interest in our work was simply incredible – we are seeing a shift from “Why do I need to know Kawasaki Disease?!” To “Tell me more, because I need to make sure I don’t miss a case!!”

We are determined to get Kawasaki Disease known, so we make sure we make a HUGE impact when we have opportunities like this – an opportunity to speak to hundreds of doctors who care for our children.

And it’s YOUR support that makes this possible. Your donations, your fundraising and your regular contributions make all of this possible. THANK YOU for helping to make this a very special conference indeed – one where we have absolutely, tangibly and definitely protected tiny hearts.



Kawasaki Disease resource packs at a hospital near YOU!

As part of our Hospital Partnership Programme, Societi created Kawasaki Disease resource packs for clinicians to use and share with their teams. We’ve sent out lots already to partnership hospitals! And there’s more ready to go! Up to 100 of these will have reached the hands of doctors in hospitals by the time you’re reading this.

The packs draw together really useful Kawasaki Disease educational resources: our Spotting Zebras booklet, NICE guidance, new long-term guidance, Kawasaki Disease myths and facts and clinician’s Q&A to name just a few!

We had such INCREDIBLY positive feedback from the doctors we showed them to at the RCPCH conference, lots of them grabbing one for their bags!!

We’re sending follow-up mailings too with resources doctors can share with families in their care, including our brand-new parent booklet! Future updates will include best practice care guidelines, KD-CAAP trial learning, research findings and much more. We are building EXPERTISE in our community of children’s doctors. They need to know Kawasaki Disease to make sure YOUR children get the care they need. With your amazing support, and the generous support of the Randal Charitable Foundation, this life saving, life transforming work is possible.

We have been overwhelmed too by supporters who have sponsored packs to go to their local hospitals – we are very grateful! If you want to make sure one reaches your local hospital, you can donate £30 for each hospital you’d like one to go to – just **donate** and **let us know** your hospital details. They will be sent!!!



Clinical trial update

Thanks to the simply amazing team led by Scientific Advisory Board

members Professor Despina Eleftheriou and Professor Paul Brogan, significant progress is being made in the KD-CAAP research trial, which is investigating acute treatments for Kawasaki Disease. 26 hospitals (or centres) across the UK and Europe are now actively recruiting patients, and another 31 centres are expected to be open by the end of the year. That’s great news!

Societi continues in its role as co-investigator for the trial and as well as highlighting the trial to patients and the public, we’re also supporting the hospitals involved by providing lots of Kawasaki Disease information and resources including KD-CAAP specific posters to help in their recruitment.

Visit our **KD-CAAP web pages** to find out more about the trial, or why not follow our dedicated **KD-CAAP Twitter account** to get the latest updates.

Publishing our Diagnosis Day research

Thank you to the many Societi supporters who took part in our Diagnosis Day research poll.

It’s clear that experiences of Kawasaki Disease diagnosis varies greatly from family to family and, through the poll, we’ve been able to understand more about just what is happening when our children are first being diagnosed.

We’re now working with our Scientific Advisory Board to publish the results of the study and make them available to clinicians across the UK. Publishing the results will further clinicians understanding of this enigmatic disease and will benefit families affected by Kawasaki Disease in the future – and help them have quicker, more accurate diagnosis. Thank you to everyone who took part and made this possible.



WATCH it, SHARE it!

Have you seen our new Kawasaki Disease awareness animation yet? WATCH it [here](#) and SHARE it with everyone you know!



This fantastic little film is a valuable resource for us at Societi Foundation that has already worked hard for us, and will continue to do so, spreading our vital message; that EVERYONE needs to know Kawasaki Disease. Knowing Kawasaki Disease could save a child's heart from its all-too-often devastating effects.

It's YOUR support for our charity, YOUR donations and fundraising that have made this little film possible!! THANK YOU. Kawasaki Disease is INCREASINGLY COMMON and it's the leading cause of acquired heart disease in UK children. EARLY diagnosis and treatment reduces the risk of serious, lifetime heart damage. Together we WILL get Kawasaki Disease known, we WILL protect tiny hearts.

THANK YOU to ALL our regular donors!

A HUGE THANK YOU to our WONDERFUL supporters that make a regular donation to Societi Foundation – meaning we can plan ahead for our work, raise awareness and commit to long-term projects. Quite simply, we couldn't do it without YOU. We appreciate – more than you could know – the commitment to our cause. INCREDIBLE supporters who set up regular donations fund our work and our promise to you, in return, is to keep getting Kawasaki Disease known! THANK YOU!



If you'd like to make a regular donation, please just visit our [JustGiving page](#).

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



A Fabulous Charity Football Match... and so much more!

Societi supporter Geoff was determined to get Kawasaki Disease known, after his son was diagnosed with this serious illness. Geoff's local football club, Waveney Swifts Football Club held a charity football match for Societi Foundation and raised an incredible £2450!!! As well as this, Geoff pledged to run 5k every day for 30 days. AMAZING!! We are incredibly grateful to Geoff, his fantastic football team and to everyone that took part and donated. Thank you for helping to get Kawasaki Disease known.



Putting the FUN into fundraising!

When Societi supporter Steve messaged to say, he was planning an event for Societi Foundation and it was going to be A LOT OF FUN, we were very intrigued ...

Steve, his friends and family raised an AMAZING £600 for Kawasaki Disease awareness by racing indoor electric skateboards at Maidenhead Go-Kart track. A LOT OF FUN WAS HAD! Not only did they raise a fantastic amount of money, but everyone who took part; family, friends and everyone at the track now KNOWS KAWASAKI DISEASE. Thank you, Steve, and everyone that took part and donated, all of the Trampa ESK8 crew, Evolve Boards and Absolutely Karting. Because of YOU we are making real impact in the U.K. for Kawasaki Disease. THANK YOU!!

Racing electric skateboards isn't the only thing Steve's been up to, to raise funds for Societi! We were so thrilled to receive an INCREDIBLE donation of £500 following Coaleys Amateur Dramatic Society's village panto – Humpty Dumpty – that both Steve and his son, Noah appeared in! Each year, the Coaleys Amateur Dramatic Society choose a charity to donate to – and we were absolutely DELIGHTED that they chose Societi Foundation! They raised this brilliant amount of money over the course of 5 performances and obviously put on a truly GREAT show!

A huge thank you to Steve and Noah who made this happen – we are so grateful for your efforts and ALL that you do for our charity and Kawasaki Disease awareness.



A runners high!

Craig and Kate ran Brighton Marathon in April for Societi! We were in awe of their incredible running, fundraising and awareness raising achievements – we're so GRATEFUL and PROUD of them both!! Craig and Kate had so much WONDERFUL support on the day from family and friends. Societi banners and flags were flying high! The difference these runners and their support teams, families, friends and sponsors have made for Kawasaki Disease awareness is huge! We can't thank Craig and Kate enough for taking on this enormous challenge for us – raising much-needed funds for our charity and vital awareness of the number one cause of acquired heart disease in U.K. children.



Turning Padova RED!

Marie and her AMAZING friends and family have done it again! You might remember Marie ... back in 2019 she and #TeamThomas ran a half marathon, 9 incredible team members formed a sea of red passing through the streets of Swansea! Everyone saw "Kawasaki Disease" that day... well, this time it was the turn of the Padova Half Marathon in Italy!! This remarkable group, led by the wonderful Marie, made a massive difference with ALL the incredible work they put in – training, fundraising and DEFINITELY getting Kawasaki Disease known. The team made an amazing contribution raising almost £2000 for Societi through this challenge!! Thank you so much Marie for all your incredible hard work, passion and determination – it really is inspiring and we are enormously grateful.



5 days, 5 Marathons!

Rich SMASHED his self-set challenge of walking 5 Marathons in 5 Days. What an absolutely AMAZING achievement. Over the Easter weekend, Rich walked the North Down's Way (Farnham to Dover!) to raise awareness of Kawasaki Disease and funds for Societi. Over the challenge Rich was joined by his wife Sarah, and they were interviewed on BBC Radio Surrey and Dover Community Radio along the way. This challenge was a HUGE team effort with friends and family joining at various stages and helping enormously with logistics too. A total of well over £5,000 was raised. Well done and a HUGE thank you to Rich and the remarkable people who supported him!

A first for Societi – FAB five's sponsored boat pull!

Jill, Anne, Dawn, Hilary and Elaine spent a weekend in April pulling a 72 feet narrow boat, weighing about 10 tons (!!) along the Chesterfield Canal for Kawasaki Disease awareness. These WONDERFUL WOMEN raised more than £400 for Societi Foundation – we are enormously grateful and we were absolutely thrilled to receive their amazing photos! What a fantastic and original challenge! HUGE THANKS to Jill. She got her group of wonderful friends together, booked a date and the boat. Then together they proceeded to raise so much Kawasaki Disease awareness on the day, and an amazing sum for our charity too.

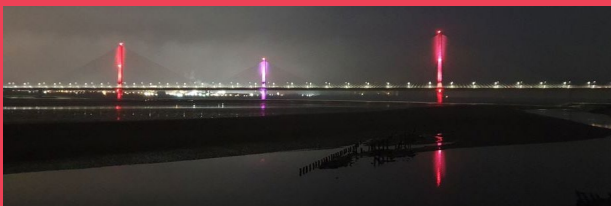


Kevin's 214 Wainwright Challenge

Long-standing Societi supporter, Kevin, has set himself an absolutely MAMMOTH challenge – to climb all 214 Wainwrights in the Lake District! So far, Kevin has completed 68 Wainwrights which, in itself, is a fantastic achievement – more than most will achieve in a lifetime. Fantastic progress. But this challenge is a marathon and not a sprint. We're HUGELY grateful to Kevin for all that he continues to do for Kawasaki Disease awareness and our charity – resolute in protecting tiny hearts from the devastating consequences of this cruel disease. If you'd like to show Kevin your support, you can visit his Go Fund Me page, [here](#).

#TeamSocieti – there's lots of ways to GET INVOLVED – read more to find out!

Shine a light on Kawasaki Disease



We know it's summer, but it's NEVER too early to start thinking about International Kawasaki Disease awareness day! Thanks to our fabulous supporters, landmarks across the UK lit up on 26 January this year for Kawasaki Disease awareness and we need your help to make an even bigger impact next year. Can you speak to your council or landmark owner to ask if they can light up your local town hall, cathedral or a landmark and get THOUSANDS of people in your area talking about Kawasaki Disease? **Get in touch** and let us know who you have contacted and if you have any luck – we'd really like to know so we can send local media a press release – and shout about on our social media for EVERYONE to see!

Tell your story to help others!

The stories our families tell have a huge positive impact across many aspects of our work. They're so valuable for families going through similar experiences, they raise much needed awareness and help doctors understand issues around Kawasaki Disease from a family perspective too.



Thanks to support from the Chemical Business Association, we're able to start this important project and create a new set of family films – after all, it's 6 years since we made our first ones!

We can't produce family films without you...! So, we're looking for volunteers from 4 different families, who have had different experiences. Could you share your experience of Kawasaki Disease to help others? Are you able to have a day with us in London for filming and spend some time beforehand preparing? We can meet travel expenses for our volunteers and we'll need to choose 4 families with a range of different experiences. If you'd like to be considered, please **get in touch**. We anticipate LOTS of offers of support (❤️) so do let us know as soon as you can, we only have 4 places this time!

Could you run London?



If you're looking for a great marathon and a great cause to run for in 2022... YOU COULD RUN THE VIRTUAL TCS LONDON MARATHON for Societi in October! We have just 3 spots so please register your interest as soon as possible. London is the largest UK marathon, so the awareness opportunities are huge for Kawasaki Disease.

Or swim Serpentine?



More of a swimmer than a runner? Why not take part in the fabulous open water Swim Serpentine event at Hyde Park in September? There are 3 distances available to choose from! Please help us make an impact through one of these amazing events in 2022! Just **get in touch!**

Our new parent booklet is coming!

Facing a diagnosis of Kawasaki Disease can be a difficult time for families. Having access to trusted information to help families understand their Kawasaki Disease diagnosis better can help alleviate some of the worry.

We've worked very closely with our Scientific Advisory Board and gathered together responses to a survey – where YOU told us what information you think families want and need when facing a Kawasaki Disease diagnosis. The booklet will be reviewed by a panel of parent volunteers to help make sure the booklet is as helpful to families as possible.

With printing and postage funded entirely by the generous donations from Chemical Business Association members, and work to develop and guide it funded by YOUR amazing fundraising, we'll be sending out thousands of booklets to hospitals across the UK in time for World Heart Day! We're so grateful for all the amazing support we have received from our doctors too (Prof Tulloh, Prof Brogan, Dr Herberg) in producing a doctor-backed booklet families can trust! THANK YOU to everyone involved!



Help us protect tiny hearts on 29 September – World Heart Day!

We can't wait for 29 September – WORLD HEART DAY!! This is simply a MASSIVE day in our Societi Foundation calendar, second only to International Kawasaki Disease Awareness Day on 26 January! There's so many exciting things going on in preparation for World Heart Day

at Societi this year, including the creation of a new expert podcast, distributing our brand-new digital Kawasaki Disease resource packs to hospitals across the UK and Europe, getting our parent booklet to over 100 hospitals, working with the World Heart Federation to raise awareness of children's heart health... and so much more!

Get involved!

World Heart Day is the perfect time to raise awareness of Kawasaki Disease and protect tiny hearts! So, why not get involved? Help us make plans, take part and let's make World Heart Day a HUGE success.



Why not have a **KAWASAKI CONVERSATION OVER COFFEE AND CAKE** in your local community, or just with friends! What a brilliant excuse (if we needed one...) for eating CAKE!!! Whilst raising funds to protect tiny hearts! Download your fundraising pack [here!](#)



Or why not hold a **WEAR RED DAY** at work, or at your child's school or nursery? Make a statement in RED to help fundraise and get this sinister disease known! Download your fundraising pack [here!](#)

Societi Active's Virtual 10k is back!



Our flagship annual Virtual 10K event is back for 2022 – BIGGER and BETTER than ever (thanks to our FABULOUS Societi Active Committee).



This year you can choose from two different levels of entry! **Standard entry is £10**, or **exclusive entry is £40** which includes an **event exclusive** Societi running jacket (pictured here) to help you raise awareness of Kawasaki Disease whilst completing your walk/run. All participants will also receive a special 50% discount code to use in our Societi shop on either a running vest or t-shirt – or both if you want! AND free entry into a lucky dip for a chance to win prizes including wristbands, stationery and a Societi hoodie!

ENTER THE VIRTUAL 10K [HERE!](#) Or, if you've already entered, why not set up a JustGiving fundraising page [here](#) where your friends and family can sponsor you to complete the Societi Active Virtual 10K.

