

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



Welcome to our 2022 Christmas Newsletter!

Oh! Where has 2022 gone? Time has flown since our summer newsletter... and no wonder! We've been so busy and together, with your support, we've achieved so much!

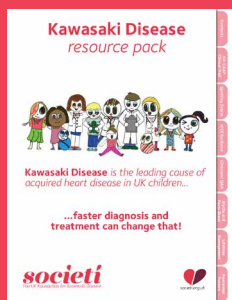
I found myself reflecting recently, after a supporter got in touch asking about our name. I was thinking about the choices I made when setting up Societi. Our name was one, shaped by my own strong feeling that the **leading cause of acquired heart disease in our children** must be a matter of concern for **everyone** in our society...

and today that still drives me to get Kawasaki Disease known. I was also reflecting on my decision to never use identifiable images of children in our work, to avoid any permanent, digital 'reveal' of their private health concerns, before they are old enough to decide for themselves. These decisions fundamentally shaped our approach, inspired our Societi Kids and more.

We'll always work hard to get this terrible disease known, and with your help **I feel certain** that we'll reach every one of the 68 million people in the UK. And we'll always do this in a way that respects our children's right to privacy, as **we work to protect the tiny hearts of children** everywhere in the UK. 2023 will bring opportunities and challenges for our charity - I'm excited for the year ahead - 12 new months in which to campaign and make a lot of noise, frankly, as we take even bigger strides to get Kawasaki Disease known. **We can't do any of this without you** - so I very much hope to have your continued, fabulous support in the months ahead. Meantime, have a wonderful Christmas, and hey - let's do it all again in 2023.

Best Wishes, Rachael, Societi Founder

Huge progress for Children's Hospital Partnership Programme



In our Christmas newsletter last year, we reported the super exciting news that Societi had received generous investment and support from the Randal Charitable Foundation, to embark on a 3 year Children's Hospital Partnership Programme.

It's designed to dramatically improve Kawasaki Disease knowledge in hospitals all over the UK and in Europe too and we've had a simply amazing first year! Our goals are to reduce both heart damage from Kawasaki Disease, and loss of life - by educating doctors so they can spot Kawasaki Disease quickly, shortening diagnosis times and make sure children get the rapid treatment they need.

Investment from the Randal Charitable Foundation has allowed us to develop relationships with key contacts in hospitals, provide detailed clinical training information packs and support materials for doctors caring for families affected by Kawasaki Disease. This amazing support also allowed us to directly reach hundreds of paediatricians at the RCPCH conference, and has helped in our work with Nottingham University Hospitals Trust and NHS England, as we improve understanding of how the number of cases of Kawasaki Disease is changing in the UK. We'll use this data to make sure we can really assess the impact we make with our work too. We've also distribute learning packs digitally to every single NHS Trust and Health Boards in the UK! The result - there's **more** information in the hands of **more** doctors in 2022 **than ever before**, because of this project. Amazing!

Work will progress into 2023 as our relationships with these key hospitals continue to grow and more hospitals join the programme too. **None of this transformational work to protect thousands of tiny hearts would be possible without the support provided by the Randal Charitable Foundation, and for this, we are deeply grateful.**



Kawasaki Disease Symptoms



Persistent fever



Cracked lips /
'strawberry' tongue



Rash



Swollen fingers/toes



Bloodshot eyes

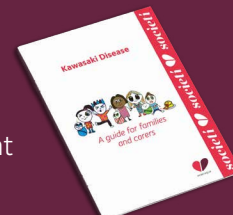


Swollen glands



Sharing our parent and carer Kawasaki Disease guide

A business lunch fundraiser held by the phenomenal Chemical Business Association this year raised one of our largest ever single donations - meaning we have been able to print 1,000 copies of our brand new parent and carer booklet. Over 700 of these booklets have now been distributed to hospitals and it's been made available digitally on our website. Filled with everything families need to know after receiving a Kawasaki Disease diagnosis, these booklets are now in the hands of doctors in every part of the UK, ready for families when they need them!



Our sincere thanks to all the project's many contributors: everyone who completed our survey and told us how important having this type of support would be, to our parent reviewers, our brilliant doctors who helped write the booklet and of course, the remarkable and generous members of the Chemical Business Association, whose transformational support made all this possible. You can read it [here](#) - we're certain it will bring invaluable reassurance and support to help families facing a Kawasaki Disease diagnosis in the future.

Outstanding support from Clear Channel!



We received extraordinary support once again from our wonderful partner, Clear Channel UK. During our World Heart Day campaign, they generously donated space within their extensive outdoor advertising network to truly make a difference for children affected by Kawasaki Disease. Our awareness raising messages were displayed in shopping centres nationwide, including in some of the biggest UK cities! The impact was simply immense. MILLIONS of people have seen our Know Kawasaki Disease campaign, from Aberdeen to Bristol to London and everywhere in between!

We are so very privileged to have this remarkable support through Clear Channel's Platform for Good. This tremendous opportunity was only possible thanks to Clear Channel UK – creating impact at scale, truly driving change for our children, by protecting thousands of tiny hearts. Thank you Clear Channel! **It's impossible to imagine how we'd achieve such a phenomenal public awareness, without your absolutely immense support.**



Phenomenal filming day for family stories and doctor films!

We had the most amazing day in November, filming our incredible families and amazing doctors – a huge step forward in the production of our brand new suite of films! Thank you to Alister, Manda, Laura and Olivia for generously volunteering to tell your special story. You were just wonderful! An emotional day, and so much shared by you all, so that other families will feel empowered, and not alone. What an incredible gift to give to help others. We can't thank you enough.

And thank you to the always brilliant Dr Jethro Herberg and Dr Harsita Patel. Expertise and brilliant leadership from both will help ensure more doctors get to know Kawasaki Disease.

We're excited to be moving this hugely important project on to the next phase now with the expert guidance and creative talent of The Animation Guys – in time for the BIG reveal on 26 January! It's our BIG day after all!

A huge thank you to every one of our supporters, fundraisers and donors, who have made this terrific project possible, including the Chemical Business Association whose mega-donation earlier this year filled our budget gap – and meant this game changing project could happen sooner rather than later.



Experts keep Kawasaki Disease on the radar

In September, we brought UK leading clinical voices together, to focus on getting Kawasaki Disease known by doctors and healthcare professionals. Experts Professor Damian Roland, University Hospitals Leicester, Professor Paul Brogan, Great Ormond Street Hospital and Professor Simon Kenny, NHSE Clinical Director worked with us to record a 'for doctors' podcast, to make sure Kawasaki Disease stays high on the radar of doctors this winter. It's especially important now, as this is when we know most cases of Kawasaki Disease will be seen in the UK and Europe.

They covered topics around spotting Kawasaki Disease, differentiating between Kawasaki Disease and other illnesses and a national perspective on NHS priorities and programmes, underpinning delivery of better outcomes for our children.

We are extremely grateful to the brilliant doctors who generously gave their time and shared expert knowledge to help protect tiny hearts. Our thanks too, to the team at NHS England who supported this project and helped us reach even more doctors. If you'd like to listen to the podcast [click here](#).



KD-CAAP clinical trial

The KD-CAAP clinical trial is well underway, investigating whether we can find a better treatment for Kawasaki Disease to reduce heart damage in children. Our role is co-investigator and we lead PPI (patient and public involvement). Many trial sites are now open across the UK and Europe, patients are being recruited into the trial and we're on programme, despite Covid! That's thanks to the simply amazing and dedicated trial team.

Our work now includes raising awareness of the trial and of Kawasaki Disease with the public and doctors (hey – that's what we do!) We also support the clinical teams involved in the trial by providing them with training resources and support information for families in their care.

Visit our **[KD-CAAP web pages](#)** to find out more, or why not follow our dedicated **[KD-CAAP Twitter account](#)** to get the latest updates.



Thank you to everyone who helped to protect tiny hearts from Kawasaki Disease on World Heart Day 2022



**WORLD HEART
FEDERATION®**

This year, 29 September – **WORLD HEART DAY** – was just phenomenal! Working with our partners at the World Heart Federation, we had the fantastic opportunity to also work alongside our wonderful supporters and many more exceptional partners, as we raised awareness of Kawasaki

Disease and children's heart health. Right from the start of September, our World Heart Day campaign focused on 'Protecting Tiny Hearts', getting Kawasaki Disease known by families, carers, clinicians – EVERYONE.

Together we shared awareness raising messages, highlighted our KD-CAAP clinical trial work, released our podcast, shared our World Heart Day Statement and highlighted Kawasaki Disease to the UK Government. All these brilliant projects and many more in this newsletter highlighted Kawasaki Disease and the urgent need to prevent heart damage in our children. We also raised over £4,000! **We are so grateful to everyone who made our World Heart Day campaign so visible and so high impact this year – truly helping to protect tiny hearts from Kawasaki Disease.**

Societi Active's Virtual 10k

Societi Active's Virtual 10K returned for World Heart Day thanks to our fabulous volunteers Hayley, Vikki and



Gayle, once again, bringing together our community. There were some incredible achievements this year with a truly inspiring fundraising effort which went along with it. Huge thanks go to Elinor and Jack, Manda and Emily and Alister for their amazing fundraisers – thank you to friends and family who sponsored them raising £2,220!

Thank you to absolutely EVERYONE who took part in the Virtual 10K and helped protect tiny hearts. A huge amount of Kawasaki Disease awareness was raised in communities throughout the UK by our participants, all in their Societi running jackets, t-shirts and running vests – fabulous!

#TeamSocieti – you're AMAZING!

To EVERYONE who has contributed in every way, no matter how large or small in 2022.... THANK YOU! Here's just a few stories from our AMAZING #TeamSocieti – that's YOU!

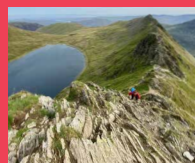
Thank you to our Facebook super supporters and top fans! Sharing our awareness raising messages across social media really does help us in our work. Thank you to Lisa, Carol, Mike, Roseann, Keisha, Natalie, Sandra and many more – you know who you are!



We are extremely grateful to Steve, Children & young people's Nurse, for his immense support on Twitter. Supporters like Steve help to build much needed Kawasaki Disease awareness and protect tiny hearts.



Even though the Swim Serpentine event was postponed, Sam still took to her local lake to swim the half mile distance! Thank you Sam for such stunning support and determination to protect tiny hearts.



Continuing his mammoth challenge to scale all 214 Wainwrights, Kevin dedicated the notorious Striding Edge route of Helvellyn to World Heart Day. Amazing! Kevin – we think you're BRILLIANT! Thank you!

Diane – an exquisitely talented artist – created this fabulous pencil drawing of Rachael's pup, Nutmeg. Diane decided to donate the fee for the work to Societi! What a simply amazing and generous gesture. A paw-fectly lovely thing to do...



Imagine running 26.2 miles in the dark, starting at 1.30am! That is exactly what Shane did! We are EXTREMELY GRATEFUL to Shane for taking on Virtual London Marathon for us once again this year.



Rachel trained hard for the Virtual London Marathon, so when she suffered an injury, we were all disappointed! But Rachel's solution?! Complete the 26.2 miles on a bike! Rachel – you're AWESOME! Thank you!

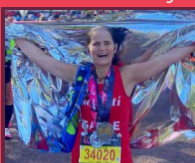


We are so very grateful to Russ for completing the Cardiff Half Marathon. He has raised an AMAZING amount of money for Societi Foundation in the process. What more can we say but WOW! And THANK YOU!!!

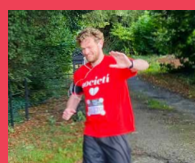
We are so grateful to Zachariah, one of our youngest supporters! Zachariah completed the Junior and Mini Great North Run for the second time (!!!), raising a huge amount of money for Societi and Welbodi Partnership. We can't thank you enough Zachariah!



We always look forward to hearing from super-supporter Julie! Julie got in touch to let us know she had donated funds following a pumpkin challenge and hot dog supper. Julie we are so grateful for all you continue to do!



THANK YOU to Gayle for all you continue to do! A part of the Societi Active committee, Gayle also ran London Marathon and held a business fundraiser for Societi this year, raising Kawasaki Disease awareness!



Ben ran the virtual London Marathon for Societi Foundation and Kawasaki Disease awareness. We're so moved that Ben chose to run his first marathon for our charity. He absolutely smashed it!! And we're so grateful.



A very Merry Christmas to all our supporters!

Huge thanks to EVERYONE who has helped to raise awareness of Kawasaki Disease throughout the year. We're so fortunate to have the immense support of so many supporters – all determined to make change happen – to protect tiny hearts.

Every single achievement has been the result of the tireless work of many, simply wonderful people. YOU! THANK YOU for making 2022 an incredible year for Kawasaki Disease awareness. Every single contribution has made a difference to children who have been or will be affected by Kawasaki Disease!

Our best wishes for a peaceful Christmas to all our supporters. By supporting Societi, you've protected children's hearts throughout 2022 and we look forward very much to doing it all again – and more – in 2023! Happy Christmas.

International Kawasaki Disease Awareness Day 2023!

It's time to get EXCITED!!! Our most important day in Societi's calendar is not very far away...

THANK Kawasaki Disease

International Kawasaki Disease awareness day is on **26 January** and we've been planning things for some time now! Have a look below to see just some of our plans and ways you can get involved:



Help us shine a light on Kawasaki Disease across the UK!

You may remember the Mersey Gateway Bridge, Nottingham City Hall, Ness Bridge and many more landmarks, illuminated bright pink and red on International Kawasaki Disease Awareness Day 2022 – beams lit up the sky and it was breathtakingly beautiful!

We want to make an even bigger impact for Kawasaki Disease awareness day in 2023, lighting up as many landmarks as possible for Kawasaki Disease awareness! Can you help us shine a light on International Kawasaki Disease Awareness Day 2023? Speak to your local council to ask if they can light up your local landmark and get THOUSANDS of people in your area talking about Kawasaki Disease? Get in touch at info@societi.co.uk



Team LEWIS – a HUGE HELPING HAND to protect tiny hearts

Earlier this year, we were contacted by fabulous Team LEWIS, an expert, international public relations and digital marketing company with an exceptional offer of help. After having personal experience of Kawasaki Disease and seeing the devastation it can cause, Team LEWIS colleague Sian donated £1,000 – just amazing! But the help hasn't stopped there...

We also received an offer of help with our International Kawasaki Disease Awareness Day campaign. Team LEWIS really are the experts when it comes to all things in publicity and communications – as we're so exceptionally lucky to have their help and guidance as we approach our BIG day. After meetings and brainstorming sessions Team LEWIS put forward some incredible suggestions for UK-wide publicity around International Kawasaki Disease Awareness Day. We are so incredibly excited and will reveal all very soon – **watch this space!**



Look out for our new family and doctor films

We've been planning our new family and doctor films for some time and we're getting VERY excited for their launch as International Kawasaki Disease Awareness Day approaches. Working with The Animation Guys who produced our new awareness animation launching in January 2022, our new films are taking shape – right now! The amazingly successful studio day with our families and doctors was hopefully a great pre-cursor to how beneficial these films will be to families affected by Kawasaki Disease and to clinicians as valuable learning resources too! Keep a look out for their release this January 26!

Get involved! We're here to help make your event a success!



Getting Kawasaki Disease known WILL reduce the rate of heart damage in affected children. To push our Kawasaki Disease awareness raising messages as far and as wide as possible, **WE NEED YOUR HELP**. Hold a coffee morning, a cake sale, a wear red day... The possibilities are endless! Download our awareness raising poster pack to get some ideas. If you'd like to raise awareness just **get in touch**. We'd love to hear from you and we'll do all we can, with tonnes of awareness raising materials ready to send you, to help you make your event a success!

THANK YOU to ALL our regular donors!

Regular donations mean we can plan ahead for our work, raise awareness and commit to long-term projects. We are so grateful to our wonderful supporters that make a regular donation to Societi Foundation – **Gemma, Hayley, Roseann, Carole L, Mr and Mrs S, Craig, Pat and Donna** to name just a few – amazing supporters who set up regular donations and fund our work. Our promise to you, in return, is to keep getting Kawasaki Disease known! We hugely appreciate your generous commitment to our cause. THANK YOU!

Want to make a regular donation? There are a variety of different ways you can set up a regular donation. JustGiving, Charities Aid Foundation, Facebook and direct bank transfer are all ways to donate regularly. See below for details.

Ways to donate



JUSTGIVING – A JustGiving fundraising page is great for sharing your story and keeping track of how much you're raising. For one-off donations or to set up a regular donation, you can visit our JustGiving checkout here without fees.



CHARITIES AID FOUNDATION – We're registered with Charities Aid Foundation. Through their website you can securely make donations to Societi including regular donations without fees.



FACEBOOK – You can now make a donation through our Facebook page – including setting up a regular donation. Facebook cover all fees for donations and fundraisers made to charitable organisations and you can claim Gift Aid too!

MAKE A PAYMENT DIRECT TO US! If you'd like to avoid fees you can make a direct payment to our account, either by cheque or BACS transfer. You can also set up a standing order to make a regular donation. **CONTACT US** for details

Or if you'd like to make a one-off Christmas gift to Societi why not **TEXT YOUR DONATION TO 70450** – Grab your phone and text SOCIETI 5 to donate £5 or SOCIETI 10 to donate £10 to 70450. Simple!



Use code
AMAZING22
for 25% discount

Bag some merchandise to raise awareness of Kawasaki Disease!

Raising awareness of Kawasaki Disease is our number one aim and raising funds allows us to do this to the best of our ability. That's why Societi merchandise is so important. It allows us to generate much needed funds and at the same time enables our supporters to raise awareness of Kawasaki Disease where ever they are in the world! Win, win!

We love designing new Societi goodies to put up for sale on our online shop! Recent additions to our shop include our GORGEOUS thermal travel mugs. They are just the perfect Christmas present, the perfect office accessory, the perfect accompaniment to your home desk too.... Or just in the cupboard... for your special cuppa!!

Another new addition to our online shop won't be around for long but we think it's a product worth investing in, so pop it in your basket sooner rather than later – the Official 2023 Societi calendar! It's really rather special this year.... and that's because we invited our supporters to include their special birthdays in the calendar and, with so many people wanting to be involved, it really was a labour of love to create. But oh, so worth it! The calendar really is a very special tribute to the wonderful people in our Kawasaki community.

Of course, all of our other merchandise is still available too. From bags to hoodies, pens to swim caps, tea towels to running vests and much more.

As a thank you to our supporters for being so utterly amazing throughout the year, we'd like to offer you a special treat – 25% discount off your shopping with Societi! Have a good browse of our shop, select your favourite items, add them to your basket and simply use the code AMAZING22 to receive 25% off the total.

