

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



Welcome to our 2021 Christmas Newsletter!

What can I say... we have had another exceptional year!! We are still in such uncertain times – but like the world over, we have adapted and continue to make huge advances in the landscape around Kawasaki Disease. I want to send a warm welcome to our new supporters that have found Societi Foundation this year and a massive thank you to our long-standing supporters too – you are the beating heart of our charity, and we are so grateful for your determination and passion to help get Kawasaki Disease known.

Through our work together, awareness of Kawasaki Disease has just grown and grown. With your support, we've reached many more people this year, and raised thousands of pounds that will help thousands of children.

I hope you enjoy reading this Christmas newsletter – our recap on a brilliant year of fabulous fundraising and incredible work of so many phenomenal Societi supporters. TOGETHER we are making change happen, people are getting to know Kawasaki Disease and that means tiny hearts WILL be protected! We work hard at Societi HQ to improve outcomes for children affected by this serious disease and we're always looking for new opportunities and partnerships. This year, particularly, has been a milestone year – and because of a huge injection of support we will see another step change in Kawasaki Disease awareness as we start 2022 (find out more below....exciting!) I very much hope I can count on your support into 2022 as we continue together, doing everything in our power to protect tiny hearts from Kawasaki Disease.

Merry Christmas and Best Wishes, Rachael, Societi Founder

Societi awarded Randal Charitable Foundation grant!



We are so excited and just delighted to announce the start of our 3-year children's hospital partnership programme – something we've had as a goal for some time! And it's thanks to investment and support from the Randal Charitable Foundation who have awarded us a grant! This programme will include vital work to dramatically improve Kawasaki Disease knowledge and early disease identification by doctors, to shorten diagnosis times and enable rapid treatment of Kawasaki Disease – the leading cause of acquired heart disease in UK children.

This fantastic opportunity, thanks to the Randal Charitable Foundation is a milestone moment for our charity and will accelerate our work dramatically. Such powerful support means we can really drive forward with knowledge building among children's doctors, who will then be equipped to ensure timely diagnosis and improved care for affected children. Our goals include a reduction in both loss of life from Kawasaki Disease and in the rate of heart damage in children over the course of this fabulous partnership programme. YOUR support, as we match fund this programme, has been KEY to our ability to secure this investment! THANK YOU for playing such an important part in our work – and sharing in our success! If you'd like to fundraise or donate in 2022 to help this transformational programme, please get in touch! Find out more about the Randal Charitable Foundation and the amazing work they do [here](#).

Kawasaki Disease Symptoms



Persistent fever



Cracked lips /
'strawberry' tongue



Rash



Swollen fingers/toes

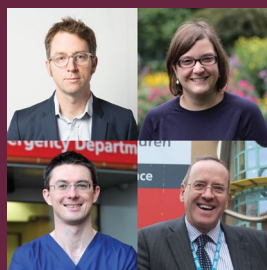


Bloodshot eyes



Swollen glands

Bite sized podcasts released



Fabulous contributions from our Scientific Advisory Board allowed Societi to release a 4 part mini-series of podcasts, hosted by Founder, Rachael.

Members of our Scientific Advisory Board – leading physicians and leading Kawasaki Disease experts – generously gave their time to help produce the podcasts which include vital information, all about Kawasaki Disease. Titles in the series include; 'Presenting the Facts and Dispelling the Myths', 'What Everyone needs to know about Kawasaki Disease', 'The Latest Kawasaki Disease Research' and 'Protecting Hearts into the Future'. You can access the podcast mini-series [here](#).

And, if you fancy a read rather than a listen, you can download transcripts of the podcasts too – you'll find them [here](#).

Generously sharing stories



We know sharing family stories is an extremely powerful way to raise awareness of Kawasaki Disease. AND in doing so it undeniably brings hope to those newly affected, inspiration and an insight into what the continuing journey for families affected by Kawasaki Disease might hold.

We have put together a collection of Societi supporter's stories which can be read [here](#).

We are deeply grateful to the families that have generously shared a part of their unique Kawasaki Disease journey to help grow understanding, awareness, and knowledge about Kawasaki Disease. THANK YOU!

Would you like to share your story? We have created a short online form [here](#) for you to fill in. We hope it will make it really simple and easy for you to put your thoughts onto 'paper'.

Thank you to everyone who helped to protect tiny hearts from Kawasaki Disease on World Heart Day 2021

We just love World Heart Day! It gives us an amazing opportunity to work with our fabulous supporters, brilliant partners and a whole host of exceptional organisations to raise awareness of Kawasaki Disease and heart health. World Heart Day 2021 was no exception! We ran our campaign 'Let's Protect Tiny Hearts' throughout the entire month of September and our partners and supporters #TeamSocieti worked incredibly hard to make 29 September – World Heart Day – a fantastic success. Our campaign focused on raising awareness of Kawasaki Disease with families, clinicians and just about EVERYONE who can make a difference and help to protect tiny hearts.

Thank you to every single one of our supporters and partners who made World Heart Day such a special day for our children – by helping to protect tiny hearts from the #1 cause of acquired heart disease in UK children. Together we are getting Kawasaki Disease known – we WILL improve outcomes for our children and improve care in the UK for those who have already been affected. THANK YOU!



Thank you to all our amazing runners!

We want to say a huge thank you to all the people who have put their bodies through absolute exhaustion to help protect tiny hearts this year!

THANK YOU to our Brighton Marathon heroes – Phil Jack and Si. THANK YOU to Rebecca for completing the Great North run on the very same weekend! And THANK YOU to our London Marathon superstars – Gayle, Dave, Shane, Jack and Andrew! We know just how much time and effort goes into training and fundraising for challenges like this – the commitment is monumental, and we are so grateful. We can't thank you all enough for taking on these HUGE challenges – the impact you have made WILL make a difference and it will help to change outcomes for children affected by this serious and life-threatening disease.



Societi Active's Virtual 10k

Societi Active's Virtual 10k returned for its 3rd year in a row, thanks to our incredible volunteers Hayley, Vikki, Gayle and Lucy who dedicate hours of their time to organising, planning and running the event. Each year, our virtual 10k event is even more successful than the year before – and this year was monumental. This was our biggest Virtual run yet with over 80 supporters taking part and well over £3,650 raised to help raise awareness of Kawasaki Disease! Thank you to EVERYONE who took part!

A special thank you too, to Sarah and her family, who completed their Societi Active virtual 10k and kindly asked for donations via Facebook making an incredible £1800 – AMAZING!!!

Aside from the important funds raised by the Virtual 10k a huge amount of Kawasaki Disease awareness was also raised in communities throughout the UK (and even as far afield as Italy!) by our participants, all in their brand new Societi running shirts – simply stunning!

If you'd like to take part in one of our future Societi Active events, make sure to follow our dedicated Societi Active Facebook page to find out what's coming up! You can find the page [here](#).



Thank you #TeamSocieti!

We never cease to be astonished by the absolute dedication and simply astounding support from #TeamSocieti. Circumstances have continued to be difficult for everyone this year, but that hasn't stopped you taking on fantastic challenges, raising much needed funds and raising awareness of Kawasaki Disease. To EVERYONE who has contributed in every way, no matter how large or small.... THANK YOU!!!



Coast to Coast Ultra Challenge

Steve took on this HUGE challenge with his dear friend and teammate Tom – the gruelling South West Coast to Coast Ultra Challenge. Huge Kawasaki Disease awareness raised and huge fundraising goals reached – this is an inspirational achievement. Quite brilliant. The Cove family are long standing Societi supporters, and not a year passes without a notification of a new challenge being taken on by a member of their family. THANK YOU ALL!



Reaching new heights for Kawasaki Disease

Kevin and his team Ben, Paige and Harry – colleagues at Manchester airport – reached the summit of the UK's highest mountain – Ben Nevis – and raised an incredible £1000. Kevin and the entire #TeamLyons family have continually supported Societi over the years – but we think this incredible challenge reached new heights(!) THANK YOU #TeamLyons



Cycling up the Alpe D'Huez – 3 times!

Alister raised a remarkable £2115 for Kawasaki Disease awareness with the INCREDIBLE undertaking.... to cycle up the Alpe D'Huez – 'cycling's most famous climb the sport has' – three times consecutively (on Zwift, a virtual training world) AND HE DID IT – in a variety of costumes too! Alister and Ali are simply brilliant supporters who have made an amazing impact for Societi, over many years now. THANK YOU!

Our fastest growing fundraiser EVER

Thank you to the remarkable Lenehan Family! Chris, John and Callum took on the huge challenge of running a combined 300k in April. When we were notified of the new fundraiser, never could we have imagined just how quickly the funds would stack up! The family have since gone on to raise over £5,000 for Societi – just astounding! We were quite blown away, and deeply grateful to Chris, Loren, John and Callum and all their incredibly generous friends and family – who have donated. THANK YOU!

Take part in our Diagnosis Day research poll



Societi is working to collect information as part of an important update to a research project conducted in 2018

– on **YOUR EXPERIENCE OF KAWASAKI DISEASE DIAGNOSIS**. It's clear the diagnosis experience varies from family to family and we need to understand more about just what is happening when our children are first being diagnosed. If fewer misdiagnoses are happening today compared to our research in 2018, that means we can continue to focus our training in those areas we have been working on since that time.

Whether you had an immediate Kawasaki Disease diagnosis or an initial misdiagnosis, your reply will help direct and focus our work to benefit families affected by Kawasaki Disease in the future. If your child was diagnosed with Kawasaki Disease in the U.K. between April 2018 and March 2021, we'd really like you to complete our short survey. We will use the anonymised information we gather to highlight any ongoing challenges families are facing if diagnosis is being delayed or confused with other illnesses. [Click here to complete the Diagnosis Day research poll](#).



Clinical trial update

Societi is continuing in its role as co-investigator for KD-CAAP – a clinical trial for acute Kawasaki Disease treatments. The trial is well underway, with fantastic achievements reported including in-country protocol adoption, site openings, patient recruitment, clinical network establishment and more – ahead of programme. Despite the unrelenting backdrop of Covid and the differing challenges this has presented across participating countries, significant progress has been made. Success to date is testament to the expertise and dedication of the team led by Scientific Advisory Board members Professor Despina Eleftheriou and Professor Paul Brogan and a fabulous and diverse team from statisticians to clinicians. 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.

Ways to donate

JustGiving

[JUSTGIVING](#) – A JustGiving page is great for sharing your story and keeping track of how much you're raising. Fees do apply!



[CHARITIES AID FOUNDATION](#) – We're registered with Charities Aid Foundation and through their website you can securely make donations without fees.



[FACEBOOK](#) – You can now make a donation through our Facebook page. Facebook cover all fees for donations and fundraisers made to charitable organisations and you can claim Gift Aid too!



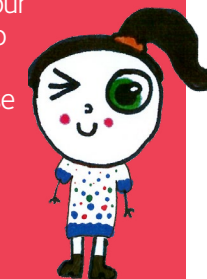
Text Giving – The newest and possibly easiest way to donate. Just grab your phone and text SOCIETI 3 to donate £3, SOCIETI 5 to donate £5 or SOCIETI 10 to donate £10 to 70450. Simple!

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. [CONTACT US](#) for details

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!

Want to make a regular donation? [Visit our JustGiving page](#)

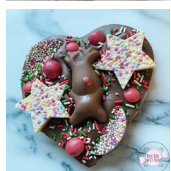


Our HUGE THANK YOU to #TeamSocieti - that's YOU!

We rely 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!**



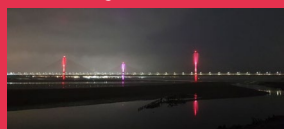
Merry Christmas to ALL our Supporters



We LOVE Christmas at Societi and we've been busy decorating our Christmas Tree with these beautiful, hand-crafted glass and ceramic Societi decorations. This year we wanted to create something a little bit special to offer you, a keepsake... a celebration of just how far we have come in getting Kawasaki Disease known. We love them and, as they sold out in under 24 hours (!), we know you did too! They are a reminder of what it means to be part of #TeamSocieti - a passionate and determined group of people, dedicated to protecting children's hearts. And, did you see our limited edition chocolate hearts made especially for Societi Foundation!? These carefully designed wonderful treats were so popular, selling out very quickly too. Thank you to everyone who bought a decoration or chocolate heart - or both! Every single item sold this Christmas is helping to protect children's hearts. The money made goes right back into raising awareness of Kawasaki Disease. **THANK YOU!**

International Kawasaki Disease Awareness Day 2022

As so many of you will know, our biggest and most important day is not very far away... International Kawasaki Disease awareness day is on **26th January** and to ensure we make a BIG impact; plans start NOW!!!! Momentum is building and we are making big inroads in getting Kawasaki Disease known thanks to the incredible support from YOU as well as the many activities that are happening behind the scenes at Societi HQ.



You may remember the Mersey Gateway Bridge and the Council House in Nottingham illuminated bright pink and red on Kawasaki Disease Awareness Day 2021 - beams lit up the sky and it was breathtakingly beautiful! We want to make an even bigger impact for Kawasaki Disease awareness day in 2022, we want to light up as many buildings and landmarks as possible for Kawasaki Disease awareness and we've been working hard to try to make that

happen. Will you help us shine a light on Kawasaki Disease? Can you speak to your council to ask if they can light up your local town hall, cathedral or 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!

International Kawasaki Disease Awareness Day is the BIGGEST day of the year for Societi! We're so, so excited and we'd love you to join us and help make January 2022 the BIGGEST campaign for Kawasaki Disease awareness yet!

THANK YOU #TEAMSOCIETI 2022 HERE WE COME!!



We need your help...

... to get Kawasaki Disease known this Awareness Day! We know the current situation means it isn't easy to make plans and everything is a little bit unpredictable. Fundraising has been hit hard - for all charities! But we must keep pushing on with our life saving work. With still so much confusion around Kawasaki Disease and PIMS-TS we need to get Kawasaki Disease known!! January is our most important month, in the build up to Kawasaki Disease awareness Day on the 26th January. With

many supporters wondering how and what they can do to support charities close to their hearts, we have come up with some ideas that you can do, to fundraise and raise awareness of Kawasaki Disease in January from your home:

FUNDRAISE WITH YOUR FAMILY - and challenge your children to raise money by completing household tasks like cooking, washing up and tidying their rooms for a donation to Societi Foundation. (We'll be sure to send them a little Societi 'goodie' as a thank you too!)

VIRTUAL WORKOUT - Could you lead an online fitness class through Facebook Live or Instagram Live? It could be yoga, zumba, pilates or aerobics. Set up a Just Giving page and ask for a donation from friends and anyone within your community that would like to attend.

BE A SOCIAL MEDIA AMBASSADOR - Share, like or comment on any of our social media posts. Simply interacting with our updates, images and videos we share; liking, retweeting, sharing or commenting on them, alerts all the people in your personal network - helping to spread our vital message to even more potential supporters.

VISIT THE SOCIETI SHOP - Order a pack of Societi Foundation wrist bands to give to your friends and family to wear. If you have a Societi hoodie or a T-shirt - wear it when you're out and about. Buy a super Societi jute bag and take it out when you shop to get Kawasaki Disease known. You can find the Societi shop [here](#).

All these ideas and more can be found on our Fundraising From Home resource [here](#). Please let us know if you try any of these ideas out - or any of your own ideas too! Please let us know and share them with us on social media! Let us know how we can help you and we'll always try to provide you with what you need.

Thank you for all your support!

