



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



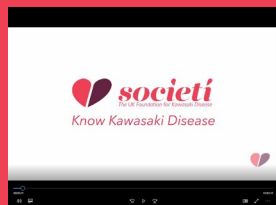
Welcome to our Christmas Newsletter 2020!



It's been an exceptional year. Coronavirus has impacted our lives deeply – and brought Kawasaki Disease into the headlines – with world leaders talking about it. We were flooded with questions and concerns and it was all systems go at Societi HQ to ensure trusted facts were shared quickly. We called on YOU #TeamSocieti to help and without hesitation YOU stepped up; accelerating our work to raise awareness of Kawasaki Disease – YOU raised thousands of pounds for our crisis appeal and got our awareness message out there – thank you!

When I think about 2020 and set aside the worry and uncertainty it brought, what persists is a word that lays at the heart of our charity – community. In the pandemic chaos, a stronger sense of community spirit, a stronger feeling of being connected and of kindness is so very clear to see. I remain deeply grateful for your unrelenting support – and I am proud of #Teamsocieti; our dedicated community that works so hard to protect children from the devastating consequences of Kawasaki Disease. We have achieved so much this year, our impact has just grown and grown. It's just fantastic.

I hope you enjoy reading about the incredible work of so many phenomenal Societi supporters in our Christmas newsletter. To everyone who has supported our charity this year, you have my personal and heartfelt thanks. Together, we truly are making change happen. There's much more to be done and I very much hope I can count on your support into 2021 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's powerful new campaign video

We recently released our powerful and hard-hitting campaign video featuring parents, whose children have been affected by Kawasaki Disease, sharing their sincere plea, to 'Know Kawasaki Disease' – the leading cause of acquired heart disease in UK children. We're delighted at how successful the video has been – you've been busy watching and sharing – and it's doing an amazing job raising awareness. If you haven't seen it yet, you can [watch it here!](#)

On average children are misdiagnosed 2-3 times before receiving a correct diagnosis of Kawasaki Disease. Delay in diagnosis and treatment means significantly increased risk of lifetime heart disease. Our campaign video highlights the devastating effect Kawasaki Disease can have on families.

We are so grateful to the simply incredible families featured in our 'Know Kawasaki Disease' film! It isn't always easy to share experiences about the devastating consequences of this serious disease. We want to say a HUGE thank you to everyone who volunteered to take part. Our 'Know Kawasaki Disease' video will help grow understanding, awareness, and help us protect even more tiny hearts.



Heart to Heart success!

We had an unstoppable Kawasaki conversation with our WONDERFUL Scientific Advisory Board in September, marking World Heart Day with a very special Heart-to-Heart virtual round table. Our amazing team of expert clinicians answered YOUR questions, talking through topics that you want to know about – like long term issues, aspirin and lifetime care.

At Societi, sharing expert, up-to-date and FACT-based knowledge to families and carers of children affected by the all-too-often devastating consequences of Kawasaki Disease, remains at the *top* of our agenda. Our HUGE thanks to our Scientific Advisory Board – all giving their time generously as volunteers to support Societi and our families, in an astonishingly busy period for them.



Foyle Foundation help fund new portal

We were delighted to receive simply BRILLIANT NEWS this autumn – that we would receive a grant of £9,100 from The Foyle Foundation – an independent grant making trust that distributes grants to UK charities. The grant is earmarked for our new and exciting project – "My Societi" Young People's Portal.

"My Societi" will be a hub of online info, designed for and by young people who've been affected by Kawasaki Disease and want to know more. Backed by doctors, it'll be content that young people and parents can trust.

When launched, young people will be able to ask our experts questions, listen to podcasts and watch videos made especially for "My Societi". We're now in the advanced stages of creating this resource and moving quickly with HUGE thanks to Form Digital and O-Street.

We're set to launch the "My Societi" on Kawasaki Disease Awareness Day – 26 January 2021! That's not far away! We are hugely grateful to the Foyle Foundation for their support and shared pledge to build a resource that will provide essential and trustworthy information to young people, tailored to their specific needs.



Kawasaki Disease Symptoms



Persistent fever



Cracked lips / 'strawberry' tongue



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands





A truly amazing World Heart Day

World Heart Day 2020 was an utterly exceptional day for Kawasaki Disease awareness. So many people and so many partners contributed – many throughout the entire month of September — as we planned, prepared and worked on content for 29 September 2020 – World Heart Day itself! This year our campaign theme was “FACTS not fear”. We highlighted the urgent need for more public awareness and investment to raise awareness of Kawasaki Disease. We are particularly grateful to everyone who contributed this year – there was so much awareness raising activity going on! Below are just a selection of the phenomenal contributions made by fabulous #TeamSocieti. If you'd like to know more, you can read our World Heart Day impact statement [here](#).



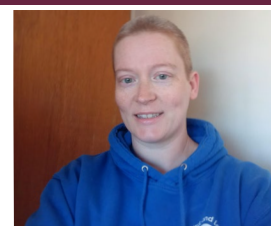
Societi Active's Virtual Victory!

Our fabulous Societi Active Committee, Vikki, Hayley, Gayle and Lucy worked so hard to organise the World Heart Day Virtual Run. We were absolutely overwhelmed by the success of this year's event.

69 entrants to the virtual race and linked events raised nearly £4,000 AND... not only that – all those participants ran their individual races up and down the UK raising much needed Kawasaki Disease awareness in their gorgeous new Societi Active t-shirts. We are immensely grateful to every member of #TeamSocieti for the astonishing effort put into the event to make it such a massive success – THANK YOU!

Hair-awareness Raising!

As a member of Ladies Circle, Lizzie has been a firm supporter of Societi since we were named as their presidential charity of the year in 2019. On World Heart Day, Lizzie made a phenomenal contribution to raising awareness of Kawasaki Disease, going to extreme lengths by shaving her hair to raise funds. Lizzie also donated her lovely locks to The Little Princess Trust. Thank you Lizzie for such an amazing gesture and for getting Kawasaki Disease known.



Lindsay's Brilliant Bake Sale

A HUGE thank you to Lindsay and her friends and family for holding an outstanding bake sale for World Heart Day. A bake sale can be hard work at the best of times, but add to that Covid-19 restrictions and social distancing rules and you've got a big task on your hands! Despite this, Lindsay and friends did a fantastic job and their cakes looked delicious! The event raised a huge amount of awareness for Kawasaki Disease and an eye-watering £850. It's safe to say that the day was a wonderful success! Thank you to everyone involved!

Miles of Awareness

Super-supporter Laura and friends took on their biggest challenge yet this year! On 12 September they walked from Weymouth to Swanage on the South West Coastal path – just over 30 miles of stiff climbs, on jaw-dropping coastal trails. For all their hard work they were treated to some of the most stunning coastal views – the pics were stunning! They raised an incredible £425 for Societi – AMAZING!! Thank you Laura and your wonderful friends for taking on such a huge challenge – and for being so determined to protect tiny hearts – every step of the way!



Fantastic Fundraisers!

It wasn't just for World Heart Day that #TeamSocieti got busy raising awareness and funds. Even through these tremendously difficult times, you've continued to go above and beyond to ensure that Kawasaki Disease gets known. Support from YOU is just vital if we are to carry on our work. If you're reading this – and you've been there for Societi through 2020 as a fundraiser – Thank you! Because YOU make our work possible!



CONGRATULATIONS ZARA YOU DID IT!!!!!!

You may have seen us talking about Zara's simply AMAZING challenge of running 2020km in 2020 for Kawasaki Disease awareness aiming to raise a phenomenal £2020 along the way! We're delighted to let you know that Zara completed her mammoth challenge at the end of November – a whole month early. Not only that, but Zara has also managed to smash her target, raising a HUGE £2,500! We can't thank you enough Zara! Her resilience and steadfast commitment to completing this challenge and raising awareness of Kawasaki Disease is truly inspiring and what a simply remarkable legacy to her dear friend Liz.

Taking awareness to great heights!

Emma, brother Karl and brother-in-law Paul were due to hit the skies in April but due to covid-19 their Skydive was postponed and a new date was scheduled for 30 August. This simply fantastic trio finally jumped 15,000ft for Kawasaki Disease awareness and WOW – we are impressed. Just look at this BREATHTAKING picture! A massive thank you to Emma, Karl and Paul and to EVERYONE who made a donation. The group raised a phenomenal £2,300 – BRILLIANT!



Fundraising from home

The current situation is affecting all our lives in lots of different ways and now more than ever your support is so important to us. If you'd like to start fundraising for Societi Foundation, or maybe your existing fundraising plans have been postponed or cancelled, we put together a few ideas for virtual fundraising – all that you can do from home instead! You can read the full guide [here](#) but we've put a few of our favourite ideas here too – get in touch and let us know how you'll be fundraising! We'd love to feature you on our social media!



Declutter & donate

With Virgin Money Giving and Ziffit. You might have seen our recent posts on Facebook about this brilliant idea. It's an opportunity to clear out your bookshelves and cupboards and turn your unwanted items into valuable donations for Societi Foundation. See [here](#) for more details.

Donate your commute

We know times are tough right now and not everyone will be able to do so, but if you are able to, can you donate the price of one day's bus/train/tube ride to help raise awareness of Kawasaki Disease and protect children's hearts? **TEXT COMMUTE4HEARTS TO 70450**



Donate your birthday

If you can't go out to celebrate your birthday, why not ask your family or friends to make a donation to Societi in your name. It is as simple as following this link. It is an easy and accessible way to fundraise and raise awareness of Kawasaki Disease. If you want to donate your birthday to protecting tiny hearts – YOU CAN!

Amazon Smile shopping

Your last-minute Christmas shopping can raise money for Societi – at NO cost to you! Shop on Amazon via Amazon Smile – smile.amazon.co.uk (same products, same prices, same service!). Choose Societi Foundation as your nominated charity and we'll receive a small percentage of what you spend, each time you shop. A huge thank you to everyone who already supports us when they shop online!



KD-CAAP Clinical Trial begins

We're so excited that KD-CAAP, an exciting trial to try and find improved acute treatments to protect tiny hearts is now underway!

KD-CAAP is a clinical trial being run by doctors to find out whether adding another treatment, right at the start of a child's treatment for Kawasaki Disease, will improve outcomes and reduce serious heart damage – compared to the standard treatment for Kawasaki Disease which children get today.

We are thrilled to share the news the trial has begun recruiting and Societi is closely involved as a co investigator. The trial is being led by a team of UK doctors and was designed by UK doctors with help from UK families.

The trial includes hospitals right across Europe – in 15 European countries and 57 hospitals altogether – take a look at the map to see where the trial is happening throughout Europe – or better still visit our new dedicated web pages where you can find lots more information and get updates about the trial.



Getting Kawasaki Disease known in UK Parliament

We continue to work hard to get our voice heard in the UK Parliament. Societi Foundation, with exceptional help from Lexington Health communications team, contacted a staggering 55 UK MPs in the lead up to World Heart Day. We've had some BRILLIANT conversations with

MPs across the UK who recognise the urgency of getting Kawasaki Disease known.

These conversations have led to MPs asking questions to Government – in the House of Commons – about things like what steps are being taken to raise clinical and public awareness, access to suitable treatment and the effects of Covid-19 in the number of patients receiving treatment for Kawasaki Disease.

If children in the U.K. are to get the rapid treatment they need, the profile of Kawasaki Disease needs to be much higher in the minds of politicians and decision makers – recognising the increasing risk to children's heart health that Kawasaki Disease presents.

Kawasaki Disease needs the Government investment that other serious children's diseases have – so we can raise awareness and prevent life long illness. We're hopeful that we can. We will make progress and we will keep having these important and powerful conversations until we do – watch this space for updates!

THANK YOU to ALL our regular donors!

Carol & Gareth
Hayley
Andy & family
Gemma
Carole
Peter
Julie
Amy
Jenny



Our regular donors are regular heroes! We deeply value these quietly made, precious contributions which bring us certainty in some of our income – and which really underpin our ability to carry on our work – THANK YOU!

Want to make a regular donation?
Visit our [Virgin Money Giving 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 just LOVE Christmas at Societi and we've been busy decorating our new interactive Christmas Tree with baubles just for you! For every donation you make this festive season, we'll dedicate a bauble to ****YOU**** on our [Societi Christmas tree](#)! Make your donation and within a day you'll be able to click on the baubles and find yours! And, did you see our limited edition chocolate Societi reindeer? These were available on our shop during November. They were so popular that by December they had all sold out! But we couldn't resist sneaking a pic of them into the newsletter - they are just too cute! If you didn't manage to get a Societi reindeer in time, why not get an official Societi calendar instead - they'll last a lot longer than the reindeer - a whole year in fact - and they look just as good!



Brighton Marathon

This year really has been a tough one for everyone. Not least for our Brighton Marathon runners. With the race postponed (twice) and now scheduled for September 2021, our runners have had to get their heads and their bodies around constantly moving training targets - something which is not easy. We're so excited for September 2021 when all their dedication, hard work and determination to complete the marathon will come to fruition.



Share your story

An important aspect of the information we share on our website is that of other's personal stories about their Kawasaki Disease experiences. Whilst no two cases of Kawasaki Disease will ever be the same, we believe that knowing someone is out there who has had similar experiences you can relate to is hugely helpful - especially when newly affected by Kawasaki Disease. If you'd like to share your story about your families experience with Kawasaki Disease to help others, get in touch.



Ways to donate!

We're often asked about this! So here's a rundown of 6 easy ways.



VIRGIN MONEY GIVING - Create your own fundraising page through our [Societi Page](#) and add your story. You can even claim Gift Aid on your donation!

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



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!

International Kawasaki Disease Awareness Day - 26 January 2021

It's the BIGGEST day of the year for Societi! We're so, so excited to get going and we'll be building up awareness throughout the whole of January! We'd love you to join us and help make January 2021 the BIGGEST campaign for Kawasaki Disease awareness yet! Get involved and make plans on the actual day or anytime during January, that doesn't matter! Let us know what you have planned - and [get in touch](#) if you need fundraising packs or info!

If you're stuck for ideas of what to do for Awareness Day, then look no further! Our amazing Societi Active committee have been busy again, organising a new challenge. Join them on a massive awareness raising journey, clocking up miles throughout the UK to a distance equivalent of Societi HQ to Tokyo - the birthplace of late, great Tomisaku Kawasaki who first identified Kawasaki Disease. That's a humongous 5,885 miles! Participants can run, walk or cycle their way throughout January, adding their miles to the group total - let's see if we can get to Tokyo! We'll be posting more details about this soon - so keep an eye out on Facebook, Instagram and Twitter!

Shine a light on Kawasaki Disease - If you're really not the active type and are still wondering how you can raise awareness of Kawasaki Disease for Awareness Day, why not help us light up the UK for Kawasaki Disease awareness? On 26 January the Mersey Bridge and the Nottingham Council House will both light up pink to highlight Kawasaki Disease (we can't wait to see the pics!!) - 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!

Whatever you decide to do for International Kawasaki Disease Awareness day, get in touch and let us know - we'd really like to know and we'll always help out where we can.

