team societi news

We are the UK Foundation for **Kawasaki Disease**

Societi Christmas newsletter 2023
societi.org.uk

Donate here!
What have we been up to?
What have YOU been up to?
Get involved!

Welcome to our Christmas newsletter!

WOW – what a year 2023 has been! With your support we've made the BIGGEST impact ever! We really are on the way to getting Kawasaki Disease known. Tiny hearts are now safer from Kawasaki Disease than ever before, thanks to YOUR help.

It's been a year of making impact in so many different ways – and this newsletter aims to share just a few of the many exciting ways we've been making a difference together, right across #TeamSocieti. Thinking about spreading our influence as we grow, I was excited to join the Clinical Studies Group (U.K.) for Paediatric Rheumatology this year, which looks at the research needs for children's rheumatological illnesses. You might be wondering "Why rheumatology, Rachael?" It's because Kawasaki Disease is the second most common vasculitis in children. Vasculitis is a rheumatological condition which means it causes swelling of the blood vessels. So, when Kawasaki Disease first starts it is a rheumatological illness. In far too many children, it progresses to be the cause of heart disease, because it can cause damage to the blood vessels of the heart. This group provides us with an opportunity to lay more foundations for a greater focus for Kawasaki Disease research in the future. YOUR support is central to making sure we can contribute to fantastic projects like this – so THANK YOU!

I hope you enjoy our Christmas newsletter. I continue to be so inspired by all that's being achieved! We can't do all this without you – so I truly hope your New Year's resolution will include carrying on the AMAZING support you give Societi, in 2024...! Meantime, have a wonderful Christmas and let's make 2024 our best yet – together, we will!

Merry Christmas and my very best wishes for the year ahead. Rachael, Societi Founder

YOU helped us reach the RCGP conference – THANK YOU!

Back in April, we shared our Spring Supporter Survey, as we wanted to hear more from YOU – to understand your thoughts on where we should focus and the support that you want us to offer.

We received some amazing feedback and suggestions which led us to exploring more GP awareness! YOU told us that you want us to target GPs, and grow their awareness. What better way than to attend the Royal College of General Practitioners (RCGP) annual conference, attended by hundreds of GPs and healthcare professionals each year!

Without funds set aside for this, we knew we needed to launch a fundraiser to help us get there... Well #TeamSocieti, we'd like to say a HUGE THANK YOU! You raised a whopping £2,644.00, which allowed us to attend and grow Kawasaki Disease awareness at this amazing event!

The 2-day conference was a huge success, with our team speaking to at least 200 healthcare professionals, as well as giving out lots of important awareness raising information. Our "Little Book of Kawasaki Disease", a newly created GP booklet and awareness posters were so popular! We made a massive impact and had so many important Kawasaki-conversations. Attending the conference was a first for Societi, and this formed part of our Children's Hospital Partnership Programme, but we very much hope it won't be our last! With your support once again, we'll aim to attend both the RCPCH and RCGP conferences in 2024, as our work continues to get Kawasaki Disease known!

A warm WELCOME to our newest team member!

Lucy – Programme and Project Lead

We are just delighted to be able to welcome Lucy to our team as Programme and Project Lead, thanks to a grant from the Randal Foundation. Lucy has spent many years leading programmes in the NHS and is excited to bring her skills and knowledge to Societi. We have some really fantastic, projects on the horizon for 2024 and Lucy is already making a huge impact for us!

Societi merchandise

Our Societi shop has had a busy year with lots of fabulous supporters choosing to raise awareness of Kawasaki Disease - wearing our lovely tops and t-shirts whilst out and about, using our badges or bags or even whilst enjoying a cuppa with our super Societi mugs.

This year we launched our first ever craft kit with our beautiful Societi shortbread hearts to decorate. A perfect activity to get you into the festive spirit...! The kit comes complete with red heart sprinkles (of course!) plus gold and white sprinkles and white icing to decorate 4 tasty Societi heart shaped biscuits. The kits are limited edition so get your orders in quick - just click here - they won't be around for long! We are really looking forward to seeing your creations over the coming weeks.

UPDATE: Our Supporter Survey

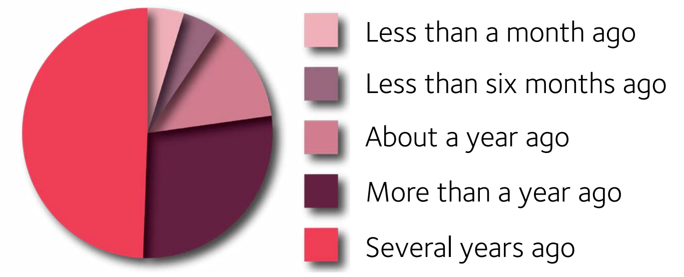
THANK YOU to all those who gave feedback in our recent survey. Nearly 100 super-supporters took the time to share their views and experiences of Societi. The results are in and show HUGE support for our work! ...We know there are always things we can do better too though - and you told us what these were! You told us you'd like more information on the effects of Kawasaki Disease beyond heart damage, and more information on the possible longer-term effects that Kawasaki Disease can have for some children.

You also told us that you'd really love to be able to use a professional advice service, with access to a healthcare professional, who really knows Kawasaki Disease. We have been working hard to produce a report summarising the findings with lots of actions that we have been working on and will continue to do so into 2024. We'll need funds - of course - to make new services happen and we'll be taking your feedback to our Trustees, to help plan our future priorities.

Fabulous feedback!

Our survey showed that over three quarters of our supporters have been part of #TeamSocieti for over a year - and half have supported us for several years - that's just phenomenal! Your amazing support means we can do more to raise awareness of Kawasaki Disease - thank you!

How long ago was it when you found out about us/ first visited our website or our Facebook page?



The KD-CAAP clinical trial

The KD-CAAP clinical trial is well underway, investigating whether we can find a better way to treat Kawasaki Disease which helps reduce the likelihood of heart damage in children. Our role is co-investigator and we lead on patient and public involvement. 48 sites are now involved in this study, and the number of patients recruited at the time of writing is 74. The study is ongoing until July - after which we will start to learn about the findings and how much difference (if any!) our trialled treatment made.

Our work includes raising awareness of the trial and of Kawasaki Disease with the public and doctors. We also support the clinical teams involved in the trial by providing them with training resources and 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 information on the trial.

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*Thank you to everyone who made World Heart Day 2023 a *huge* success for Kawasaki Disease awareness!*

29 September – World Heart Day, is such an important date in our calendar and this year it was bigger than ever! Once again, we worked with our wonderful partners at the World Heart Federation to deliver a campaign with a focus, this year, on Kawasaki Disease into adulthood. 28% of all affected children will suffer some heart damage – children grow into adults… and so treatment and management of the effects of Kawasaki Disease into adulthood is very important to us.

Below is just a snapshot of some of the phenomenal achievements of our fabulous partners and super supporters. You can read more in our World Heart Day Impact Statement here. We are so grateful to EVERYONE who made our World Heart Day campaign in 2023 so successful and so high impact this year. THANK YOU!

"Kawasaki Disease into adulthood" – a podcast series

As part of our drive to ensure doctors and health professionals THINK Kawasaki Disease, we released five podcasts on World Heart Day, based on the theme of 'Kawasaki Disease into adulthood'. Click here to listen.

The series features an interview with leading UK clinicians Dr Tom Johnson and Professor Rob Tulloh. They are joined by four incredible supporters, Rosie, Kris, James and Massoud, all of whom have been affected by Kawasaki Disease and have lived with the effects into adulthood. We are so grateful to our experts and supporters for generously sharing their time, knowledge and their stories!

Social Media Success

This year our World Heart Day campaign reached further than ever with our Kawasaki Disease awareness raising messages reaching over 650,000 social media accounts! Thank you to every single one of you who shared messages! We couldn't have achieved such reach without the fantastic Hinch family too. They shared our posts and Insta stories which had a phenomenal effect on our ability to get Kawasaki Disease known.

THANK YOU everyone for all your amazing and ongoing support!

An international Virtual 10k

A HUGE Thank you to EVERYONE who took part in our Virtual 10K, raising much needed funds for Societi and raising awareness of Kawasaki Disease in your communities! This year, the Virtual 10K was completed in no fewer than EIGHT countries, right across the world! We are so grateful to everyone who joined us in our race for awareness!

Family stories podcast series

Thanks to the generosity of five remarkable supporters, we were also able to produce and release a suite of family story podcasts in the run up to World Heart Day. Click here to listen.

Huge thanks to Sian, Alister, Manda, Laura and Olivia whose stories are unique, powerful and will make a huge difference to other families going through Kawasaki Disease.

Donate here!

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THANK YOU to our regular donors!

Regular monthly donations to Societi enable us to plan ahead for our work, raise awareness and commit to long-term projects. We hugely appreciate our amazingly generous supporters who donate regularly - each one of these INCREDIBLE donations helps to power our work everyday and helps us to keep getting Kawasaki Disease known! THANK YOU!

Click here to make a regular donation

Celebrating #TeamSocieti - and YOUR amazing achievements!

We're showcasing just some of the many fabulous, dedicated people who have supported Societi recently. Thank you to EVERYONE who has donated, raised funds and raised awareness of Kawasaki Disease. We are hugely grateful!

John Biddulph's Charity Music Night

On 27 September, a charity music evening took place at the Servant Jazz Quarters in London, organised by Societi supporters John and Jack Biddulph, to raise funds for Societi! The venue was jam-packed, with the full ticket allocation sold out – standing room only! An absolutely brilliant evening of music was enjoyed by so many. John kindly donated the profit from ticket sales, which totalled £650! A HUGE THANK YOU to John and all who were involved for arranging a very special Societi music event!

Andrew Steel's Worksop Half Marathon

We're once again saying a special Societi THANK YOU to....amazing Andrew Steel! Not only did Andrew recently complete Societi's Virtual 10K for World Heart Day 2023, he also completed the Worksop Half Marathon on Sunday 29 October whilst wearing a Societi running vest! A super-Societi supporter, we think you'd agree - raising Kawasaki Disease awareness with every step! Well done and thank you once again, Andrew!

Aileen and Family's Edinburgh Kilt Walk

On 17 September, #TeamSocieti members Aileen, son Finlay, Aileen's dad Alan and sister Claire all took on the Edinburgh Kilt Walk for Societi! After their family faced Kawasaki Disease, they have been keen to do all they can to raise awareness! Both Finlay and mum Aileen completed the 5 mile 'Wee Wander', whilst Claire and Alan completed the 'Mighty Stride', which was indeed a 'mighty' 21 miles!! Aileen and family raised a total of £250 for Societi and we are incredibly grateful!

Ben Jarvis completes **another** run for Societi

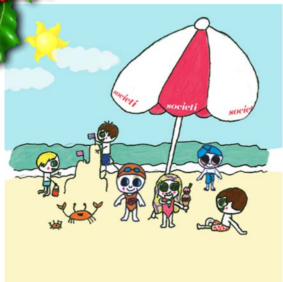
After completing Societi's Virtual 10K in September, Ben also recently completed the Alton Towers half-marathon! Up to 10,000 people were in attendance on the day, so by wearing his Societi T-shirt for his run, a huge amount of awareness will have been raised by Ben! Thank you for continuing to spread the Kawasaki Disease word, Ben! Your support is simply phenomenal!

The Kilimanjaro Crew (led by Gayle) - new heights for Societi!

Long-standing Societi superstar Gayle, who has taken part in many fundraisers and big events for Societi, recently climbed Mount Kilimanjaro! And of course, did so whilst wearing her Societi T-shirt with pride! Not only this, Gayle took supplies of Societi merchandise to share - with T-shirts and wristbands being worn by other members of the climb team to raise additional awareness of Kawasaki Disease! And we were absolutely over the moon to receive some very special photos from Gayle, right from the summit!

Inspired? What could YOU do?

Raising awareness of Kawasaki Disease is our #1 priority - it's the most effective way we have to protect tiny hearts. We aim to reach EVERYONE in the UK - that's 66 million people! WE NEED YOUR HELP! There are so many things you can do to raise funds and awareness of Kawasaki Disease! Run a marathon - not a runner? Hold a cake sale - not a baker? Hold a coffee morning! Or why not display some posters around your local community! Whatever you decide to do, we'll be there to help. Visit **our website** for more ideas and **get in touch** - we'll always try to help where we can!



A special Societi summer event...?

The word on Societi street is that there may be a very special Societi summer event in store! Plans are in early stages, but we can reveal that an event for all the family, and all of #TeamSocieti is coming in June 2024! We've received lots of requests for a dedicated event to bring all of our supporters together, so watch this space, because we can't wait to tell you more (when we can!!). Get in touch if you'd like to be added to a mailing list to be first to find out more.

AMAZING supporters plan to GET KAWASAKI DISEASE KNOWN!

Steven Plumstead's Darts Competition

Professional Darts Player and super Societi supporter Steven Plumstead, will be playing in the Modus Super Series professional darts tournament for 3 days, starting from 15 January 2024. The competition, based in Portsmouth, is due to be shown on several TV channels, such as Sport Stuff TV (SKY 427, Freesat 250, Freeview 271) and streamed Live on the Modus Super Series YouTube Channel everyday, with additional highlights shown in the evening! Steven is set to play 5 games each day (impressive!) and has created a bespoke darts t-shirt on which 'Societi Kawasaki Disease Awareness' has been stitched. How incredible! Steven told us he was keen to promote Societi's work and wanted to use this opportunity as a platform to make people aware of Kawasaki Disease. We think that's absolutely wonderful! Steven's son was diagnosed with Kawasaki Disease earlier this year, and this has powered Steven's passion to get Kawasaki Disease known! He also plans to wear and use lots of additional Societi merchandise throughout the competition, raising awareness whenever he can! It's safe to say that all of #TeamSocieti will be right behind him - and we very much look forward to seeing the matches on live TV! From all of us, GOOD LUCK STEVEN!

Two Societi supporters to take on the London Marathon 2024, for Societi!

We're just delighted to share that wonderful Andrew Steel and Chloe Cheeseman will be running the 2024 London Marathon for Societi! We're amazed by both Andrew and Chloe, who have taken on many other challenges for Societi in the past! We're wishing them GOOD LUCK for their biggest challenge to date! Why not support Andrew or Chloe's London Marathon run? All donations count and make a difference, no matter the size!

El's London Landmarks Half Marathon

April 2024 will see lovely El complete another amazing fundraiser - the London Landmarks Half Marathon. El is a member of 'Team Thomas' - a magnificent group of people, all dedicated to supporting Societi and getting Kawasaki Disease known. We can't wait to see pics of El's run through London! If you'd like to support El's London Landmarks Half Marathon and help her as she runs to protect even more tiny hearts, you can sponsor her **here**.

Kevin's Wainwright challenge continues!

Super-supporter and long term fundraiser, Kevin, continues to tackle the 214 Wainright challenge, scaling all 214 peaks within the Lake District's national park. He currently has a staggering 112 under his belt - he's made it over halfway! We're so inspired by Kevin's dedication and determination to get Kawasaki Disease known and protect tiny hearts. If you'd like to lend some support to keep Kevin going in his mammoth challenge, you can do so here!

Yorkshire 3 Peaks challenge!

From one set of peaks to another - we were delighted when Ellie at Opes International Limited got in touch to let us know she, along with a team of colleagues, will be taking on the Yorkshire 3 Peaks challenge for Societi – stay tuned as we look forward to providing an update on their progress in 2024! If you'd like to take part in a challenge with your work colleagues to raise awareness of Kawasaki Disease and funds for Societi, just get in touch!

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Have your say with our Societi Supporter Panel

We have recently launched our brand new 'Societi Supporter Panel'. With lots of exciting projects on the way we want to ensure that YOU continue to be at the HEART of everything we do.

A number of respondents to the Societi survey earlier in the year, who'd agreed to be contacted, were sent an invitation to join the panel. A huge thanks to the ladies from across all parts of the UK that have joined the panel so far! However, we really want to see some dads, granddads and uncles on board. Come on boys! If you are interested please get in touch. We want the panel to be as representative as possible of our community.

And for those not on the panel, we'll still be giving you plenty of opportunity to have your say too!

International **Kawasaki Disease** *Awareness Day 2024*

THINK Kawasaki Disease

As you know, January 26 is the most important day in our calendar – **International Kawasaki Disease Awareness Day**. As we edge closer to the BIG day, preparations are very much underway – and we are very excited! We want everyone to THINK Kawasaki Disease, and we're aiming for our most successful Awareness Day yet! This year, we're planning a fabulously amazing national campaign that's so HUGE.... it is spanning all the way into March! There is so much in store but, as always, we need your help to make it a true success. Take a look at the below to see just some of the ways YOU can GET INVOLVED!

Powerful partnerships for Plasma... We need YOU!

We are thrilled to announce that, as part of our national awareness campaign, we will be partnering with NHS Blood & Transplant to hold an event in the Houses of Parliament in March, to increase awareness of the need for plasma donations. Kawasaki Disease treatment, IVIG, is a treatment made from blood plasma, so donations are VITAL to help protect tiny hearts of the future.

BUT we need YOUR help! We need YOU to write to your local MP to encourage them to attend the event, make them aware of the need for plasma donations - and make them aware of Kawasaki Disease! Why not email your MP - we've drafted an email you can use to tell them about the event - and about Kawasaki Disease too! Just click here.

NHS Blood and Transplant

NHSBT invited us to work with them after successful joint projects in the past. Whilst they are meeting the majority of the event costs, we'll need some new resources to make the most of the event, for Kawasaki Disease awareness. **For this we need YOUR help. Can you donate or fundraise**? We have set up a dedicated JustGiving fundraising page where you can HELP us to grow MP awareness of Kawasaki Disease and it's all important treatment!

LET'S WORK TOGETHER TO ENSURE TINY HEARTS OF THE FUTURE ARE PROTECTED!

Help us shine a light on Kawasaki Disease

We're looking forward to SHEDDING SOME LIGHT on Kawasaki Disease by asking venues and landmarks to light up RED once again on 26 January 2024. Thanks to YOU, a record number of landmarks lit up to raise awareness of Kawasaki Disease in 2023, and we're asking for your help again for Awareness Day 2024! **There's still time to contact your council or landmark owner** to ask them to light up your local town hall, cathedral or a landmark to get THOUSANDS of people in your area talking about Kawasaki Disease!

Don't forget to let us know who you have contacted and we'll send them our press release too!

Get involved in protecting tiny hearts!

THINK Kawasaki Disease

International **Kawasaki Disease** *Awareness Day 2024*

Fundaising poster pack

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

societi.org.uk

Kawasaki Disease Awareness Day is the perfect time to fundraise and 'shine a light' on Kawasaki Disease! So, why not get involved? Go on... take part and let's make Awareness Day 2024 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! Or why not change the dress code for the day at your office or your child's nursery or school? We've been sharing our specifically designed nursery and school awareness packs over the past few weeks. It is SO important that all parents KNOW and THINK Kawasaki Disease, so **get in touch if you'd like a pack too**!

There's lots of easy options to choose from; you could arrange a **WEAR RED DAY** to make a statement in RED to help fundraise and get this sinister disease known! Or perhaps a non-uniform or fancy dress day? Download your fundraising pack here!

Donate here!
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