



Hello from our special Guest Editor, Hayley!

Hello my name is Hayley and it is my absolute pleasure to introduce myself as the Guest Editor for the Societi spring/summer newsletter. Societi has been a part of my life since my daughter, (now 12) was diagnosed with Kawasaki Disease at the age of 4. Like many people, we had not heard of Kawasaki Disease before. We were very lucky to receive treatment within 5 days of the first symptoms appearing and my daughter, thankfully, made a full recovery. Since that time, we have tried to raise awareness of the symptoms wherever possible to help protect those precious children's hearts. Thank you to my company, Twenty Essex, for providing me with the volunteer day to do this newsletter!

Hayley, Super Societi Supporter & Guest Editor



Welcome to our Spring/Summer newsletter!

Spring has finally arrived, and we are very much in full swing for the upcoming brighter months. At Societi headquarters we never have a sluggish start to the year as we are always straight into preparations for our biggest day of the year - International Kawasaki Disease Awareness Day on 26 January. Although, this year was a little different - with the amazing support of #TeamSocieti - we delivered a 3 month long campaign, reaching more people than ever before. Through your posts, likes and reposts on social media alone, we were able to reach well over 700,000 people who may otherwise never have heard of Kawasaki Disease.

We were thrilled to see so many parts of the country lit up in red to raise awareness of Kawasaki Disease. Thanks to YOUR donations, we had the Blackpool Tower light up, with a red heart of course, and across the UK some very special places lit up. That included Alex's Oak Tree shop in Devon, the Morgan Hotel in Swansea, Heckington Windmill in Lincolnshire and all the way up to Ness Bridge in Inverness - we can't thank everyone enough for their huge support - we are SO grateful. Special thanks must go to Natalie, whose determination to get landmarks lit up was....immense!

Not only did we hugely increase our reach on social media, FABULOUS Clear Channel once again displayed our Kawasaki Disease awareness messages to millions of shoppers across the UK. This year we also took our campaign to Parliament with NHS Blood and Transplant, to speak to MPs and to the Royal Conference of Paediatrics and Child Health in March.

It really has been a phenomenal few months. So much awareness has been raised all over the UK and there is a tangible shift in attitudes to Kawasaki Disease, how serious it is and how important it is to KNOW - that is all thanks to YOU. Without YOUR overwhelming support, we simply couldn't do what we do - THANK YOU! **Rachael, Societi Founder**

Become a Societi member!

You may have seen on our social media channels that we launched a NEW membership for our very special supporters!

On joining, you'll receive some exclusive goodies including a gorgeous one-off exclusive Societi keyring, discount codes for our shop, first access to tickets to Societi events and a range of other member exclusive online events - the first of which was held on 1 May. This was a chance for our members to 'Ask The Expert' Professor Robert Tulloh, who answered YOUR questions in our online webinar. It really was a special opportunity for members to have access to a highly regarded and top expert in Kawasaki Disease.

When you become a member, your support will enable us to continue our valuable work - including growing support for our families and more training resources for medical professionals.

By signing up to our membership, you're not only making a really valuable donation to our work, but you're showing us your support for a whole year and enabling us to plan ahead.



We know it isn't about the goodies and the perks for you...but we just like to say THANK YOU for your support whenever we can!

Membership for 2024 costs just £20 for 12 months. You can find out more [here](#) or, if you'd like to become a Societi member, you can sign up [here](#).



A huge WELCOME to Lilly...

Lilly – Social Media and Communications Assistant

We are thrilled to welcome our newest member of the team, Lilly, as our Social Media and Communications Assistant. Lilly has excellent social media experience and there is NOTHING she doesn't know about Instagram! Lilly is already doing an amazing job at breathing new life into our social media posts and visuals and we're looking forward to seeing new ideas.

...and a warm WELCOME BACK to Rachel!

Rachel – Supporter Liaison and Administrator

A very warm welcome back from maternity leave to Rachel, our Supporter Liaison and Administrator. To be honest, it feels like Rachel never went away – she was always there, keeping an eye on our social media and being the brilliant Societi champion she is! We have missed you Rach, and are delighted to have you back at Societi HQ!



Education is key... in so many ways



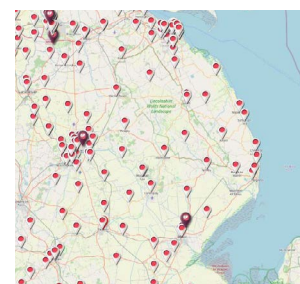
Our Children's Hospital Partnership Programme, generously funded by the Randal Foundation, continues to go from strength to strength.

We were thrilled to attend the Royal College of Paediatrics and Child Health Conference in March where we dramatically increased the number of our hospital partners to 98 individual contacts from 62 different UK hospitals! Our stand was loaded with great resources for clinicians to take back to their hospitals, including our new quick guide on the lifetime management of patients with Kawasaki Disease (written for doctors!)



We also had the honour of delivering our Kawasaki Disease symposium. Societi Founder, Rachael spoke alongside Dr Ifeanyichukwu Okike, Deputy Chair of the BPSU Scientific Committee and Professor Robert Tulloh, Paediatric Cardiologist and expert in Kawasaki Disease. This was made possible by a very special long-time supporter Lisa, who made a truly PHENOMENAL donation which went directly towards the symposium. Lisa's donation inspired other supporters to donate too – we put out a call to our generous supporters and were thrilled to raise £1,955 in total. This meant we were able to fund the presentation session and share stories of our extraordinary families, to make it a truly informative day.

Using supporter funds raised and your donations, at the request of a family who tragically lost their son to Kawasaki Disease in January, the Societi team got together and packaged 99 GP awareness raising packs! We sent these to EVERY GP practice across Lincolnshire. This will truly make a difference to children across that county. This work strengthens our Children's Partnership Hospital Programme. It is so important that we reach the front line and educate the people who will look after our children and our Children's Partnership Hospital Programme is designed to do just that! Thank you to all who have been involved in making it such a huge success!



KD-CAAP clinical trial



The KD-CAAP clinical trial is continuing to investigate acute Kawasaki Disease treatments and whether we can find a way to reduce the likelihood of heart damage in children. Societi leads on patient and public involvement for the trial and is also co-investigator. There are currently 53 active sites across Europe which are now involved in the study, and the number of patients recruited has grown to 94. After July, we will start to learn about the findings of the trial 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.



Donate
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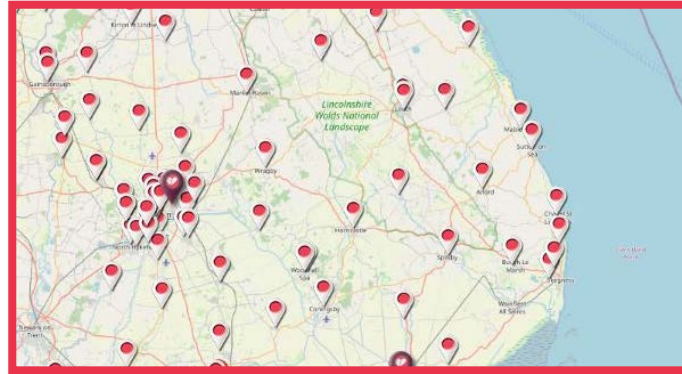
BIGGER IS BETTER! – a snapshot of our 3-month International Kawasaki Disease Awareness Day campaign

We set ourselves the much bigger target this year of running our International Kawasaki Disease Awareness Day campaign over 3 months rather than the usual 1 month...! We worked to reach as many people as possible, through social media, education and awareness. Despite Kawasaki Disease being increasingly common, low public awareness means it's often initially misdiagnosed, putting children's hearts at risk. Our 3-month campaign was designed to cover every aspect of awareness – from the general public, to clinicians and even to our MPs – to help stop Kawasaki Disease having the devastating effect it has on far too many children, and their families.

We are so thankful to all our phenomenal partners and our amazing #TeamSocieti who made our campaign such a success. Below is just a small snap-shot of our 3-month campaign period. If you'd like to know more, you can read our [International Kawasaki Disease Awareness Day impact statement here](#).



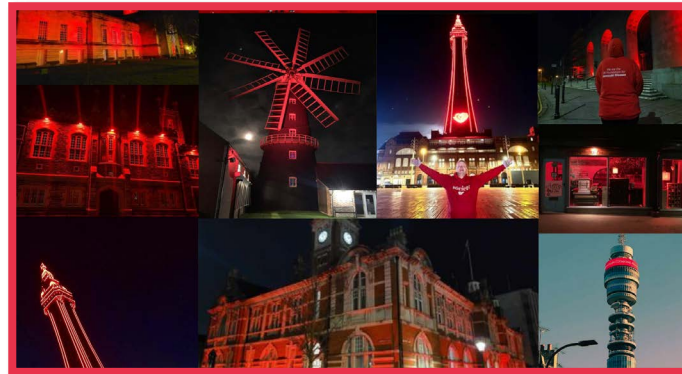
Our Kawasaki Disease awareness raising messages appeared to millions of shoppers in shopping centres right across the UK, thanks to extremely generous and ongoing support from the brilliant Clear Channel.



We used our 3-month campaign to help grow our Children's Hospital Partnership Programme including creating new clinical resources and sending GP packs to every single GP practice in Lincolnshire.



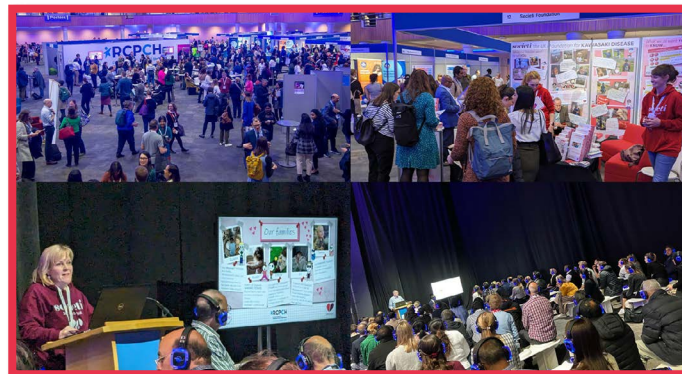
The fabulous Mrs Hinch introduced us to Hannah Chapman, the businesswoman behind Ava Mayfair. Hannah and her team created a simply divine wax melt pack to raise funds and awareness for Societi.



17 buildings and monuments across the UK lit up red for Awareness Day, including the iconic BLACKPOOL TOWER. The total population in the areas where buildings were lit up was a staggering 11.5 million!



We worked with NHS Blood & Transplant to hold a parliamentary event. This session for MPs highlighted plasma donation and how important it is to make life saving medicines, such as IVIG, used to treat Kawasaki Disease.



We had HUNDREDS of fantastic conversations with doctors at the RCPCH conference in March. We also presented a patient and clinical perspective on Kawasaki Disease to a PACKED audience! Phenomenal!

Regular donors – YOU are the heart of Societi!

We rely greatly on the support of our regular donors, whether that is through a monthly or yearly donation – we couldn't do it without you. We never take for granted your unfailing support to help us raise awareness of Kawasaki Disease. Having a regular donation from you helps us to plan more strategically. If you would like to be a regular donor, you can use the button opposite or [contact us](#) and we can let you know the best ways to support us.

Click here to
make a regular
donation



Donate
here!

Celebrating #TeamSocieti – and YOUR amazing achievements!

Darts, clothing lines, running, birthdays, teddies.... What's next? We are thrilled this year to have had so much support and some new firsts for Societi! THANK YOU to EVERYONE who has raised funds and awareness for Societi!

Good arrows!

A huge thank you to Steven Plumstead who donned his very special darts shirt with "Societi Kawasaki Disease Awareness" on the back of his shirt together with his Societi pin badge in full view of the TV cameras to take part in the Modus Super Series darts competition at Portsmouth in January. Not content with this already amazing exposure, Steve also hosted a charity darts event in March – you scored a 180 with us Steve!!

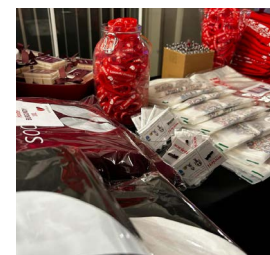


A tracksuit fit for fundraising!

Brilliant business owner and Societi supporter, Maria Bond not only launched an Instagram fundraiser for Societi which exceeded its target... but also launched a brand new colour of tracksuit with her company 'Conscious Citizen'. What an amazing and novel way to raise awareness of Kawasaki Disease! If you'd like to support Maria and Societi, you can find her clothing range on her website [here](#). 10% of each special purchase from Conscious Citizen is to be donated to Societi – thank you Maria!

A whole community of support

The whole community of Stamford made an overwhelmingly supportive response when a little boy, Tommy, lost his life to Kawasaki Disease at the beginning of the year. Tommy's family have been truly inspirational leading their community in support of Societi and raising awareness of Kawasaki Disease. Huge thanks all the partners, businesses and people who have supported so many events, from Easter activities to 10K Wolf Runs, Societi hoodie purchases (there's more hoodies in Stamford than anywhere on the planet...!), Easter celebrations and church collections – and MORE! Raising huge amounts of awareness and valuable funds for Societi. Thank you Katie and Dan for all you do.

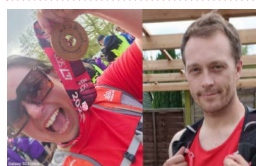


Gayle continues to go from strength to strength!

To anyone who has been following us for the past few years you will know who Gayle Harvey is – Gayle is a member of our Societi Active Committee and a huge supporter of Societi and quite possibly the most active person we know! Gayle organised a great social charity 10k for Societi in March – thank you Gayle you are a Societi HERO giving so much of your time to help protect children's hearts.

Running, running, running...

A huge THANK YOU to all those who have been racing for awareness! Thank you to Madeline who completed the Cambridge half marathon, Matt and Ben who took on the Rutland Spring half marathon, El who completed the London landmarks half marathon. And THANK YOU to Ellie who secured herself a place for the London marathon fun mile and wore her Societi running top to raise awareness, and explained to her friends about Kawasaki Disease.



London Marathon heroes

Super supporters Andrew and Chloe ran the London marathon for Societi raising huge amounts of awareness. Andrew raised £1,355 and had the brilliant idea to have sponsored supporter names on his running vest which we are sure helped power him round the brutal 26.2 mile course. Chloe raised a fantastic £623 – just amazing! A huge THANK YOU to Andrew and Chloe for all their hard work and determination!

Heather's Glasgow Kiltwalk

Heather has been fundraising for Societi and raising awareness of Kawasaki Disease since the loss of her little boy. She is an incredible inspiration and her determination has us all in awe. At the end of April, Heather took part in the Glasgow Kiltwalk wearing her Societi t-shirt – and kilt of course – and raised an amazing £325! Apparently, Heather's dog, Greta got all the attention during the walk! We can completely understand why!! Thank you, Heather.



Miles and miles and miles...

Throughout the whole of April, Eden worked especially hard to walk/run/cycle 1,000 miles. 1,000 miles is an awful lot for one person but it was always the plan to get as many people involved as possible to donate their miles!! With help from friends and family Eden smashed through her target of 1000 miles and achieved a grand total of 1127 miles and raised a massive £1420!! Astonishing!!

What have we
been up to?

What have YOU
been up to?

Get involved!



SAVE THE DATE! YOU'RE INVITED! SAVE THE DATE!

We've received lots of requests for a dedicated event to bring all our supporters together and we're well on the way with planning our very special **Societi Supporter Summer Social event** for all the family in Nottinghamshire. We are so grateful to the band [Mansfield Avenue](#) who have generously agreed to provide us with live music for the event free of charge – and we hope to have food and entertainment for the family too. We are looking to hold the event on Sunday afternoon, 18 August this year. We're hoping to have at least 50 people attend, so if you'd like to join us in our summer celebrations, [register your interest here](#) – You'll be the first to know when we confirm!

What will this year hold for you?

At Societi HQ, we love hearing about what fun activities our wonderful supporters are up to and which new and exciting fundraisers are being held. Over the years we have had everything from shaved heads to snooker-jazz and sky diving, and this year it has been new clothing lines, wax melts and darts! If you have an idea that you would like our support with, we will be behind you 100% of the way – [just get in touch](#). Maybe this year is the year to bring back a bath full of baked beans? Some of you may remember the programme 'kids say the funniest things' from the 90's – if you need some inspiration, why not see what ideas your children can come up with – we look forward to seeing these come to fruition!



AMAZING supporters plan to GET KAWASAKI DISEASE KNOWN!

Businesses join the fight against Kawasaki Disease!

As well as our brilliant wax melt collaboration with Hannah Chapman and her business, Ava Mayfair and Maria Bond offering support for Societi through her business, Conscious Citizen – we have been delighted to receive offers of support from other business too! Both Rozanne of Flutterbuy Treats and Ciara of Even This Candle have offered support through awareness raising and by donating a proportion of their profits to Societi. We're over the moon to receive so much support in this incredible way. If you'd like to support Societi through your business, [just get in touch](#) and we'll let you know the best way to do it.



Kevin's Wainwright challenge - UPDATED!

You may have seen us talk about the amazing Kevin who has supported Societi for many years! He is currently completing all 214 Wainwrights (or fells) in the Lake District – INCREDIBLE!. We received an update from Kevin recently, letting us know he has now completed 125 in total and he sent us some brilliant pics from his last few climbs! We are just in awe of Kevin and the massive challenge he has taken on. If you'd like to donate and support Kevin in his mega challenge, you can do so [here](#). Keep going Kevin!!

Yorkshire 3 Peaks challenge!

The Opes team – Jessica, Dani, Ellie, Harriet, Sophie, Neil, Kayleigh and Leon, took on the Yorkshire 3 Peaks Challenge for Societi at the beginning of May. The team at Opes heard about Societi and about Kawasaki Disease when we were invited as charity of the year to the Chemical Business Association annual lunch. They were so moved by Societi's story that they decided they wanted to do something to help too – how amazing! A huge THANK YOU to everyone who was involved!



Alan's Kilt walk and Glencoe Challenge!

Last year, Societi supporter Alan completed the Edinburgh Kiltwalk for Societi along with his family to raise funds and awareness for Kawasaki Disease. We think Alan has caught the bug, as not only is he entered into the Edinburgh Kiltwalk for September this year, but he will also be completing the Glencoe Challenge in July too – all to raise funds for Societi and awareness of Kawasaki Disease! We can not thank Alan enough for his dedication and his amazing support for Societi – THANK YOU for helping to protect children's hearts.

Racing for awareness!

We were delighted when Chantelle got in touch to say that her eldest son who is a racing driver would be naming Societi as their charity of the year. After their family were affected by Kawasaki Disease last year, they want to raise awareness and will be displaying Societi's logo on their racing car and raising awareness of Kawasaki Disease at every racing venue they go to. This is another simply fabulous first for Societi and we are so thrilled that Chantelle thought to support Societi.



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Have your say and join our supporter panel!



Being a part of our Societi supporter panel gives you the opportunity to share your thoughts on a range of topics and shape our work in the ways you feel – as a family who has been affected by Kawasaki Disease – are most appropriate. Panel members are contacted every few months to participate. For example, there may be a survey that we'd really value your input on. To make our research effective it's important that we cover all demographics. We would love some more input from our **male supporters**. If you can spare us 10-15 minutes every few months and would like the opportunity to have your say and help to shape our work, please [get in touch here](#) or email us at info@societi.co.uk.

Support us through our online shop!

Going for a run, doing the weekly shop, taking notes or doing the dishes... Whatever you are doing, do it with Societi merchandise and raise awareness of Kawasaki Disease! Societi merchandise is so important as it allows us to generate much needed funds and at the same time enables our supporters to raise awareness of Kawasaki Disease whatever they are doing and where ever they are in the world! Win, win! Get your Societi merchandise in our [shop here](#)!



There's something for everyone in our Societi shop and we're adding to it all the time. We love designing new Societi goodies to put up for sale on our online shop! Watch out for our gorgeous new notebooks that will be available soon!

And on World Heart Day, we'll be running a competition for and revealing a very special piece of merchandise – something so special, we'll be waiting until Christmas to release it! We can't wait to let you know our plans, so watch this space.

And, don't forget, if you are a Societi member, we will send you your very own Societi membership discount code to receive 10% off every purchase. Sign up here to a Societi membership [here](#) to get your discount!

Complete our Diagnosis Day Survey!

We're working to collect information as part of ongoing updates to a research project we first conducted in 2018 and again in 2022 – on your EXPERIENCE OF KAWASAKI DISEASE DIAGNOSIS. It's clear this varies from family to family and we need to understand more about just what is happening when our children are first being diagnosed.

If your child was diagnosed with Kawasaki Disease in the U.K. between February 2016 and April 2024, 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.

If misdiagnoses are happening before Kawasaki Disease is correctly diagnosed, we need to understand what Kawasaki Disease is being confused with so we can share this information with doctors and focus training about Kawasaki Disease to help overcome any problems being faced. To complete our survey, [just click here](#)!



Let's protect children's hearts...
from Kawasaki Disease!

World Heart Day 2024



Help us protect children's hearts this World Heart Day



World Heart Day on 29 September is the second biggest day in our calendar and it always a great time for our supporters to get involved. Why not get planning a 'wear it red' day, a bake sale or a coffee morning at school or work? We'll be releasing details of our World Heart Day activities soon, so keep an eye out.

We'll also be sharing more family stories this World Heart

Day. As well as raising awareness, family stories are a brilliant way to support families who have just received a diagnosis of Kawasaki Disease. They help comfort families and help them to know they are not alone in their experience. If you'd like to share your Kawasaki Disease family story this World Heart Day, you can fill out this form [here](#) and we'll be in touch.

Whatever you decide to do this World Heart Day, please [get in touch](#) and let us know your plans. Together, we can make this the most successful year ever. **Together we can protect children's hearts!**



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