# societi

the UK Foundation for Kawasaki Disease

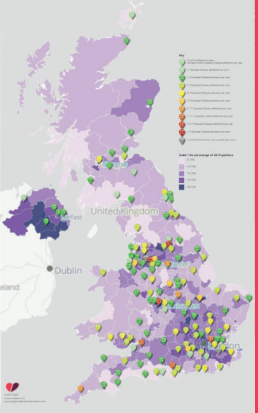
## Kawasaki Disease is the leading cause of acquired heart disease in children in the UK

...it's time we changed that

## Welcome to our Christmas Newsletter 2019!

Wow! What a year! With an ever-growing army of utterly fabulous Societi supporters, a simply terrific year unfolded through 2019! Our work together, our impact and the awareness raised has just grown and grown. With your support, we've reached many more people this year, including hundreds of GP surgeries (that's thousands of GP's!) thousands of paediatricians through RCPCH conference and our webinar – and even politicians! We've contacted over 150 hospital Trusts too, going on to receive information on thousands of Kawasaki Disease hospital admissions, addressed over 100 doctors at a symposium, spoken at many events... and then there's the hundreds of wonderful Societi supporters – YOU! – who have raised awareness of Kawasaki Disease in your communities – reaching tens of thousands of people – together. Read on to find out about our fabulous fundraisers and the incredible work of so many phenomenal Societi supporters – and more! TOGETHER we are making change happen, people are getting to know Kawasaki Disease! There's much more to be done too though – and I very much hope I can count on your support into 2020 as we continue together, doing everything in our power to protect tiny hearts from Kawasaki Disease. *Merry Christmas and Best Wishes, Rachael, Societi Founder*

## Major New Research – Societi study is largest ever



No-one has an accurate record of how many children are affected by Kawasaki Disease in the UK. We find that shocking! And we were determined to try and correct that! Our ambitious research project involved contacting 155 Trusts /Health Boards in England, Wales Scotland and Northern Ireland requesting information on Kawasaki Disease admissions between 2006 and 2018. 149 organisations have responded and with valuable data which will help us learn more about Kawasaki Disease – in every corner of the UK.

We've received information on a staggering 7,459 UK admissions for Kawasaki Disease since and estimating numbers to fill in gap years, we know this total is likely to be over 8,600 – this is simply the BIGGEST research project of its type and the data being revealed is nothing short of phenomenal. With no central data on admissions, this study gives us a unique insight into this SERIOUS & increasingly common disease, helping us protect tiny hearts! Our information gathering is now complete and we have begun to analyse the findings. This important study will help us plan our work in years ahead as we continue to raise awareness of the LEADING cause of acquired heart disease in our children!

## TEMPERS goes international

**Malattia Di Kawasaki?**
*Ricorda* **COLLERA**
*I bambini affetti da* ***Malattia di Kawasaki*** *si contraddistinguono per una caratteristica irritabilità.*

**C**aldo – **FEBBRE PERSISTENTEMENTE ALTA**

**O**cchi rossi, congiuntivite senza pus o secrezioni

**L**infonodi del collo ingrossati, spesso su un solo lato

**L**ingua a fragola, bocca secca e dolente, labbra screpolate

**E**ritema, mani e piedi arrossati e gonfi

**R**ash

**A**gire tempestivamente – **UN TRATTAMENTO PRECOCE RIDUCE I RISCHI DI DANNI AL CUORE**

*Se un bambino ha una* **FEBBRE PERSISTENTE** *e due o più dei seguenti sintomi,* **PENSA ALLA MALATTIA DI KAWASAKI.**

5 Giorni di febbre?

PENSA ALLA MALATTIA DI KAWASAKI

societi.org.uk

www.justgiving.com/societi

With Societi supporters right across the globe – and a recognition that one of the problems facing Kawasaki Disease is confused and conflicting information is so many different places, we were delighted to work with wonderful supporter Marie, in Italy to create a version of TEMPERS in Italian! This means Marie can continue her amazing awareness raising work with family and friends who are English and Italian speaking too – brillante!!

The Italian TEMPERS – COLLERA, meaning "angry" in Italian, will help protect thousands more tiny hearts right across Italy! Thanks to Marie and Mattia for the brilliant work in translating TEMPERS – we're always so excited to create new Societi resources to help protect children from Kawasaki Disease!

## Societi speaks at Symposium

Founder, Rachael had the privilege of speaking at and being part of the Institute of Child Health Symposium event at Great Ormond Street Hospital – on Kawasaki Disease! This was thanks to an invitation from the fabulous team we are fortunate to work with at the Great Ormond Street Hospital for Children.

Over subscribed, the symposium was an amazing success with over 100 doctors in the room. It was just incredible to meet so many wonderful clinicians who want to get Kawasaki Disease known, want to learn from the experts and who are determined to now THINK Kawasaki Disease!

All the speakers gave such insightful presentations – and special thanks to Dr Filip Kucera for organising and leading this transformational event. Discussions like this really do protect tiny hearts and we are so grateful to have had the opportunity to be a part of it!

### Kawasaki Disease Symptoms

- Persistent fever
- Cracked lips / 'strawberry' tongue
- Rash
- Swollen fingers/toes
- Bloodshot eyes
- Swollen glands

# Celebrating #TeamSocieti - and YOUR amazing achievements! Read on.......!

Societi was privileged to be invited to attend the Veswas Gala Ball - a spectacular event in EVERY sense - from the gorgeous canapés and drinks reception, to the excitement of the grand entrance to the ball, fuelled by fabulous music, a light show and a carpet of dry ice. The Veswas team clearly had a vision for this amazing night and created a truly memorable evening.

As a charity ball, we were privileged to be one of two charities being supported by Veswas. The WONDERFUL Veswas directors - Depesh, Rahul and Gary were determined to make a difference by giving a HUGE boost to two charities, making a MASSIVE difference to their work. And that's exactly what they did - with a PHENOMENAL donation of almost £19,000 being given to Societi. A truly enormous sum and every £1 is precious! Every £1 will help us to get knowledge about Kawasaki Disease into the hands of many, more people - and protect many, more tiny hearts!

## A (table) top fundraiser!

Super Societi-supporter Lisa ran a table top sale in October. Weeks in the planning, and with the support of some very special friends and family, she raised a staggering £503.50 for Societi! There were cakes, cuddly toys, crafts, raffle prizes and.....men in donkey outfits!? Oh and so much more. The day was a HUGE success with powerful awareness raised in Lisa's community and much needed funds raised too. Lisa's phenomenal energy and expertise in leading and organising events is invaluable to Societi and it never ceases to amaze us! Keep going with the ideas, Lisa! We're here to support your plans whenever we can!

## Lovely ladies continue their support

Societi has been lucky enough to be chosen as the 2019/20 Ladies Circle GB&I President's charity. President Lindsay Pickard started in office in May and since then we've had just IMMENSE support from Circlers all over the UK. Lindsay's presidential ball raised a massive £1,000, Lizzie organised a CPR event where she raised awareness of Kawasaki Disease and will shortly undertake a fundraising head shave!! Leigh organised a sell-out charity luncheon and fashion show for over 200 ladies...and so much more besides. We're so grateful to the BRILLIANT members of Ladies Circle for everything they are doing to raise funds and awareness for Kawasaki Disease, protecting tiny hearts!

## Community event raises awareness to hundreds

Neeta has been busy raising awareness ALL YEAR and in September she took a stand at the Mela - a huge event for her community and one that Neeta has attended for a couple of years now to protect tiny hearts! She worked throughout the day, speaking to hundreds of visitors to her stand and telling them all about Kawasaki Disease. She's pictured here with MP Bob Blackman, Conservative Member for Harrow East who has been well and truly converted as an ambassador for Kawasaki Disease - all thanks to Neeta! Same again next year Neeta?

## Crafty Fundraisers raise an incredible £900!

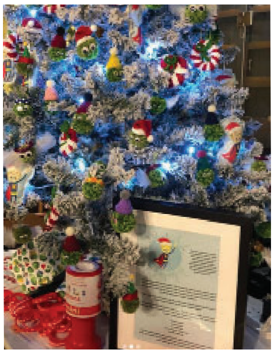
Dedicated Societi supporter Julie, a long term supporter and 'tour-de-force' for Kawasaki Disease in Yorkshire had immense support from her incredible family and phenomenal friends who've been busy crafting, knitting, sewing and baking in preparation for a spectacular Kawasaki Disease fundraiser. They even provided a butler service on the day - AMAZING! Thank you to Julie and her army of supporters! We're constantly inspired by all you do . You've given so much support to our mission to get Kawasaki Disease known.

## A first for Societi - Our very own scarecrows!

Societi supporter Jo, spent HOURS creating two simply STUNNING Societi scarecrows, for her village scarecrow competition - surrounded by beautiful hearts too! This is one of many of the successful awareness and fundraising initiatives Jo has held for Societi - and you'll not be surprised to learn that this one stopped traffic! Her prize winning Societi scarecrows were just fabulous! A first for Societi for sure and what a BRILLIANT and novel way to raise awareness of Kawasaki Disease!

## A Tale of Two Trees...for Kawasaki Disease!

Awareness raising is never ending - even during the festive period! In fact, two FABULOUS supporters Lisa and Lucy, turned Christmas to their advantage in a unique way - by decorating Christmas trees at Minehead's and Hitchin's Christmas Tree Festivals! Both trees have Kawasaki Disease awareness messages - what a fantastic idea! We pondered about the time taken to create all those decorations - oh, imagine!! But both trees look absolutely stunning and we're sure that many, many people will get to know Kawasaki Disease thanks to Lisa and Lucy and this brilliantly festive idea!



## Our race for awareness

We have been overwhelmed this year by the number of people raising funds and fabulous awareness for Kawasaki Disease simply by running or walking. Nick ran the 2019 Bournemouth Marathon, Hayley completed the London Marathon and Maldon half marathon, Teresa completed Oxford Half Marathon Vikki, Rosann and Beverly ran the Great North Run - all in their Societi running vests - even tiny 3 year old, Zachariah completed the mini Great North Run, raising a massive £1,045!

societi Virtual Run

World Heart Day 2019

We'd also like to say a HUGE THANK YOU to everyone involved in this year's Virtual Run. Whether walking a Fun Mile or completing a Family Marathon, we are so grateful for everyone's input into this hugely successful event, which raised much-needed awareness of Kawasaki Disease and over £6,000 in funds! Every single participant helped to protect tiny hearts - thank you so much! There's been some brilliant stories and photos that have come out of this year's events – too many to mention individually but, as a TEAM, we've achieved incredible awareness of Kawasaki Disease.

A special thank you must go to the Societi Running Committee who hosted this year's event – volunteering their precious time. Thank you Vikki, Hayley & Lucy for everything that you do, including hosting our Societi Virtual Run Facebook Group. If you'd like to see all the amazing photos from this year's Virtual Run, join our Facebook group and maybe you can find some inspiration for next year too! And, if you're inspired reading this, why don't YOU join our Brighton Marathon Team and run for #TeamSocieti? If you're interested, email info@societi.co.uk. You'll need to hurry though, there's only 1 place left!

NICE
National Institute for
Health and Care Excellence

## Updated NICE Guidance is huge step forward for Kawasaki Disease!

Societi has been working with NICE – the National Institute for Health and Care Excellence to update Fever in Under 5's guidance which was published in November. The revised guidance is based on the evidence reviewed by, and experience of, appointed NICE committee. Our Founder, Rachael, was appointed to the committee to work on the guidance for Kawasaki Disease. The updated guidance urges doctors to be aware of the possibility of Kawasaki Disease in children with fever that has lasted 5 days or longer. The changes are VERY important indeed and this new guidance is a massive step forward in helping to improve diagnosis, treatment and outcomes, for our children.

**Updated NICE guidance 2019 states:**

**Kawasaki disease**

**1.2.26 Be aware of the possibility of Kawasaki disease in children with fever that has lasted 5 days or longer. Additional features of Kawasaki disease may include:**

- **bilateral conjunctival injection without exudate**
- **erythema and cracking of lips; strawberry tongue; or erythema of oral and pharyngeal mucosa**
- **oedema and erythema in the hands and feet**
- **polymorphous rash**
- **cervical lymphadenopathy. [2019]**

**1.2.27 Ask parents or carers about the presence of these features since the onset of fever, because they may have resolved by the time of assessment. [2019]**

**1.2.28 Be aware that children under 1 year may present with fewer clinical features of Kawasaki disease in addition to fever, but may be at higher risk of coronary artery abnormalities than older children. [2019]**

If you want to find out more, go to https://www.nice.org.uk/guidance/ng143/chapter/Recommendations

societi
Awareness
Ambassador

## Political Ambassador successes!

A HUGE thank you to ALL supporters that have requested a Political Ambassador pack. And MASSIVE thanks to Laura, who followed up a meeting with her local MP – Mr Richard Drax. Mr Drax was very keen to learn about Kawasaki Disease and was honest enough to admit he hadn't heard of it – he is not alone! Laura explained that there is a lack of awareness around Kawasaki Disease, despite it being INCREASINGLY COMMON. She was also able to give him a Societi Kawasaki Disease info pack too!

Mr Drax has since written to Baroness Blackwood, Parliamentary Under Secretary for Department of Health & Social Care, about the points Laura raised in their meeting. It sounds like the meeting between Laura and her local MP went brilliantly – precisely what we were hoping our political ambassadors would achieve!

We need to get Kawasaki Disease higher on the political agenda and it sounds like Laura's meeting with Richard Drax MP helped to do exactly that. If you'd like to become a Societi POLITICAL AMBASSADOR contact us at info@societi.co.uk or via the contact form on our website - www.societi.org.uk

## THANK YOU to ALL our monthly donors!

*Gemma*
*Carol & Gareth*
*Andy & family*
*Hayley*
*Pat*
*Carole*
*Leanne*
*Amy*

No space to list you all but you know who you are and we are so grateful!

**Want to make a regular donation? Visit our Virgin Money Giving page or PayPal and you can!**

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

We rely solely 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!**

## What's coming up?

I'm sure you'll agree, it's been an incredible year – and we've so much planned for next year that we can't wait to get started (after we've had our Christmas dinner, of course!) Have a look at what's planned for Societi and for Kawasaki Disease awareness in the coming months. And if you have any events or plans yourself, please be sure to let us know about them. We love to hear about all that you are doing to help get Kawasaki Disease known.

### FOI analysis

We've had a staggering response to our FOI request and now have information on Kawasaki Disease hospital admissions right across the UK! After initial analysis, we plan to have this data analysed in depth to really understand what's happening in the UK around Kawasaki Disease – a detailed picture no-one has ever had before! We hope this will be so powerful going forward in our URGENT work to raise the profile of Kawasaki Disease in the UK!

### Societi is trial partner

The upcoming clinical trial titled KDCAAP (Kawasaki Disease Coronary Artery Aneurysm Prevention) will begin shortly and as a trial partner, Societi will be involved throughout. We will be leading work with families and producing patient information and clinical awareness resources. The clinical teams led by the Institute of Child Health have advanced all the groundwork so our trial can get fully underway in 2020. We can't wait to get started!

### Kawasaki Disease Registry

A patient registry for Kawasaki Disease is a priority for Societi. A registry will mean improved communication with patients and families, opportunities for participation in research and will create a powerful evidence base for more investment and more resources to support families affected by Kawasaki Disease. There's a cost of course but we're going to work together – and with your support we can make this happen!

### GP Course launch

Our GP E-learning course is almost finished! It will be online and available to all UK GP's and paediatricians early next year. WOW! What an incredible and huge group to be reaching with this valuable course! We're excited as this course will ensure GPs can access the vital information they need when making a Kawasaki Disease diagnosis. The course really does have the potential to change Kawasaki Disease outcomes for our children. YOUR support made this possible!

### GP Packs update

Our project to get Kawasaki Disease info to every GP in the UK is still very much underway – we're sending packs out all the time. We've been just delighted that some CCGs have agreed to distribute our information packs to their surgeries and even keep them on their intranets for doctors to refer to easily when they need to. With 7,000 practices in the UK we've got a long way to go, but we'll keep going with YOUR support until every GP in the UK knows Kawasaki Disease!

### Brighton Marathon!

We're so excited to be entering a team into the 2020 Brighton Marathon! And so grateful to our runners for all the effort they are putting in, in training and in getting Kawasaki Disease known! We still have one place remaining for the Marathon, so if you think you could go the distance to protect tiny hearts, get in touch!

### International Kawasaki Disease Awareness Day – 26 January 2020

We're counting down!! Join us – make plans, take part and let's make January 2020 the BIGGEST CAMPAIGN for Kawasaki Disease awareness yet! Help us protect tiny hearts! This year we are hoping to see events raising awareness of Kawasaki Disease throughout January – so if you can't get involved on the actual day, that doesn't matter! As we get closer to 26 January (a Sunday) we know there'll be more events being held and a busy week we are sure, from 20th January onwards! Let us know what you have planned - and get in touch if you need fundraising packs or info!

International Kawasaki Disease Awareness Day is such a big day for us in so many ways. The fundraising that our Societi supporters achieve on this day – and throughout January in fact, provides a CRITICAL source of income that helps us in our work for the year ahead, helping us to prevent heart damage in children from Kawasaki Disease.

In 2019 we achieved our BIGGEST impact to date. That remarkable impact was thanks to hundreds of AMAZING supporters, partners and key organisations who ran events, led fundraisers, ran press releases, joined us on social media, delivered awareness raising materials and much, much more. We want 2020 to be even BIGGER and even LOUDER, so that EVERYONE hears about Kawasaki Disease! Please join us and the rest of #TeamSocieti in making International Kawasaki Disease Awareness Day 2020 an amazing success!