



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 Family Resource Portal wins National Award

We were privileged to attend a September award ceremony as our Family Resource Portal was commended at the British Medical Association (BMA) patient information awards. Judges said our Portal was clear, easy to use and navigate and contained relevant links to clinical information.

Since being launched in January 2018, feedback from families who have used the Portal has been extremely positive. One parent said "I was given just an A4 leaflet when we got our diagnosis and I needed more information. Once I found the Societi website I haven't looked at any other!" Family feedback means such a lot to us - and we were delighted that the clinician reviewer panel of the BMA thought it was a great resource for our families too!



Welcome to our December Newsletter!



It's been a while since we updated you, though I know many of you follow our pretty-much-daily updates across social media. So I thought we'd send a pre-Christmas newsletter, and report back on lots (and lots!) of things that have been going on over the last 6-ish months. It's been a very busy period, and I hope in these few packed pages you'll be inspired by supporters stories, read our project updates and see some of the many ways which the fabulous funds you raise are being used. Together we ARE getting Kawasaki Disease known! Thank you for your support, EVERY initiative taken forward contributes to tackling the challenges we face. Into 2019, we've much to do and I hope that you'll continue to support Societi. Meantime though, my very best wishes for a wonderful Christmas and a fabulous 2019.

Rachael, Societi Founder.

P.S. Have you made your plans for 26 January 2019? I hope so!



UK & Ireland Kawasaki Disease study reveals worrying findings

Findings from the much anticipated British Paediatric Surveillance Unit (BPSU) study, published in August, show that the risk of serious heart damage from Kawasaki Disease in the UK and Ireland is currently among the highest recorded globally. The study found that a worrying 39% of infants (children under one) with Kawasaki Disease and up to 20% children affected overall develop coronary artery aneurysms. All these children will now need specialist lifetime care.

Kawasaki Disease is increasingly common - a Societi study showed hospital admissions increased fourfold in England over the last 10 years. But there's been **no improvement** in outcomes for children since the 1990s. The BPSU study found a reduced risk of heart damage in children treated before 7 days of illness. So, **awareness of Kawasaki Disease is critical** to stem the growing number of children living with lifelong heart damage, as a result of Kawasaki Disease.



Professor Tulloh, UH Bristol, who authored the paper noted that low levels of both public and clinical awareness about Kawasaki Disease across the UK may be linked to our high levels of heart damage, since delay in diagnosis leads to a delay in treatment. With increased awareness, rapid diagnosis and treatment, we can reduce the risk of lifelong heart damage in children. **Our work has never been more urgent!**

Societi Foundation & Kawasaki Disease

Societi, the UK Foundation for Kawasaki Disease was established in 2015. Through our work we raise awareness of Kawasaki Disease - a disease which affects hundreds of children in the UK each year. **Kawasaki Disease is the leading cause of acquired heart disease in children** in the UK. Raising awareness of the disease is extremely important, as recognising the symptoms and treating early could save a child's heart from life-long damage.

Little known but increasingly common, the symptoms of Kawasaki Disease are similar to many other common childhood diseases such as Scarlet Fever. Too often, this leads to misdiagnosis and a delay in treatment, severely affecting outcomes. In the UK 28% of diagnosed children have heart damage and 39% of infants develop coronary artery aneurysms. These are serious complications which may be avoided if children are treated early.

Know Kawasaki Disease!

Kawasaki Disease symptoms include a **persistent fever for five days or more**, rash, bloodshot eyes, "strawberry" tongue, cracked, dry lips, redness of the fingers and toes and swollen glands in the neck, often just on one side. Kawasaki Disease can be present with some or all of these symptoms. A **persistent fever** is the one defining symptom and will always be present. The symptoms of Kawasaki Disease can also appear one after the other, over a few days.

Kawasaki Disease Symptoms



Persistent fever



Cracked lips / 'strawberry' tongue



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands



Our People – Societi Fundraising Heroes & Star Supporters of 2018

Without our Societi Supporters, our progress to get Kawasaki Disease known and take forward projects which benefit affected families would be so much slower. We are hugely grateful to every single Societi Supporter – whether that's those who've been working to raise awareness, raise funds, shop with us – or support us on social media. Your support means that together, we reach more people and have greater impact. For our children. So here's just a few of our Societi fundraising heroes in 2018. There's simply too many to mention you all! ...But you are all heroes!

Vocal Fusion Choir

We had immense support from this outstanding Choir, being the beneficiary of proceeds from their August concert – amounting to a staggering £3,446.75! Thank you to everyone at Vocal Fusion – for your incredible contribution which is helping us fight Kawasaki Disease!



Kutch Golf Society Competition Day

A wonderful £5,000 donation was made by the KGS committee, following their fabulous charity tournament. Huge generosity was shown by everyone attending and those who worked so hard to make the day such a success. Thank you KGS for your incredible support as we combat Kawasaki Disease! We're deeply grateful to all the committee for choosing to support our work, and protect tiny hearts.



Stevenage Half Marathon

Well over 600 brilliant athletes ran this fabulous half marathon, with race proceeds being donated to 3 charities including Societi. This incredible donation was inspired by Andrew & Lucy Patterson, both keen runners and dedicated Societi supporters. They raised over £3,100 and incredible Kawasaki Disease awareness along the way – all of which will power our work into 2019.



SKLP Cardiff Community

A tremendous day of awareness raising, community activity and sport was held in August, building life-saving knowledge and raising transformational funds for Societi. A donation of £4,550 was presented to us at the community Diwali celebrations! Funds raised will directly benefit the Cardiff area as we work with GP's to build Kawasaki Disease awareness.



Societi Virtual 10k

With a passion for both running and Societi, supporters Vikki & Hayley decided to host a Virtual run. Leading and driving every aspect of the project, with Andrew providing expert training advice too, the event kicked off on World Heart Day! They built an international community of 120 supporters and raised an impressive £2,300!



Greenstones & Shetland Soap

Without the support of this fabulous firm, our partnership with social enterprise Shetland Soap to create our "All Heart" hand soap wouldn't have been possible! Bottles of this FAB product are now busy raising awareness in homes and offices everywhere. Thank you Simon for being determined to prevent heart disease in children!



Star Supporters

Throughout the year there have been incredible achievements from a host of Societi Star Supporters. These are people who have gone above and beyond for our charity – committing energy, time, personal resources and ideas. We're hugely grateful for the **extraordinary** contribution they have made to Societi's aims.

Diane Conway

Ali & Alister Jenkins

Neeta Patel

Lucy & Andrew Patterson

Vikki Waldron

Julie Jenkins

Hayley Poole

Carol & Gareth Davies

Mareanne Bradley

Lisa Freegard

The Star Supporters above have all featured on our social media through the last six months, highlighting their incredible initiatives which are as diverse as...

∞ **A very brave sponsored head shave!** ∞ 5km (very cold!) open water swim ∞ **Bringing ideas & energy** ∞ A London marathon record attempt ∞ **Running 5km every day for a month** ∞ Remarkable awareness raising in their community ∞ **Securing high profile sponsorship** ∞ Leading key projects for Societi ∞ **As a research volunteer** ∞ Major donations from their own volunteering ∞ **Inspiring others to support Societi** ∞ Climbing mountains ∞ **Running marathons** ∞

**A HUGE
thank you to
ALL our supporters!**



Our Partners

Societi has worked with many partners in the last 6 months, each partner has extended our reach and increased our impact. You'll see some of our partner logo's throughout this newsletter. But there are more! And we're deeply grateful to ALL of them.



Our Projects – Raising Awareness

Since our last newsletter (March 2018) we've sent out a staggering **841** parcels of awareness raising materials! That includes Societi Hospital packs and GP/Primary Care packs, TEMPERS, posters for community awareness events and more! Our Supporters across the UK have been so active, determined as we are, to get Kawasaki Disease known!

We've added new products to our shop, raising awareness with every item sold. Over **7,000** Societi wristbands are now in circulation, designed through a primary school competition on Awareness Day 2018! We've posted over **1,000** lovely Societi pens, **100** 2019 calendars and almost **100** 'All Heart' hand soaps. All of this merchandise, as well as raising funds, generates critical awareness in every part of the UK.

Since March, we've also established a Facebook page, with over **200** posts shared, and an average reach now of about **20,000** people each month. Twitter still plays a vital role in our work and we've generated a brilliant **394,700** impressions since March. We're busy on Instagram and LinkedIn too – much of our reach is amplified by our fabulous supporters, who like, retweet and share what we write so that together, we get Kawasaki Disease known!

Working with many of our Supporters, we led a phenomenal Kawasaki Disease campaign in September 2018 for World Heart Day, working directly again with brilliant colleagues at the World Heart Federation to highlight Kawasaki Disease.



Our Projects – Sharing Knowledge



With NHS England, we comprehensively updated the NHS Choices pages on Kawasaki Disease, making current, accurate information on Kawasaki Disease available to all, through NHS Choices.

We supported specialist Kawasaki Disease diagnostic and technical training for 100+ paediatricians with expertise in cardiology, from right across the UK. This was led by Professor Robert Tulloh, with Societi materials for every delegate.

With both NHS England and the MHRA, we published guidance on Kawasaki Disease and vaccines, providing important clarifications on previously published materials, to inform families.



We re-wrote the KSSG information leaflet, re-publishing this to the KSSG pages on www.societi.org.uk. Hugely valuable as one of the initial information source many families receive when finding themselves affected by Kawasaki Disease, this is now fully updated reflecting the latest facts and figures!

Work has advanced through our expert writing group, led by NHS Clinical Directors, to deliver comprehensive long term management guidance for those affected by Kawasaki Disease, and updated acute guidance. The publication of this guidance will significantly improve the care of Kawasaki Disease patients in the UK.



We conducted a study on the diagnosis day experience of UK families affected by Kawasaki Disease, revealing important information on the illnesses Kawasaki Disease is most commonly misdiagnosed as – delaying treatment times.

We've expanded our clinical web content, including increasing the number of research links to almost 40. There are many research papers on Kawasaki Disease (thousands!) but those on our website are UK led, or relevant to our UK population.



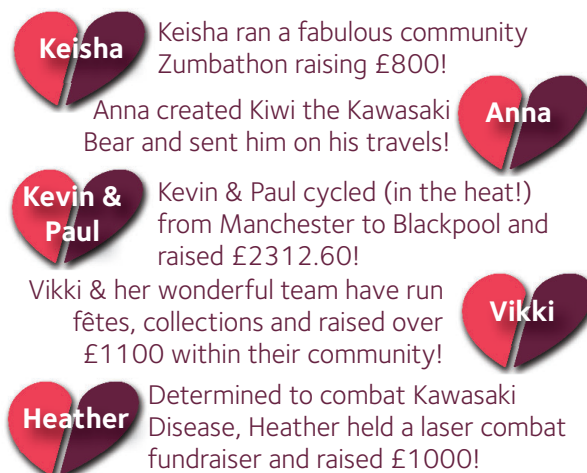
Incorporating RCPCH endorsed TEMPERS, we launched and have started distribution of our Societi Hospital packs and Societi GP/Primary care packs – building Kawasaki Disease clinician knowledge. Want one? Please just get in touch! And, we reached hundreds of paediatricians at the RCPCH conference in Glasgow, with posters and talks led by Professor Robert Tulloh, building critical clinical awareness

Our Progress...progress...progress!

Societi has been established now for almost 3 years! In that time we've achieved a great deal, together with our supporters. July 2018 marked an important milestone, our 1st anniversary as a registered charity. Our continuing impact since gaining registered charity status has been phenomenal! With a growth in Societi Supporters every single week, more and more ambitious fundraising projects underway and awareness of Kawasaki Disease growing by the day, we are accelerating our EXCITING trajectory to combat Kawasaki Disease! Here's a few more highlights of our work and our supporters:

- ♥ An increase in the number of all-important regular donors to Societi Foundation
- ♥ Continued development of www.societi.org.uk with new pages and many additions to this increasingly well used resource for families and clinicians
- ♥ Updates to our RCPCH endorsed TEMPERS information leaflet, with new BPSU study findings.....we've now sent out over 70,000 TEMPERS leaflets with YOUR support!
- ♥ Advancing development of our acute treatments clinical trial, now progressing through the funding appraisal process
- ♥ Taking forward our clinician E-Learning module to be based now on emerging updated UK acute guidance
- ♥ Advancing UK clinical policy and advocacy through our UK Steering Group for Kawasaki Disease comprising UK health influencers and leaders
- ♥ Waitrose, Winton donated to Societi thanks to Steph and wonderful supporters Sue and Diane, with £420 being received!
- ♥ Strengthening our strategic partnerships with the World Heart Federation, British Heart Foundation, Royal College of Paediatrics and Child Health, NHS England and the parent support group KSSG

We've so many people to thank! *Here's just a few more!*



Thank you to every single one of our supporters!

Societi Kid Family Grows

Societi Kids are a really important part of our charity. They work hard for us by raising awareness of Kawasaki Disease and at the same time, help to protect the privacy of children affected by Kawasaki Disease.

It is our policy to never produce or distribute images of child patients and Societi Kids help us get Kawasaki Disease recognised as a disease which affects children – and are super cute too of course! Each Societi Kid has been hand drawn by our very own junior artist. There are now well over 100 and that number keeps on growing. Some of our newer Societi Kids have even been inspired by our Societi Supporters themselves! Together they're now working hard for Societi, raising the profile of Kawasaki Disease! Keep an eye out for our new Societi Kids as they appear across social media and on our awareness raising material!



Our Plans – 2019

As we move into 2019, there is absolutely no let-up in our determination to get Kawasaki Disease known! We're **EXCITED** about a range of possibilities, projects and partnerships which we hope will develop in 2019. We've made grant applications to several organisations, as we continue to look for ways to support our work and our growth. We'll keep you posted on those, please keep your fingers crossed! Here's a glimpse of a few projects planned for 2019...

26 January, Kawasaki Disease Awareness Day

*Help us make this the **BIGGEST** and **BEST** yet!* Check out the dedicated page on our website! Now's the time to be firming up plans! Why not see if you can speak to school/work before the Christmas break!

More Films!

We'll be launching a series of new films to add to the ever growing number of information and experience films we've already made, to help both affected families and help clinicians. Keep an eye on the Societi YouTube channel for updates!

13–15 May, RCPCH Annual Conference

As in 2017, we are exhibiting at this fabulous event and this time, leading a workshop on Kawasaki Disease diagnosis too. It's the largest paediatric conference in the UK – we'll be speaking with 100's of paediatricians!

Clinician Webinar – Kawasaki Disease 'how to'...

Working with the RCPCH, Prof Tulloh & Societi will hold a Kawasaki Disease technical webinar, building knowledge with doctors who may see children with Kawasaki Disease!

January–May, Develop and launch a NEW Children & Young People's Resource Portal

Inspired by the World Health Organisations focus on the mental health of young people, and the often scary and inaccurate information found online about Kawasaki Disease, we have committed to the development of a tailored online space for children and young people affected by Kawasaki Disease, which we are working with young people to develop!

New Partnerships!

We will be announcing one, perhaps two new partnerships for Societi in 2019. This is **HUGELY** exciting and if they advance, they will help us significantly grow our impact and reach. Watch this space!

E-Learning Module for Clinicians

Now to be based on updated guidance, we paused development of this whilst the new acute guidelines were developed. All the content is complete now and we are working with our software developer to get this finalised and launched!

29 September, World Heart Day

Together with the World Heart Federation, we'll be working to ensure this global event puts Kawasaki Disease in the spotlight – and grows awareness in the UK and beyond! Join us with a fundraiser!

Questions of the Heart – Research

With funds being raised weekly for research, we'll soon be in a position to progress with this family led research project, identifying and answering a question or questions which our families want answered!

Kawasaki Disease Symptoms



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