

*societí*

*Your  
Kawasaki  
Conversation*

*Let's make a plan!*





Persistent fever



Cracked lips/  
'strawberry' tongue



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands

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*We want everyone in your community to know Kawasaki Disease – and prevent heart damage in children*

## Our U.K. Kawasaki Conversation

### What is Kawasaki Disease?

It is the leading cause of acquired heart disease in children in the UK. It affects hundreds of children every year and because of low levels of awareness, potentially many more go undiagnosed, with life threatening and life-long consequences. Kawasaki Disease is serious. Awareness is urgent.

### What's the plan?

For International Kawasaki Disease Awareness Day 2018, Friday 26 January, Societi would like to help you to create a **Kawasaki Conversation** – with an ambitious aim to involve as many people as possible. We want communities right across the UK to take part and in small ways and more, grow our Kawasaki Conversation – building knowledge and awareness which can protect children's hearts.

### What's the aim?

We want every person, every doctor, **every family in the UK to know Kawasaki Disease** – as early diagnosis and treatment of the disease is directly linked to better outcomes including reduced heart damage. By being involved in International Awareness Day 2018, or raising awareness at any time, you can help us directly in achieving this aim.

Affected children will only get an early diagnosis if people can recognise Kawasaki Disease. Research by the British Paediatric Surveillance Unit shows that early diagnosis directly improves outcomes, reducing the likelihood of lifelong heart damage.

### How do I get involved?

Getting involved is easy – and fun! You can share Kawasaki Disease information with family and friends – or how about sharing TEMPERS leaflets at your place of work, local school, GP surgery or pharmacy? Perhaps you'd like to raise funds as well as raise awareness? Fundraising is hugely important to us as only with your support can we continue our work. If you want to fundraise you could:

- Hold a cake sale
- Have a wear red day at your local school or at work (even red socks count!)
- Have a non uniform day
- Hold a coffee morning

...there are lots of other ways to raise funds and our supporters have run marathons, done sponsored walks, held dinner parties and evening get-togethers – all in aid of Societi!

Within this pack you'll find:

- This information booklet
- Kawasaki Disease Awareness posters
- TEMPERS leaflets
- Societi newsletters
- Thank you stickers

...all to help you with your awareness raising and fundraising. If you'd like us to create a special poster for a particular event – just get in touch and we'll help!

*Let's work together – and grow our UK Kawasaki Conversation*

### Did you download this booklet?

If so, the posters, newsletter and leaflets can also be downloaded! Or contact us with your postal address and we can send you a pack!

### Why 26 January?

Every year, 26 January is International Kawasaki Disease Awareness Day. Last year, the UK took part for the first time, led by Societi from our Nottinghamshire base. Very much an online campaign, we levered the media strength of international groups and agencies including the World Heart Federation, British Heart Foundation and the RCPCH. This year we want to have much greater impact and with your help take our awareness raising message directly to the hands of **your community**.

### What is Societi doing?

For International Awareness Day 2018, we will run an online campaign again and we hope to be working with communities right across the UK – including yours, promoting and celebrating your events and activities. We'll work once more with the British Heart Foundation, the World Heart Federation and other national and international partners. We will connect strongly into the global community – and promote our growing Kawasaki Conversation, right here in the UK.

We'll be issuing a joint press release with our partners near to 26 January and will publish this online on societio.org.uk. If you'd like to talk to your local paper about running an International Kawasaki Disease Awareness Day story – please do! Let us know and we will help!

Of course, we work through the year raising Kawasaki Disease awareness and you can start a Kawasaki Conversation at any time of year! So if you're reading this in June (or whenever!) – no need to wait, you can start your Kawasaki Conversation today!

### Let's get started!

On the following pages there are ideas for how you can raise awareness. But don't be limited by these – your own ideas will be even better! Whatever you'd like to do, please get in touch and let us know!

**societi** Building Kawasaki Disease awareness in your community

**Growing Awareness - a non-uniform approach!**

Whether it's a non uniform day at school or a dress down day at work - a "non uniform" day is a great way to raise awareness and raise funds so we can continue our work all year long!

You could promote the day with posters - download the poster below on the "26 Jan International Awareness Day" page within the Kawasaki Disease tab on our website

- societi.org.uk If you're holding a non uniform event you might suggest a donation amount for those taking part - or just have a collection on the day!

A non-uniform day at any time of year is a great way to raise awareness!



**societi** Building Kawasaki Disease awareness in your community

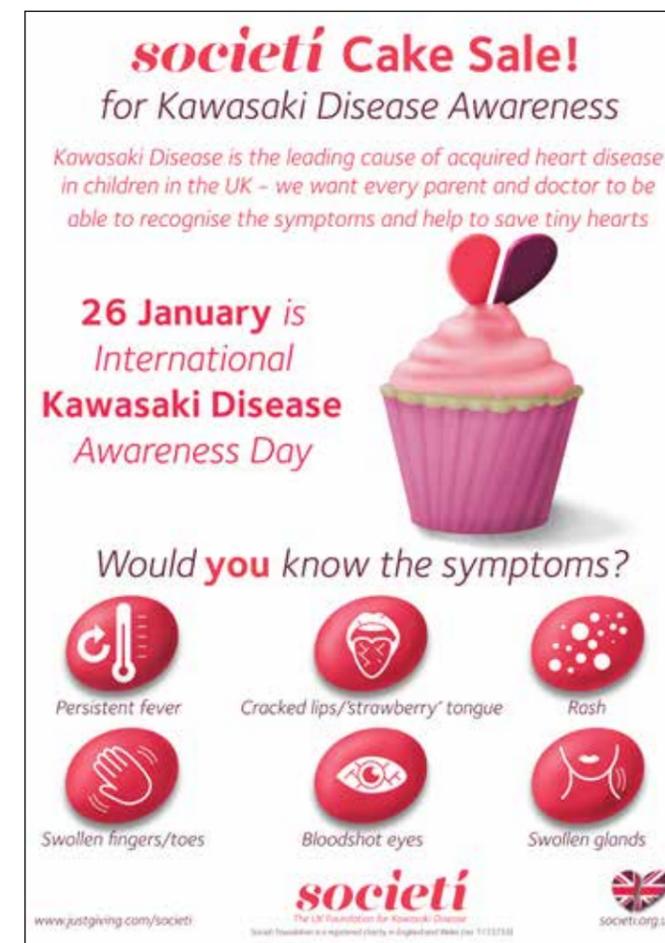
**Growing Awareness - with Coffee and Cake!**

Holding a cake sale is a simply fab way to bring people together, it's a fun.... and yummy (!) way to start a Kawasaki Conversation. Cake sales are brilliantly memorable events - small or large! Perhaps at your place of work or children's school, cake sales have happened before - why not make this one a bit different with heart shapes or heart themed cakes! Or red and white as your cake theme! To be honest,

chocolate cake works brilliantly (but maybe that's just us!!)

How about a Kawasaki bake off... the options are endless! All of them taste just as good :)

Why not add coffee to your cake sale - there's a coffee morning poster to download if you fancy, at societi.org.uk



**Growing Awareness - Go Red!**

'Red' might be the theme for your Kawasaki Conversation - Kawasaki Disease is sometimes known as the 'Red Disease'! Why red....? Well, distinctive features of Kawasaki Disease include red eyes, red lips and mouth, red hands and feet - and a red rash!

Perhaps staff at your local GP surgery or local pharmacy can be talked into wearing

red for the day to raise awareness? If they want to - let us know and we can provide them with lots of leaflets and posters too! Going 'red' for the day really will help us achieve our aims!

**Growing Awareness - Your own way**

There are lots - and lots - of ways you can start a Kawasaki Conversation in your community. Dropping off TEMPERS leaflets everywhere you go is a great start; our Founder Rachael doesn't go anywhere without a pile of TEMPERS in her handbag...!!

Simply changing your profile pic on social media to a Societí heart logo, sharing the link to our website with family and friends,

putting a poster up on a community noticeboard in your local supermarket or at work - these are all really effective ways of spreading the word. You can follow us on Twitter and Instagram too - a great way to get started.

If you'd like to do something unique, or plan a particular event, maybe later in the year - let us know and we will help where we can!

**Making Kawasaki Disease memorable in your Community**

**Remember TEMPERS**

Through our early work as an organisation, it's really clear that simply more people need to know Kawasaki Disease. As an 'enigmatic' disease which can appear in many guises, there's a reason it's been little known, and often misdiagnosed over time. We want to change that...

So, one Sunday morning, our Founder Rachael created our **TEMPERS** mnemonic to make Kawasaki Disease memorable for both parents and doctors alike. You can use this leaflet as a focus for your awareness raising in your own Kawasaki Conversation - just handing out TEMPERS leaflets is a great way to start!

**Kawasaki Disease? Remember TEMPERS**  
Children with Kawasaki Disease are characteristically irritable!

**T** Temperature - Persistent high fever

**E** Erythema - reddened hands and feet with swelling

**M** Mouth - dry, sore mouth, cracked lips, 'strawberry tongue'

**P** Pace - Treat early to reduce potential heart damage

**E** Eyes - bloodshot, non-sticky conjunctivitis

**R** Rash

**S** Swollen glands in neck, often just one side

**5 days of fever? THINK Kawasaki Disease!**

**If a child has a PERSISTENT FEVER and two or more of these symptoms THINK KAWASAKI DISEASE!**

RCPCH  
www.justgiving.com/societi  
societi.org.uk

**Kawasaki Disease is the #1 cause of acquired heart disease in children in the UK...**

...help us change this.

**Kawasaki Disease - who does it affect?**  
It is mostly a childhood illness with over 75% of those affected being under 5 years old - but it does affect older children too and can affect people of any age.

**Kawasaki Disease - what's the issue?**  
In the UK, awareness of Kawasaki Disease is low. If treated late or untreated, affected children have a significantly increased chance of heart damage. Currently U.K. diagnosis and treatment times are too slow. 28% of diagnosed children experience heart complications, 24% of children diagnosed have coronary artery aneurysms. For a few children every year Kawasaki Disease is fatal. help us change this. Early diagnosis and treatment is key to improving outcomes for our children.

**Kawasaki Disease - how common is it?**  
U.K. hospital admissions for Kawasaki Disease have increased fourfold in the last ten years. It's more common than some forms of bacterial meningitis. About 1 in 10,000 children are currently diagnosed each year and very poor levels of awareness mean even more children may be affected.

**Kawasaki Disease - what can I do?**  
Know the symptoms and remember, symptoms may not appear all at once. Not all children present with all symptoms so - if a child has a **PERSISTENT FEVER** for **FIVE DAYS** or more with two or more of the symptoms overleaf **THINK KAWASAKI DISEASE** and seek **URGENT PAEDIATRIC REVIEW**. You could save a child's heart.

**Kawasaki Disease - why haven't I heard about this before?**  
Kawasaki Disease is increasingly common in the U.K., globally cases are rising fast - but it remains little known by doctors and the general public alike. We want to change this! Too many children and young people today have heart damage because of Kawasaki Disease. The consequences of this can be very serious and can be life long. help us change this.

For more information visit [societi.org.uk](http://societi.org.uk)

RCPCH  
Societi Foundation is a registered charity in England and Wales (no. 1173755)  
societi.org.uk

**Creating Kawasaki Conversations with care**

**'Societi Kids'**

We're all alert to children's rights and children's privacy. And never-more-so when it comes to their health. So we've taken a conscious decision as an organisation to not use images of child patients in Societi produced material.

To help develop your **Community Kawasaki Conversation**, you can use our materials - with the 'help' of Societi Kids, draw attention to the **SERIOUS** nature of Kawasaki Disease - and the **URGENT** need for everyone to know the symptoms.

But that presents us with a challenge - to convey an often children's disease to an audience who doesn't know or recognise it. So we created Societi Kids working with our Societi junior artist who has drawn children for us from every walk of life - every part of our society. You'll see them in our tweets, GIFs, on our website and on our awareness raising material.

Societi Kids help us to do this in a **FUN** way, and a way which we know from experience to date allows people to **ENGAGE** well, across all ages and backgrounds.

Happy Birthday  
Have a cool Birthday!  
For you...

**societi** the UK Foundation for Kawasaki Disease  
Kawasaki Disease is the leading cause of acquired heart disease in children in the UK... help us change this.

**societi**

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

### A bit more about Societí - from Rachael!

Based in Newark, Nottinghamshire, Societí was established to raise awareness of Kawasaki Disease.

Societí works through partnerships to drive transformational change in awareness, about Kawasaki Disease. Our ambition is that everyone: every parent, every doctor and every healthcare professional knows Kawasaki Disease.

As Founder, I established Societí to bring a voice to Kawasaki Disease. It was clear that my expectation for change and action, as a parent with experience of Kawasaki Disease, would not be met without a catalyst for change. And so Societí began!

We work with pace and passion to create high visibility for Kawasaki Disease and bring about the transformation in care our children deserve. We are working to build and share knowledge amongst medical professionals and secure critical investment. Through our work **we can** stem the now rapidly rising number of children carrying a lifelong legacy of heart damage. They cannot act for themselves.

**So Societí must.**

**Rachael McCormack, Societí Founder**

### Our Aims

We are an influencing and policy shaping organisation, always working through partnerships to achieve our aims:

Societí has four aims:



**1. Awareness raising -**  
a voice for Kawasaki Disease



**2. Clinical research -**  
sharing knowledge,  
influencing funders and  
enabling co-ordination



**3. Clinical supervision -**  
shaping new care protocols  
and health policy



**4. Support for the Parent  
Support Group - KSSG**

## The UK Foundation for Kawasaki Disease

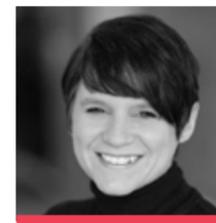
### Our people

**Rachael**, our founder, is an energetic and dynamic leadership professional with wide ranging executive experience across public and private sector organisations. She is recognised for a focus on enabling high impact, delivery through partnership, achievement of outcomes and a leadership approach which is collaborative and decisive.

**Rob**, Professor of Congenital Cardiology and Clinical Lead for Paediatric Cardiology, Bristol, is an internationally recognised expert in Kawasaki Disease. Rob leads the largest Kawasaki Disease clinic in the UK and the only Adult Kawasaki Disease clinic. He is an active researcher and collaborator and supported Societí even before our formal establishment. Rob sits on our Board as a Trustee and leads the work of our Scientific Advisory Board, providing clinical oversight for our organisation.

**Claire**, also a Societí Trustee, has 19 years of experience working within the design industry providing comprehensive, technical, graphic and research support across a broad range of projects and disciplines. A valued member of the team, she continues to apply those skills for Societí with her combination of experience and creative flair enabling her to provide proficient and flexible support.

**As volunteers**, we work together with our Board of Trustees and Scientific Advisory Board to create a voice for Kawasaki Disease across the U.K.



**Kawasaki Disease: Facts & outcomes**

**Kawasaki Disease - Facts:**

Sometimes called the 'red' disease, Kawasaki Disease is characterised by a **persistent high fever**. You'll see the symptoms in the covers of this document.

- Kawasaki Disease is the UK's leading cause of acquired heart disease in children
- Hundreds of children in the UK are diagnosed with Kawasaki Disease every year
- Across the globe, incidence of Kawasaki Disease has doubled in the last decade. In the UK hospital admissions have increased **FOURFOLD**
- Awareness in the UK of Kawasaki Disease is low, research shows delayed treatment = poorer outcomes and increased heart damage
- More UK children today are diagnosed with Kawasaki Disease than some forms of bacterial meningitis
- 20,000 children and young people are affected by Kawasaki Disease today
- If diagnosed and treated early, children have a much better chance of recovery
- **28% of all affected children will suffer heart damage. 24% will experience coronary artery aneurysms**
- **Kawasaki Disease is serious. Awareness is urgent!**

2016 Outcomes - This is where we are today



2020 Outcomes? - This is where we want to be



**Societì - creating impact through partnership**

**Where We Want to Be**

Before coming across Societì, or perhaps as a family being affected by Kawasaki Disease, it's very likely that you hadn't heard of Kawasaki Disease. We have a vision of a time when Kawasaki Disease is well known, well understood - and as a result, those centres providing expert care, quality treatment and ongoing learning - are well resourced. But there are many hurdles ahead before we achieve our vision.

**What is Needed**

The image opposite focuses on the main challenges we face and gives us our timeline - which we know is ambitious but necessary. We lag behind our European, American and Asian partners with amongst the poorest levels of awareness across our medical community of Kawasaki Disease in the western world. Amongst parents too, Kawasaki Disease is little known and it is this gap in knowledge which poses such a great threat -- as it is when treatment for Kawasaki Disease is delayed, that the most serious consequences can occur. When diagnosed and treated promptly, children have the greatest chance to make a full recovery.

If we address the knowledge gap with all our audiences, with Governments, with policy makers and funders, with medics and with members of the public, we know we can make real progress.

**Key Partnerships in Place**

But we are not standing still in the face of these challenges. Each week we take proactive steps, forge new relationships and partnerships, expand our networks, extend our online presence,

promote key messages through social media and raise the profile of Kawasaki Disease in all we do. Today, we are:

- Working actively with **NHS England and Public Health England** through our UK Steering Group for Kawasaki Disease
- Being supported by an **International Pharmaceutical firm** to develop a clinical E-Learning module for Primary Care
- In dialogue with the **BPSU and RCPCH** - working together on a range of projects to raise awareness with the clinical community
- Providing input into the **NHS Improvement Service**, working on patient information
- Proudly working with the UK Support Group, **KSSG** on a host of connected projects, including online guidance for parents
- Actively in partnership with the **British Heart Foundation** pursuing a UK Clinical Trial for Acute Kawasaki Disease
- Working with the **World Heart Federation** through social media to bring global awareness to Kawasaki Disease
- Partnering through our Scientific Advisory Board with **Bristol Children's Hospital, Great Ormond Street Hospital and St Mary's Hospital London.**

We have just started building our Societì partnership. We have many more opportunities ahead. **Your support** makes this possible.

## Ready to build you Kawasaki Conversation? We hope so!

### Let us know your plans!

Whatever you do – whether it’s taking a handful of leaflets into work or school, or a community wide fundraiser, let us know!

We’d love to hear about your projects and initiatives – and can promote your activities on Twitter too! A Kawasaki Conversation can start at any time of year so do keep in touch!

Let’s grow our Kawasaki Conversation right across the U.K – together, we can prevent lifelong heart damage in our children.

### How to send in your funds raised

If you are fundraising for Societi, there are lots of ways you can send us the money you’ve raised. You can:

- Set up a JustGiving page and donate the funds through that (see our website for more information on how to do this and a link!)
- Send us a cheque – payable to “Societi Foundation” – send it to Victoria Court, Holme Lane, Winthorpe, Newark, Notts, NG24 2NU (and do include a note to let us know who it’s from and how you raised the money)
- Donate via our website through PayPal – you’ll find a Donate button on the home page
- Send it by BACS – Contact us by email (info@societi.co.uk) and we will give you the details you need.

### Your Kawasaki Conversation Toolkit!

Ready for posters and leaflets? On the website – go to the Kawasaki Disease tab and click the **26 Jan International Kawasaki Disease Awareness** tab from the drop down menu. Here you’ll find lots of printable and downloadable resources.

If you’re looking for other things, check out the **For Families Resources and Downloads page** too – where there is even more information to print, which will help you grow your Kawasaki Conversation.

If you’d like information posted to you – contact us (info@societi.co.uk) – we can print and post leaflets, posters and newsletters. We can send you ‘thank you’ stickers too and labels for a donation box. All we ask is that you tell us about your event and how you get on!

If you’re planning a fundraiser or awareness event – at any time of year – please contact us if you need additional support and we will always try to help.

### Got Any Questions?

If you’ve any questions at all, please get in touch and we will help wherever we can!

Contact us by email – info@societi.co.uk

...or through the contact form on our website. We’d love to hear from you!

## My Kawasaki Conversation

A page for your own notes!

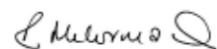
**Thank you**

Just by reading this document, which we hope has helped you grow your own ideas and plans, perhaps you now also know a little more about Societi and Kawasaki Disease than before.

For me, that's a truly valuable outcome to have achieved already. Sharing knowledge and growing the number of people who can recognise this often pernicious disease will always remain a core aim for Societi.

Thank you for reading and thank you for thinking about raising awareness together with us. Together we can combat Kawasaki Disease and the time you've already invested in doing just that means such a lot.

With my very best wishes,



Rachael McCormack, Founder  
for Societi Foundation



**Persistent fever**



**Cracked lips/  
'strawberry' tongue**



**Rash**



**Swollen fingers/toes**



**Bloodshot eyes**



**Swollen glands**



# *societí*

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[www.societi.org.uk](http://www.societi.org.uk)

