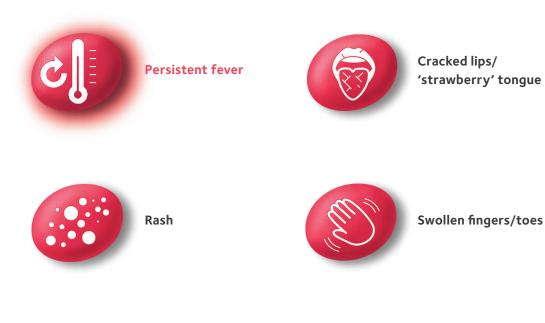
Your Kawasaki Conversation

Let's make a plan!





Kawasaki Disease Symptoms



Swollen glands

Bloodshot eyes

societí Contents

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

Our UK 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?

At Societi, we've an ambitious aim to tell 'just' 65 million people - the UK population about Kawasaki Disease but we can't do this alone! Societi would like to help you to create a **Kawasaki Conversation** in your community - your work place, your school, your sports and social clubs - everywhere! We want communities right across the UK to get to know Kawasaki Disease and help us grow our Kawasaki Conversation. Together we can build 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 - Increased awareness will promote early diagnosis and treatment of the disease which is directly linked to better outcomes including reduced heart damage. By being involved in raising Kawasaki Disease awareness, you can help us 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:

- Have a Superhero day!
- 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 or a dressdown day
- Hold a coffee morning
- · Host a bingo or quiz night!

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

There's lots of support we can give you:

- Kawasaki Disease Awareness posters
- TEMPERS leaflets
- Societi newsletters
- Thank you stickers
- · and much more

....all to help you with your awareness raising and fundraising. If you'd like to create a special poster for your 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, posters, newsletter and leaflets can also be downloaded too! Visit societi.org. uk to find out more – or contact us with your postal address and we can send you a pack!

What about 26th January

Every year, 26 January marks International Kawasaki Disease Awareness Day - a great date to set for a Kawasaki conversation! In 2016, 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. Each year we have gained greater and greater impact, reaching more and more people, working with a much bigger group of partners and hundreds of Societi Supporters. With your help we can take our awareness raising message directly to the hands of your community.

Every International Awareness Day, we run a campaign and work with communities right across the UK – could you help us to work with your community? What event or activity could you hold? Societi work with the British Heart Foundation, the World Heart Federation and other national and international partners gaining UK wide coverage. We also connect strongly into the global community – and promote our growing Kawasaki Conversation, right here in the UK.

We issue a joint press release with our partners near to 26 January and publish

this online on societi.org.uk. If you'd like to talk to your local paper or company news desk about running an International Kawasaki Disease Awareness Day story please do! Let us know and we will help!

Keep an eye on our website in November each year if you want to get involved in this - our BIG awareness day!

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! We'll help where we can.

For ALL of these events, our TEMPERS information leaflet is a great addition and a great way to raise awareness. Download it or get in touch & we'll send you a stack of leaflets.

On the next few pages are some ideas, hints and tips on how to get started with fundraising and raising awareness.

Building Kawasaki Disease awareness in your community

Ways to Grow Awareness and Fundraise -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 from 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 is a great way to raise awareness!

Our TEMPERS information leaflet can also be downloaded – great for sending home to parents or sharing with your work colleagues.



- ✓ Talk to your local school
- √ Choose a date
- ✓ Print out your posters
- ✓ Promote your event
- ✓ Collect a suggested donation of £1 per child

societí A foodie fundraiser!

Coffee and cake!

Holding a cake sale is a simply fab way to bring people together, it's a fun.... and delicious (!) 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 shaped or heart themed cakes! Or red and white as your cake colour 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 :)

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



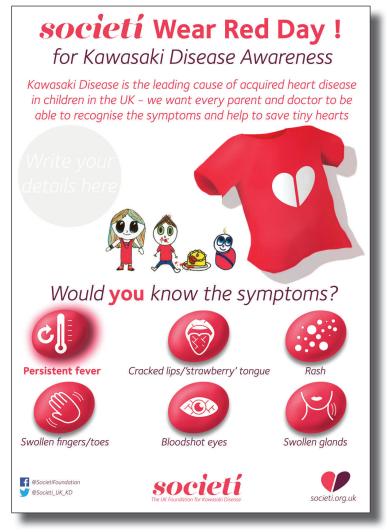
- ✓ Pick a venue
- √ Choose a date
- ✓ Print out your posters
- ✓ Have a bake day and make lots of yummy cakes!
- √ Have fun selling your delicious cakes

societí Raise awareness in red!

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! red for a day to raise awareness? Perhaps you could organise this with school, nursery or even at the office? Let us know and we can provide you with lots of leaflets and posters too! Going 'red' for the day really will help us achieve our aims!

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



- ✓ Talk to your local school, nursery, community group or your work place
- √ Choose a date
- ✓ Print out your posters
- ✓ Collect a suggested donation for everyone taking part

societí Posters, leaflets and more...

Do it 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 Societi heart logo (or choose one of our Societi Foundation

for other

ading to

RCPCH

days

frames), 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 Facebook, Instagram and Twitter too - a great way to get started. If you'd like to do something unique, or plan a particular event - let us know and we will help where we can!





@Societi_UK_KD

@societi_uk_kd



✓ Get in touch with us via the contact form on our website or email info@societi.co.uk to discuss your plan for raising awareness of Kawasaki Disease. We'll help where we can!

This is too slow!

This is too high!

societí

TOGETHER WE CAN CHANGE THIS!

societi ora uk

societí Naan-tastic - another foodie one!

Host a curry night!

Curry is the UK's favourite food and a curry night is a great way to get all your friends, family or work colleagues together and unwind after a hard week's work! Combine your curry night with lots of Kawasaki conversations and you'll have perfect evening!

Speak to your local restaurant or pub to see if they would be willing to help you

host your Kawasaki curry night and help you to raise funds for Kawasaki Disease awareness.

If curry isn't your thing, a restaurant takeover of any 'flavour' would work just as well!

A great approach is to agree a set menu for a price, add a donation amount and you're off! What a fabulous foodie fundraiser!



- ✓ Choose a restaurant
- Print out some posters
- Make a plan with the
- Invite everyone!
- Enjoy a great night out!

societí Eyes down for a great night!

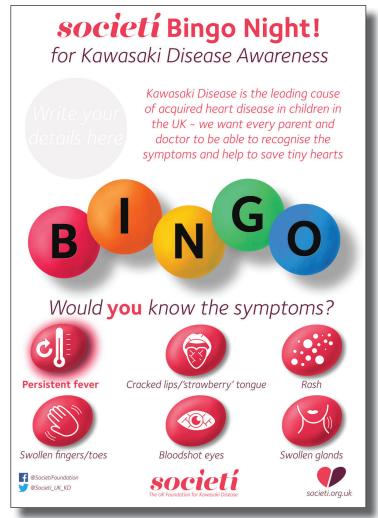
B.I.N.G.O!

Bingo nights are fun and more popular now than ever. All you'll need is some space, some bingo balls and your friends, family and community to take part!

This is a relatively simple to organise but really effective way to raise funds and awareness for Kawasaki Disease. You could even try to work in some heart related 'Kawasaki bingo calls' to raise even more

awareness - two little hearts, 22! - we are sure you could come up with something better!

Maybe there's a local bingo venue close to you - why not ask them to help with a fundraiser? And BINGO... Awareness, fun and funds!



- ✓ Pick a venue
- ✓ Print out some posters
- ✓ Organise a bingo caller and bingo cards!
- ✓ Enjoy a fun filled evening!
- √ Think about orgainsing a raffle too!

societí Here's one for everyone!

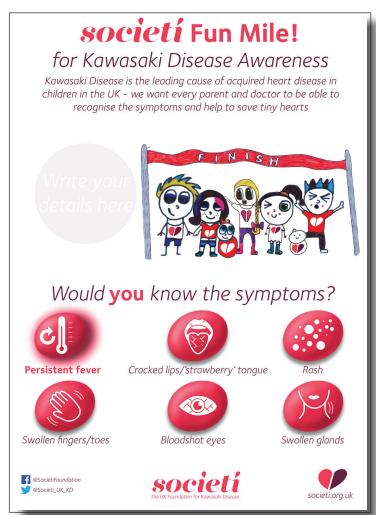
Walk a 'Fun Mile'!

Getting out and about in your community to raise awareness of Kawasaki Disease is a great idea, and it's great if everyone can be involved. Organising a 'Fun Mile' is a brilliant way to get out and get moving and also means that everyone in your community can take part.

Everyone from small children to great grandmothers will be able to complete this

fun challenge in and around the city, town or village that you live.

It's something you can fit into a lunchtime at work - or a PE lesson at school remember to get sponsored and let us know if you'd like leaflets to share - or even medals for super-serious fundraisers!



- ✓ Talk to your school or work place
- √ Choose a date
- ✓ Print out your posters
- ✓ Collect sponsorship or choose a donation
- ✓ Enjoy your 'Fun Mile'

societí Supehero? Which will you be?

Have a Superhero day!

Children love to dress up and what could be more of a boost for your children than being a superhero for a day? Why not talk to your local primary school or nursery about organising a Kawasaki Superhero Day to raise funds and awareness for Kawasaki Disease? We know that adults enjoy fancy dress too - don't limit your imagination! Just think how your boss dressed as Cat Woman or Super Man would brighten your day!



- ✓ Talk to your local school, or work place
- ✓ Choose a date
- ✓ Print out your posters
- ✓ Collect a suggested donation for everyone taking part
- ✓ Have fun being a Superhero for the day!

societí Remember TEMPERS!

Making Kawasaki Disease memorable in your **Community**

Remember TEMPERS

Through our early work as an organisation, it's really clear that more people simply 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!

If a child has a

PERSISTENT

FEVER

THINK

KAWASAKI **DISEASE!**

days of $\mathcal O$

Fever (

SUMMIT

Kawasaki

Disease



emperature high fever





dry, sore mouth, cracked lips, strawberry tongue



Pace -Treat early to reduce potential heart damage



Eyes bloodshot. non-sticky conjunctivitis



wollen glands in neck, often just one side





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 affects older children too.

Kawasaki Disease - what's the issue? In the UK awareness of Kawasaki Disease is low. Currently UK

diagnosis and treatment times are too slow. 39% of babies (under one year) treated for Kawasaki Disease develop serious heart problems. **28%** of diagnosed children experience heart complications. Overall, **19%** of children treated develop serious heart damage. For a few children every year Kawasaki Disease is fatal ...help us change this. We need everyone to know

Kawasaki Disease - how common is it?

Hospital admissions in England for Kawasaki Disease have increased fourfold in the last ten years. It's more common than some types of meningitis. About 1 in 10,000 children are currently diagnosed each year and very poor levels of awareness mean many 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 5 DAYS or more with 2 or more of the symptoms overleaf se and seek URGENT medical advice. You could save a

Kawasaki Disease is serious! Awareness is urgent! Today, most people haven't heard of Kawasaki Disease. That's

one of the biggest challenges we face. Help us get it known because Kawasaki Disease is increasingly common in the UK. Too many children and young people today have lifetime heart For more information visit societi.org.uk





societí Societi Kids

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.

But that presents us with a challenge - to convey a serious 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 on our Facebook page, in our tweets, GIFs, on our website and on our awareness raising material.

To help develop **your Kawasaki Conversation**, you can use our materials

- and 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.

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.



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

A bit more about Societi - from Rachael!

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

Societi 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 Societi 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 Societi 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 much needed 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 Societi must.

Our Aims

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

Societi 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

Rachael McCormack, Societi Founder

Relee

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 her 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 Societi 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 Societi 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 Societi with her combination of experience and creative flair enabling her to provide proficient and flexible support.



We work together with our Board of Trustees and Scientific Advisory Board to create a voice for Kawasaki Disease across the U.K.

Changing outcomes for our children

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 or measles

- 20,000 children and young people in the UK have been affected by Kawasaki Disease today
- 39% of infants (babies under
 1) will experience coronary artery aneurysms
- 28% of all affected children will suffer heart damage
- 19% will experience coronary artery aneurysms
- Kawasaki Disease is serious. Awareness is urgent!
- If diagnosed and treated early, children have a much better chance of recovery

Where we are today



of affected children with heart damage



of infants develop coronary artery aneurysms



8 day average treatment time Too slow!





Partial UK coordination knowledge pockets, poor general awareness

Where we need to be



(or less) of affected children with heart damage



dramatic reduction in infants developing coronary artery aneurysums



5 day average treatment





UK-wide coordination high levels of awareness, strong partnerships

societí Investing in our partnerships

Societi creating impact through partnership

Where We Want to Be

Before coming across Societi, 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 Societi partnership. We have many more opportunities ahead. **Your support** makes this possible.

societí Ready to go? Let us know

Ready to build your 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 and Facebook too! A Kawasaki Conversation can start at any time so do keep in touch!

Let's grow our Kawasaki Conversation right across the UK - 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 or a Virgin Money Giving page and donate the funds through that (see our website for more information on how to do this and links!)
- 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 For Families tab and click the Families Resources and Downloads tab from the drop down menu. Here you'll find lots of printable and downloadable resources.

If you'd like to fundraise for Societi, check out the **Getting Started!** tab under the Fundraising tab too - where there is even more information to print, which will help you grow your Kawasaki Conversation.

If you'd like information posting 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 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, 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!

societí Let's make a plan!

My Kawasaki Conversation

A page for your own notes!

societí With thanks from Societi

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,

Relee

Rachael McCormack, Founder for Societi Foundation



Kawasaki Disease Symptoms

societí













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www.societi.org.uk

