

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

.....it's time we changed that

### Welcome to our Spring/Summer 2017 Newsletter!

After a busy autumn and a fabulous Christmas we've had a really great start to 2017! It's such a brilliant time just now with so many exciting projects underway - thanks to your support. Read on - and let us know what you think!

Our last Newsletter finished with thanks to our partners but we're going to start this one with Thank You! Because **without you, we can't achieve our aims.**

*All our supporters ensure Societì has impact. Our thanks go to:-*

Hannah L - for her cakes (& cakes!)  
 Hayley's Mum - for her handstand!  
 Victoria O - for work raising awareness  
 Jo McB - for her contributions to our website  
 Vicki C - for her expert editing!  
 Sinoed - for huge support on social media  
 Peter - for his number crunching  
 Nicky C - for being our Facebook link  
 Helen W - for being amazing on Twitter with RTs  
 Andy - for his complete support on Awareness Day  
 Melissa B - for great awareness raising support  
 EVERYONE - who has donated to our Just Giving page (you are all wonderful)

Of course, we haven't even tried to mention everyone here but THANK YOU ALL for your contributions as Societì supporters. It means a great deal.

*These organisations and others, help us with expertise, guidance, support and hugely valuable influence. THANK YOU!*



### = STOP PRESS 29 MARCH =

AMERICAN HEART ASSOCIATION (AHA) GUIDELINES FOR KAWASAKI DISEASE RELEASED

**What is this?** The AHA guidelines have been much anticipated. They can be downloaded from a link on our website if you've not read them already. They are in fact a scientific paper on many aspects of Kawasaki Disease including recommendations for USA and Canadian doctors for USA/Canada patient care.

**What does this mean for us in the U.K?** Whilst these are the American guidelines, they give us lots of information to compare with our UK guidelines.

**What happens now?** Societì is organising a discussion to look at the 2013 UK guidelines and opportunities to link these to updated information.

### #Partnership #Passion #Pace

These are the values of our organisation. Never demonstrated more than in our permanent partnership with KSSG - without whom so much of our work wouldn't be possible. *Sue & Nicky - you're amazing!* And it's our privilege to work with you. TOGETHER we will make an even greater impact - for families affected by Kawasaki Disease.



### HELP US to do more....

If you would like to donate to Societì, visit our Just Giving page at [www.justgiving.com/crowdfunding/Kawasaki-Disease-Awareness](http://www.justgiving.com/crowdfunding/Kawasaki-Disease-Awareness)

If you'd like to fundraise for Societì, take a look at the back page for more ideas!



# societi

# &



## International Kawasaki Disease Awareness Day: 26 January 2017

We worked throughout January with a host of partners to make our mark in the UK for International Kawasaki Disease Awareness day. It was fabulous to have the support of the World Heart Federation, the British Heart Foundation, Kawasaki Disease Canada and the RCPCH - to name a few partners - to lead the UK 'leg' of this important event. The UK has never really taken part in an organised way before. The results were just fabulous!

Working through social media during Kawasaki Disease Awareness Day we reached over 50,000 Twitter accounts - with the support of the following brilliant organisations:

**COSTA**

PEACOCKS



WORLD HEART FEDERATION



Superdrug



BRITISH TRANSPORT POLICE



★ PRET A MANGER ★

## What's in store for Kawasaki Disease Awareness Day 2018?

Help us make an even bigger impact for Kawasaki Awareness Day 2018. We'll be working with partners across the globe to deliver an even larger worldwide awareness campaign. If you have ideas for raising awareness either for Awareness Day 2018 - or any other ideas for awareness raising, get in touch!

♥ Kawasaki Disease Awareness Day 2017 really showed us the powerful impact collaborations can have on our ability to realise our shared ambitions.

a massive impact, retweeting and raising awareness through their messages - WHAT A DAY! Roll on 2018!!

♥ By working in partnership, our social media campaign reached thousands of people- with Kawasaki Disease information, tweets and Facebook posts (including in Welsh and Gaelic!). 50,000 people saw our tweets and we benefited hugely when amazing partners like Virgin Trains and EE retweeted our messages. Ailsa, our Glasgow 'poster girl' connected us with Glasgow and the Scottish student community.

♥ Since January, we have been in touch regularly with Kawasaki Disease Canada to discuss progress and share new ideas. Our international partnership has recently grown again with our connection with Rari ma Speciali - the Italian support group for Kawasaki Disease.

♥ 'Our man in Bristol' tweet of fabulous Prof Rob Tulloh was our most re-tweeted tweet - we weren't surprised! The BHF and World Heart Federation tweets scaled up our impact throughout the day. A single #ShowUsYourHeart tweet of John, Chef on Virgin Trains, retweeted by Virgin Trains, reached over 10,000 people. British Transport Police were amazing, being our 'poster boys' for the London press release and re-tweeted our awareness message.

### From our Scientific Advisory Board

The publishing of the AHA Guidelines for Kawasaki Disease management is a significant milestone for us in the UK. With the information this extensive paper contains we will now progress faster to update our own UK guidelines for care.

Progress with awareness raising over the last six months has been significant and is helping to lay foundations for the work we will do in distributing the E-Learning module for clinicians, once completed.



We know that early diagnosis and correct treatment is linked to better outcomes so our work in spreading knowledge about Kawasaki Disease is essential.

Professor Robert Tulloh

♥ Colleagues in Kawasaki Disease Canada played a critical role - co-authors of our joint press release and Twitter 'companions' throughout the day. We passed the baton to them at 6pm for more great work to be done. And our amazing Twitter followers, including so many dedicated people alongside us all day, made

# Introducing Societi 100! a.k.a. 'Societi Kids'



## Building Our Awareness Raising Work



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.

Speciali, are considering using them too, to avoid always relying on child patient photos, which can also be unrepresentative of the symptoms of this complex disease.

**Societi 100!** takes this a step further with animated images of children from every walk of life - every part of our society. You'll see them in our tweets, gifs, on the website and on our merchandise. So far the interest on Twitter has been huge - **Societi 100!** tweets being by far the most engaged with tweets we have done.

But that presents us with a challenge - to convey an often children's disease to an audience who doesn't know or recognise it. We've already partly taken this step with the development of our icons for Kawasaki Disease symptoms - these have been very well received, in fact Kawasaki Disease Canada and Rari ma



We hope you like our 'Societi Kids' - we'll make them work hard for your kids!

Kawasaki Disease Symptoms



Persistent fever



Cracked lips / 'strawberry' tongue



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands



## E-Learning Clinical Module - Sharing Knowledge

The world leading Kawasaki Disease expert Prof Jane Burns M.D. has said a few times, when talking about getting doctors to recognise Kawasaki Disease "I'm done trying to make cleverer doctors..." meaning it's no small task to get doctors to "see" this disease! Prof Jane speaks jokingly of course, but we promise we haven't given up in the U.K!!

Educating doctors in recognising and treating Kawasaki Disease was highlighted as a TOP priority by our Steering Group in September 2016. We went on to secure funding from a drug company partner, SOBI, and together with our own investment we'll deliver an on line training module for doctors. Prof Tulloh is leading the clinical content development and we are very grateful for his expert leadership - without which this wouldn't be possible. We've employed a software developer, film team and have advanced work on the main content areas.

## Parent Resource - Sharing Information & Experiences

With so much - often confused and out of date - information available on line, and much of it not always relevant to our UK community, KSSG offered Societi funding to drive forward the development of an online parent resource - primarily for parents with a new diagnosis of Kawasaki Disease. We've employed a web developer to help us and a film team, along with ongoing support from our fabulous design team O Street.

Timing is brilliant - as we have also secured funding for the E-Learning module and can develop some aspects of these together. Some of the filming from our parent resource for instance will feature in the clinical learning tool - giving clinicians valuable insight into the journey a family goes through with a Kawasaki Disease diagnosis.



# Our Plan for the Next 6 months...



*We've set ourselves a pretty ambitious work programme!*

## ♥ Awareness Raising

This remains a top priority and we will not shift our focus from this. There's lots to be done!

## ♥ Fundraising

We must identify some more sources of funding if we are to continue with momentum. Please help if you can.

## ♥ E-Learning for Clinicians

We will complete the E-Learning module and start to distribute this to clinicians and professional bodies.

## ♥ Parent Information Resource

We will complete and arrange the hosting of the new Parent Information Resource funded by KSSG.

## ♥ FOI Report - Patient Safety Alert

We will publish our FOI report when all replies have in fact been received! We're nearly there....

## ♥ UK Clinical Guidelines - Kawasaki Disease

We will coordinate discussions on the 2013 UK guidelines and opportunities to link to updated information.

## ♥ National Clinical Trial

We will submit a funding application for a National Clinical trial to the British Heart Foundation this summer.

## ♥ National Steering Group for Kawasaki Disease

We will continue to lead the UK Steering Group and allow our co-ordinated Kawasaki conversation to grow.

## ♥ Partnerships

We will further develop partnerships, locally and internationally to strengthen our voice for Kawasaki Disease.



## Fundraise for us?

We have produced a range of Societi greeting cards and pin badges as part of our effort to raise funds and awareness. If you think you could sell these for us at a fundraiser or if you would just like some for yourself, please get in touch.



## Fundraising Resources

In response to requests for fundraising resources and with the aim of also increasingly sharing a common description of Kawasaki Disease, we have put together some fundraiser packs. All of these areas in the table below need your support.

Fundraising for Societi?			
I want to make a change	Today	Kawasaki Disease awareness & changing clinical practice	Societi
	Today	Family support for those experiencing Kawasaki Disease	KSSG
	Future	Research the causes of Kawasaki Disease & possible future treatments	BHF Societi Cosmic

## How do I fundraise for Societi or KSSG?

You can use our fundraising packs or our merchandise (cards, badges) to fundraise for Societi or KSSG.

We have packs and support information for:

- Schools – Wear Red Day
- Community – Coffee Morning
- Community – Cake Sale

### societi Coffee Morning!

for Kawasaki Disease Awareness

26th June

Kawasaki Disease is the leading cause of acquired heart disease in children in the UK – we want every parent and doctor to be able to recognise the symptoms and help to save tiny hearts



Would you know the symptoms?



But don't let us limit your imagination! Our leaflets and posters can be used and adapted for all types of fundraisers from sponsored walks to fundraising head shaves. Go on, surprise us! Let us know what you are up to and we will make a poster especially for you!

## Connect with Societi?

Have something you can contribute? Contact us! You can email [rachael@societi.co.uk](mailto:rachael@societi.co.uk) or complete the contact form on our website – [www.societi.org.uk](http://www.societi.org.uk) By filling in the contact form you can join our contact list and we'll keep you in touch with key updates over time.

