

## It's been a Marvellous March!



From knitted Easter chicks to paediatric conferences - March has been bursting at the seams! Our amazing Societi supporters are doing SO MUCH to raise funds and awareness of Kawasaki Disease... So much in fact that we can't fit it all into this newsletter! If you don't see your initiative here it's just because we ran out of space - THANK YOU for your fantastic support.



## Community Article!

We've created a community newsletter article for use in local papers, community, club or school newsletters. If you know of a local newsletter, why not download the article from our website and send it to the editor? An easy way to raise awareness!

### Diagnosis Day Poll

Working with KSSG we asked families affected by Kawasaki Disease since Feb 2016 how many days their diagnosis took and whether other diagnoses had been made before Kawasaki Disease. This is an important mini study and will help raise awareness with doctors. Contact us if you can help.

### Creative Cards!

Societi Supporter Julie, has been making and selling her own range of greetings cards for Societi, raising funds and Kawasaki Disease awareness. We've worked together during March to create a tailor reverse side of her cards!

### Wristbands!

We're so excited about our new wristbands! These arrived just this week! We've a number of Societi Supporters who'll be our distributors, if you'd like to know more follow us on Facebook!

### ALL our Runners!!!

We are so inspired by our marathon running supporters. Ali & family completed the Surrey half marathon in style raising a phenomenal sum, Lucy is in training for her London to Brighton ultra-marathon (wow that's 100km!) Andrew is in training for the London marathon - planning on breaking a world record for Societi and we know he'll do it! Vikki has been training hard for the Brighton marathon - on a treadmill when needed because of the beast from the east! Go! Go! Go!

### Posters & TEMPERS

Many thanks to Societi Supporters Bec and Keisha for having Kawasaki conversations with their local hospitals, GP surgeries and pharmacies - getting them to display Kawasaki Disease awareness posters! Thanks to Sue too for working with over 50 KSSG members to distribute our TEMPERS leaflets - these are being taken to pharmacies across the UK!

### RCPCH Conference 2018

We attended our second RCPCH conference in March. It was such a sucessful few days with many exciting Kawasaki Conversations which will lead to new opportunities. Read our RCPCH impact statement on our website.

### Pharmacy Raffle & Collection

Clare and Debbie are raising awareness with a raffle, posters, leaflets and ongoing counter top collections - to support Societi and grow much needed knowledge about Kawsaki Disease! Thank you ladies!

### Hatching an Easter Plan!



With Easter quickly approaching we were tickled pink to learn that Christine has been knitting flocks of little Easter chicks putting these in packs with a chocolate egg and a TEMPERS leaflets! Christine you're eggstraordinary!!

### No uniform needed - just bring£1!

Thanks go to Hayley as the organiser at Barnes Farm Infant School, who had a non uniform day in Feb and made their donation to us this month - and to Hannah too, who held a non uniform day on 23 March at William Farr School - both for Kawasaki Disease awareness, raising valuable funds for Societi.

### Bingo!

Vikki and Hayley held a bingo night on Friday 16 March, which



was an amazing success! It was a sell-out night - and everyone attending now knows

### More Family Films Made!

Societi spent a Sunday in Birmingham with two amazing familes and our film team, Pretend Lovers - who produced our existing family film. If you haven't seen these or watched our Societi Professor interview, visit our Family Portal! Our new films will soon be edited - these too will be powerful stories, helping raise the profile of Kawasaki Disease.



### Find us on Facebook!

Oh... and did we mention we're now on Facebook? Find us @SocietiFoundation New Clinical Guidelines for Kawasaki Disease

We have continued work on updating clinical guidelines through our writing group, convened by Societi, and strong progress is being made. New guidance will be published in 2018!

**Kawasaki Disease** is the #1 cause of acquired heart disease in UK children ....it's time we changed that Societi Foundation is a registered charity in England and Wales (no.1173755)

# **SOCIETI** the UK Foundation for Kawasaki Disease



### Twitter-busy & Insta-mad!

We work to raise awareness across social media - but that would be pointless without people retweeting, liking and sharing what we post. During March, Andy, Neeta, Marc, Mike, Lucy, Laura, Ben and Hannah our social media campaigning. Thank you - and thank you to everyone who supports this! Did you know a retweet, share And can make such a difference.

### Speaking for Societi....

Societi supporters Julie and Diane have both been giving Kawasaki Disease talks to community groups and organisations during March. What a great way to raise awareness of Kawasaki Disease - and funds too. These phenomenal women have been powerhouses of fundraising and are leading nothing short of regional awareness campaigns - one in the north, one in the south - and in less than a year have already raised thousands of pounds. Both have inspired others to act too - that's leadership! Thank you! We in turn, are inspired.

### Regular Donations -Secure Support

We've had new regular donors join us this month - that's something you can do through our website 'donate' button on PayPal. This includes Andy and his lovely family - thank you - a steady income for our charity means so much.

### Variety is the spice of...Societi!

Thanks to Diane – and just one of a host of initiatives she has organised - we are supported by the regional branch of a national organisation. We are their named charity through 2018 and during March a Variety Show was held raising £291.26! Thank you to all who attended and donated. A terrific boost to our funds.



























### Educational Conversations

Tony has been busy in the south taking forward conversations with his local pre school raising Kawasaki Disease awareness but stepped this up massively to engage the County education team and talk Kawasaki Disease. He's writing to local GP surgeries too, pinning posters and sending out TEMPERS -Thank you Tony!

### A World Heart Day Legacy

One of our most high impact supporters on World Heart Day, back in September, was Neeta – on the day she raised an incredible £1,261 for Societi. During March, her employer, Sky UK confirmed they are donating the same sum to Societi in recognition of Neeta's continuing commitment to our cause! Wow! What an impact!

### Running in Vests!? Yes!

Brilliant Vikki inspired Gauntlet to sponsor gorgeous Societi running vests. The vests look great and are brilliant for raising awareness of Kawasaki Disease whilst on your weekend park run, marathon - or ultra marathon! Vikki has raised a HUGE sum for Societi and contributions have been flooding in throughout March.



### Societi.org.uk Updates & Updates

Our website is never static. During March we've added a glossary of terms, a corporate and term supporters page, new research links, our RCPCH newsletter (and this one will be there soon) new Q&A's - and much more. Please check in regularly, there's always more to see.













Want a running

vest? Get in touch!













### We've gone to School!

Many thanks to Liz and to Hayley who have included the TEMPERS printable leaflet (available on our website) on their schools websites - making this crucial information available to hundreds of parents from this month. Simply fantastic.

### Inspiring Others

During March Lucy, a long term Societi Supporter and phenomenal fundraiser was given a £1,000 donation for Societi, from the fabulous Clipsham Trust. They had been INSPIRED by Lucy's unrelenting commitment and dedication to raise awareness of Kawasaki Disease through her and her families support for Societi Foundation. Lucy has given an utterly remarkable amount of time, effort and energy to Kawasaki Disease awareness and together with her own huge army of supporters, she is transforming knowledge and protecting tiny hearts in her community.

Happy Easter to all our Societi Supporters. THANK YOU for making March so marvellous... and here's to an Awesome April! Let's make it even better!



# And a Happy Easter everyone!