

# Societi Foundation Annual Report & Accounts

For the year ended July 2020 Registered charity number 1173755



# Kawasaki Disease Symptoms

# societí

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# **THINK KAWASAKI DISEASE!**











**Bloodshot eyes** 



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## Kawasaki Disease Symptoms

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Cracked lips/ 'strawberry' tongue



Swollen fingers/toes

#### About Kawasaki Disease

#### **About Kawasaki Disease**

Bloodshot eyes

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

It is a type of vasculitis that mainly affects young children but it can affect people of any age – and its impact can be most serious in the very young, particularly infants. Identified in 1967 in Japan by Dr Tomisaku Kawasaki, the cause of Kawasaki Disease is still unknown. The illness presents with several symptoms common to a variety of other childhood diseases and infections and is therefore often misdiagnosed. Kawasaki Disease is a serious disease which if untreated can cause coronary artery damage.

Kawasaki Disease has a range of symptoms including a characteristic and distinctively persistent high 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. Kawasaki Disease can be present with some or all of these symptoms and symptoms often appear in series (i.e. not all at once).

Kawasaki Disease should always be considered in any child with unexplained persistent fever. It is a serious illness that can cause coronary artery damage – damage to the blood vessels in the heart, and can lead to acquired heart disease in children.

Children affected by Kawasaki Disease have much improved chances of a good recovery with timely diagnosis and the correct treatment. Studies show that children treated early have a lower risk of serious heart damage than those treated later. Doctors should aim to diagnose and treat children as soon as possible – at five days of fever or as quickly as practical after that. The risk of heart damage increases proportionately with increasing delay.

Kawasaki Disease is increasingly common. Once thought of as a rare disease, this now outdated idea, wrongly held on to by some, leads to delayed diagnosis and with this, increased risk of serious heart damage for children. In the ten years to 2015, hospital admissions for Kawasaki Disease in England increased fourfold – and across the globe cases are doubling every ten years. This is why it is the leading cause of acquired heart disease in UK children. We are working to raise awareness to make sure that doctors EXPECT to see Kawasaki Disease and are READY to treat it.

This annual report is an important document and has been prepared by Societi Foundation for submission to the Charity Commission. It also serves to help supporters, partners, funders and anyone who reads it to get to know a little more about Societi and Kawasaki Disease – something which is hugely valuable.

The trustees present their report with the financial statements of the charity for the year ended 30 June 2020. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

Societi

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## Objectives and Activities

The objectives of our Charity as set out within our governing document are:

The advancement of education for the public benefit into the causes, detection and treatment of **Kawasaki Disease**, by such charitable means as the Trustees shall from time to time determine.

The promotion of research into the prevention, diagnosis, causes and treatment of **Kawasaki Disease** by such charitable means as the Trustees shall from time to time determine.

# **About Societi Foundation**

#### **About Societi**

Societi was established to raise awareness of Kawasaki Disease. We are an influencing and policy shaping organisation working through partnerships to drive transformational change in awareness across the UK, about Kawasaki Disease.

Progress in understanding Kawasaki Disease has been severely hampered by poor levels of awareness, lack of investment and lack of essential research in the UK.

Our ambition is that EVERYONE knows Kawasaki Disease. In the UK today, affected children face the same poor prospects in terms of outcomes as they did 20 years ago. We want to change that.

The perception of Kawasaki Disease as a rare illness hampers UK research which is stifled by a lack of funds. It also hampers clinical resource allocation for treatments and long term clinical support that research shows families need. A lack of awareness of the true incidence of Kawasaki Disease among 'front line' clinicians needs to be addressed, in order for Kawasaki Disease to be considered as a possible diagnosis at an early stage.

We enable urgently needed research and pursue changing policy and clinical practice for Kawasaki Disease. Not enough is known about Kawasaki Disease, its symptoms or its treatment. Long term care for affected families is limited. Many agencies, doctors and parents are unaware of the disease. We are changing this.

#### Significant activities - Our aims

Societi has four activity areas around which all our actions and operations are focussed. These are:



#### Awareness raising

We raise awareness of Kawasaki Disease to improve prompt diagnosis - through multi media campaigns,

reaching GPs, paediatric clinicians, health professionals and parents.



# Clinical research We work to lever efforts building on enhanced

awareness of need, to undertake and urgently e critical research to understand

advance critical research to understand, diagnose and manage Kawasaki Disease.



#### Clinical supervision

Gaps exist in current provision for Kawasaki Disease children in their long term care. We work

to close these gaps, as well as connect long term care to long term research.



#### Support for the UK Support Group - KSSG We recognise KSSG as a

We recognise KSSG as a lifeline when you're at the centre of the "flat spin"

that is a Kawasaki Disease diagnosis – so we support and develop resources for KSSG – the UK support group which voluntarily supports families with understanding, advice and compassion.

#### Public benefit

In setting our objectives and planning our activities our Trustees have given careful consideration on the Charity Commission's guidance on public benefit. On the pages which follow our delivery and impact during 2019/2020 is set out.



# **societí** Responding to Covid-19





#### Societi, Covid-19 and Kawasaki Disease

As with many organisations across the globe, Societi has been impacted by the Covid-19 pandemic in many different ways. We've worked hard to adapt in a rapidly changing world and to respond quickly and usefully to the emerging needs of our users.

As a small charity, we've been able to react swiftly to changing circumstances enabling our staff team to work remotely whilst maintaining full capacity. Already having online and digital procedures in place as a way to conduct Societi business has allowed us to carry on with our work in the face of Covid restrictions with limited interruption. For example, our Trustee Board meetings, approval systems and banking procedures were already set up in an online

We've worked hard to provide our supporters with alternative ways to continue their fundraising and awareness raising in the face of Covid-19 restrictions. We have been overwhelmed by the response of our supporters in such difficult times and are truly grateful to every single member of #TeamSocieti.

Due to the Covid-19 pandemic, Kawasaki Disease has hit the headlines like never before - but also with much confusing misinformation being circulated. Societi Foundation has been stretched to its limits, flooded with questions and concerns from worried families and worked hard to respond to media enquiries.

This HUGE increase in enquiries has meant we've had to work extremely hard to respond. We've collaborated with Kawasaki Disease organisations from around the world and worked closely with our Scientific Advisory Board to create detailed statements to give our supporters the FACTS we know they need.

Special thanks must go to **Lexington Communications** for all their amazing help and expert advice, responding to media at the peak of enquiries. A huge thank you too, to all those at NHS England including **Prof Simon Kenny**, whose support has been just brilliant.

Our work to protect children from Kawasaki Disease, the LEADING cause of acquired heart disease in children, has NEVER been more important. We're concerned that the hundreds of children who, based on our research, we know will be affected by Kawasaki Disease in the coming months, whilst the pandemic continues — may not get the urgent help they need.

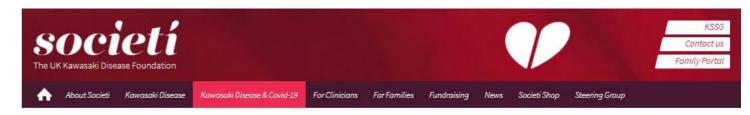
We're now accelerating our work to raise awareness far and wide, to reach families who will be unfortunate enough to be affected by Kawasaki Disease - with our aim of helping them get rapid diagnosis and early treatment.

The pages which follow describe our actions during the course of the pandemic, our response to the evolving needs of those affected by Kawasaki Disease both now and into the future and the response of the amazing #TeamSocieti to our calls for support.

#### 1. Statement on Kawasaki Disease and Covid-19

Societi received a significant increase in the number of enquiries, from March 2020 onwards, from supporters who were concerned about the spread of Covid-19 and what this might mean for those that have previously been affected by Kawasaki Disease. We therefore worked with our

Scientific Advisory Board to share a statement on our website and across our social media pages, offering information and advice relating to Kawasaki Disease and Covid-19 to anyone who may have been concerned.





#### Societi Foundation Scientific Advisory Board

#### Statement on Covid-19 and Kawasaki Disease

We have received a number of enquiries from supporters recently who are concerned about the spread of Covid-19 and what this might mean for those that have previously been affected by Kawasaki Disease. We therefore asked our Scientific Advisory Board about this and they have issued the following statement:

Societi

Children and Young adults - The Scientific Advisory Board notes that a remarkable feature of the Covid-19 reports worldwide, is that children and healthy young adults have generally had mild disease and have recovered well.

Patients with previous Kawasaki Disease - Patients with previous Kawasaki Disease have normal immune responses to all common infections, and so there is no reason to suspect that they are any more susceptible to Covid-19 infection. There is also no reason to suspect they will suffer a more severe Covid-19 infection than other children or young adults of similar age. As noted above, research suggests that children and young adults generally have mild

Children and young people 18 years and under taking aspirin - If you are 18 or under, or you have a young child taking aspirin and you/they develop a fever, follow the advice you will already have been given. Please note that advice on aspirin and fever may vary dependent on individual patient circumstances and your doctor will be able to explain more about the particular advice you/your child is given. If you are concerned, speak to your usual doctor (by telephone).

If you/your child is being treated with immunosuppressants or steroids (such as anakinra, infliximab,





# societí Responding to Covid-19



# **societí** Responding to Covid-19



#### 2. Responding to press coverage

In April 2020 Societi's Scientific Advisory Board responded to press coverage after Societi was contacted by a huge number of families regarding the severe worry caused by social media and other media coverage on Covid-19 and Kawasaki Disease. A lot of these media articles were confused and contained little factual information

and the response served to provide some clarity to those who sought it. Societi was called upon by numerous media agencies to provide information to be included in articles. Again, with the help of the Scientific Advisory Board, Societi was able to provide reliable information to help create a number of balanced, informative articles.

Share this page

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## Responding to Press Coverage – 28 April 2020

#### Societi Scientific Advisory Board response to press coverage on Kawasaki Disease and Covid-19

28 April 2020

We've been contacted by a huge number of families regarding the severe worry caused by social media and other media coverage on Covid-19 and Kawasaki Disease.

A lot of these media articles were confused and contained little factual information.

Whilst we acknowledge the important role of the medical community observing these cases and support efforts to monitor the situation closely, a lot of worry has been caused. We understand that and want to provide some clarity.

Based on all available information made available so far we note:

The cases being referred to have been reported in approximately 20 children in the UK (out of 11.5 million U.K. children) - of whom half have tested \*negative\* for Covid-19 according to their doctors.

There is no current evidence of any increased incidence or greater susceptibility to Covid-19 infection for children who

All of the c. 20 cases are new, acute illness in children.

Fewer cases of Kawasaki Disease than would be normally expected at this time of year are currently being seen - not

#### 3. International **Partnership Statement**

Societi Foundation was involved in the creation of a combined statement from a number of organisations for Kawasaki Disease around the world.

Together, we published our shared statement on 7 May 2020 after all our communities were affected by worrying

press reports. Our Kawasaki Disease networks collaborate on a global scale and we share our solidarity in providing consistent information to supporters as we all worked together to help those who have been affected by Kawasaki Disease at an extremely difficult time.



# societí Responding to Covid-19







4. Response to PIMS-TS **Answering Supporters** questions

With so many questions asked by families and with continuing reports in the press about Kawasaki Disease and PIMS-TS, we asked our experts our supporter's questions and they issued a statement containing a huge amount of incredibly useful information.

The was a phenomenal response to this latest statement from our Scientific Advisory Board. It has been read and shared by families and doctors all over the world and we have received comments to say that it was the BEST article written on this topic yet!

5. Response to **PIMS-TS** Interview with **Professor Paul Brogan** 

Thanks to the incredible filming team at Pretend Lovers, Societi were able to film an interview with one of our advisors, top paediatrician and Kawasaki Disease expert Professor Paul Brogan, Professor of Vasculitis and Honorary Consultant Paediatric Rheumatologist, Great Ormond Street Hospital.

In the film which was shared with supporters across our social media platforms, Professor Brogan talks on Kawasaki Disease, PIMS-TS and COVID-19, answering many of the questions supporters had put to Societi.





## Answering Your Questions – 24 May 2020

#### Introduction from Societi Foundation's Founder....

It's really easy to frighten people. It's less easy to find out the facts. And because parents like me want FACTS, so they can make up their own minds about what is going on, we have done some work with experts to answer the questions you've

As Founder of the UK Foundation for Kawasaki Disease, it's been really worrying for me to see the mishandling of information about the paediatric inflammatory multisystem syndrome – or "PIMS" which you will have heard of. In different parts of the world, this syndrome has been given different names. I'm frustrated, like many in our community, that it has been casually described as 'Kawasaki-like' - which has done nothing but create more confusion. Kawasaki Disease is often misdiagnosed at first because it has symptoms common with MANY illnesses - so the phrase 'Kawasakilike' is just not helpful. It might as well have been 'measles-like' or 'sepsis-like'. These are equally uninformative phrases.

Choosing the correct language at times like these is actually really important. The terms used, and headlines that have resulted, have caused alarm, panic and fear for parents and patients; what's really worrying is that these headlines have also confused doctors, Children ACTUALLY affected by Kawasaki Disease are potentially AT MORE RISK because of the confusion caused, since they may not receive treatment for Kawasaki Disease due to concerns it might be Covid-19; or from delayed presentation to hospital. As a result, children with Kawasaki Disease may not get the early diagnosis they urgently need, delaying treatment and incurring life-long cardiac damage.

It is very important that doctors quickly learn more about PIMS-TS and already, many research studies are underway to gather evidence, build up and share knowledge. It's so important to me as a parent that they do. As parents we share the same goals as doctors here - to provide the very best possible care for our children. Perhaps in learning more about PIMS-TS we will learn more about Kawasaki Disease too.

Share this page f 💟 🖂 🛨 Watch an interview with Prof Paul Brogan on Kawasaki Disease, PIMS-TS, Covid-19 and

It's quick and simple to make a



Providing clear facts has been my focus, right from starting our charity in 2015. Here are our clear, evidenced facts -

## Responding to Covid-19

# societí Responding to Covid-19





6. GOSH
Webinar on
PIMS-TS

Societi were delighted to be invited to attend the GOSH webinar on PIMS-TS, as the medical community shared data and knowledge of cases to date - in the U.K. and France.

Opened by Prof Paul Brogan, who highlighted the positive work of Societi

Foundation in his opening remarks he pointed out that the continued use of the phrase "Kawasaki-like" is unhelpful - causing confusion. The webinar provided clarity, sharing evidence and helping clinicians understand more about an emerging disease - PIMS-TS.

7. Our Emergency Appeal

With Kawasaki Disease in the spotlight during Covid-19, we urgently needed funding to continue supporting families, sharing trusted medical advice & getting Kawasaki Disease known! Societi set up an emergency appeal to allow fundraisers to give their support at a time when it was most needed. Huge numbers of

supporters contributed to the appeal with donations and their own fundraising initiatives raising just over £10,000. We are absolutely indebted to every single member of #TeamSocieti who have allowed us to carry on with our extremely important work at such a difficult time.



## Paediatric Inflammatory Multisystem Syndrome -Temporally Associated with SARS CoV2 pandemic the UK and French experience

Chair: Dr Joe Brierley (GOSH), Dr Sachin Khambadkone (GOSH)

700 – 710pm: PIMS-TS from a rheumatologist's point of view (prof Paul Brogan, GOSH)

710 – 720pm: RCPCH guidance (Dr Alasdair Bamford, GOSH)

720 - 735pm: GOSH experience (Dr Mae Johnson, GOSH)

7 35 – 7 50pm: PIMS-TS from a cardiologist's point of view (Dr Filip Kucera, GOSH)

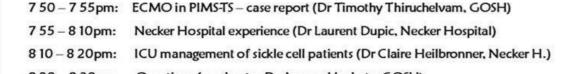
8 20 – 8 30pm: Questions (moderator Dr Aparna Hoskote, GOSH)





DATE: Thu 04/06/2020

TIME: 7pm - 8 30pm









8. 888 Lockdown Challenge In response to the difficulties of raising funds throughout a national lockdown, our 888 Community Lockdown Challenge challenged our network of amazing supporters to get active, and reach a target of 888 miles - running, cycling, swimming and walking. We were blown away by the contribution that every single participant made and supporters

achieved a staggering total of 3,631 miles – equivalent to the distance between Societi HQ and Washington USA. Fundraising for the challenge reached a BRILLIANT total – over £500! Thank you so very much to everyone that took part, donating their time, money and miles.

9. The 2.6 Challenge

Member of the Societi Active Committee, Gayle Harvey, led Societi's 2.6 Challenge – a nationwide initiative brought about in response to the postponement of many charity fundraisers due to be held on London Marathon weekend. Gayle, who was due to run the London Marathon for Societi, led Societi Supporters in the 2.6 challenge raising over £1,200! Thank you Gayle for all your energy and determination in leading such an incredible event! Massive thanks too, to everyone who took part - there were some absolutely stunning achievements from right across #TeamSocieti!





# societí Our Work - Awareness Raising



# societí Our Work - Awareness Raising



# 1. Enabling #TeamSocieti

Societi's amazing supporters, also known as the fabulous #TeamSocieti, are pivotal to everything that Societi does. This ever growing team of over 2,000 volunteer fundraisers and awareness raisers, drive and direct Societi's work and generate funds to enable the completion of Societi's project work and awareness raising.

#TeamSocieti plays a vital role in raising the profile of Kawasaki Disease throughout the UK and Societi constantly works hard to empower this incredible group of individuals, creating and supplying reliable Kawasaki Disease information and awareness raising resources throughout the UK.

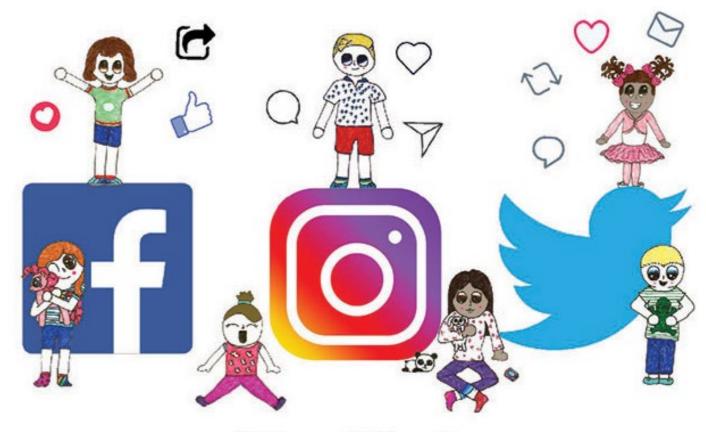
# 2. Building our social media following

In the year from July 2019 to June 2020 Societi's social media following has grown exponentially. Our Facebook page alone accounts for a 170% increase in followers along with huge increases for Twitter and Instagram too.

Societi works extremely hard to create reliable and engaging Kawasaki Disease

awareness raising material that we share daily across our social media pages. Societi's content is trusted by our followers who share our posts to increase our reach even further, helping us to continue to grow our reach and create bigger and bigger impact.





#ShareIfYouCare

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#### societí Our Work - Awareness Raising



# societí Our Work - Awareness Raising



#### 3. Updating and promoting our website and **Family Resource Portal**

Two of Societi's key assets are our information filled website and Family Resource Portal. Both resources are extremely helpful and can be a lifeline for families experiencing a Kawasaki Disease

We constantly review and update our

website and portal content to ensure that the most up to date and accurate information is available to users. Feedback received from supporters suggests that our website and portal are an invaluable tool for those affected by Kawasaki Disease and their families.

Kawasaki Disease is the leading cause of acquired heart disease in children in the U.K. It's time we changed that...

#### ...Together we will.

Societi is an influencing and policy shaping organisation which works through partnerships to drive real change in awareness across the UK, about Kawasaki Disease. Join us?

More about Societi



#### Kawasaki Disease Symptoms

Kawasaki Disease is increasingly common with c. 1,000 hospital admissions each year in the UK. Symptoms include a characteristic and distinctively persistent high fever for five days or more, plus two or more of the following symptoms rash, bloodshot eyes, "strawberry" tongue, cracked, dry lips, redness of the fingers and toes, swollen glands (often just on one side).

If a child has a persistent fever together with two or more of these symptoms, THINK Kawasaki Disease. Early treatment is critical to reduce the risk of lifelong heart disease.











Bloodshot eyes





Support Us? It's quick and simple to make a donation via PayPal



Fundraising? If you're interested in fundraising for Societi, we can provide you with the tools you'll need to do that!



#### 4. Keeping our supporters informed

We think it's vitally important to let our supporters know exactly what we are doing as an organisation to help achieve our objective aims around Kawasaki Disease in the UK.

As well as providing updates on social media and our website, Societi also produces a regular newsletter that is

distributed among our supporters. As well as informing our supporters about Societi's latest projects and activities, our newsletters also highlight the tremendous hard work and achievements of #TeamSocieti - something which is extremely important to us as an organisation.









# societí Our Work - Awareness Raising



# societí Our Work - Awareness Raising



# 5. Developing Societi merchandise

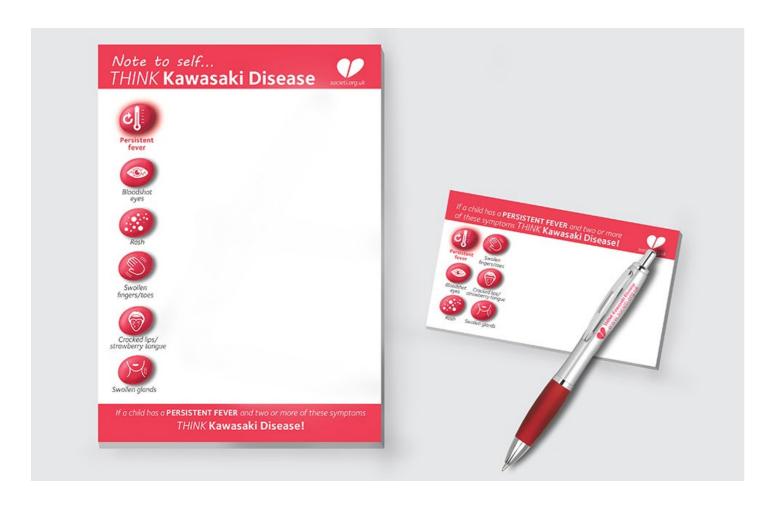
Societi continues to make merchandise available to our supporters which importantly, serves to raise both funds and much needed awareness of Kawasaki Disease. A new product recently introduced to our online shop were the fabulous Societi tea towels. Popular among members of #TeamSocieti, the tea towels have also been fantastically

repurposed as Societi Face masks by some of our supporters! Another addition to the Societi Merchandise included our new A5 notepads and post-it notes. Initially developed to make a lasting impression in our GP and hospital packs, the new Societi stationery proved a huge hit with our supporters, so we just had to make them available on our online shop too!

# 6. Nursery and schools packs

Our Kawasaki Disease Nursery and School information packs were promoted and sent out to all supporters who requested them.

These information packs contain leaflets and posters with Kawasaki Disease information suitable for display in a childcare setting and have helped to raise much needed awareness of Kawasaki Disease with parents and childcare providers across the UK. The packs also contain resources to allow schools and nurseries to hold awareness days ensuring that everyone knows Kawasaki Disease!





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# 7. Awareness ambassadors

We provided our supporters with an opportunity to become a Societi Awareness Ambassador. Each Ambassador received a Kawasaki Disease awareness raising pack and access to our families resource and download page on our website which provided all the information needed to get involved with raising Kawasaki Disease awareness in their local communities. The pack containing leaflets and posters enabled supporters to easily raise awareness at their local village or town hall, newsagent, supermarket, school or even yoga class!

# 8. Political ambassadors

Societi called on our supporters to become Political Ambassadors to help us to highlight the issues surrounding Kawasaki Disease with Government.
Political Ambassadors received a pack of information designed to give them the tools to be able to confidently engage their local MPs, raise awareness of

Kawasaki Disease with them, tell them of the urgency of getting Kawasaki Disease known and ask what help their MPs could give. Our supporters made a massive impact in contacting their MPs and some brilliant discussions were generated and awareness within Government was increased.





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# societí Our Work - Awareness Raising



# societí Our Work - Awareness Raising



# 9. Political engagement

Thanks to the amazing work done by Societi supporters and the incredible continued support of Lexington Communications, Societi has made significant progress in the engagement of Government around the issues surrounding Kawasaki Disease. Because of this crucial support, Societi were able to meet with the fabulous Kevin Brennan MP, who subsequently asked a number of Parliamentary Questions for Societi about Kawasaki Disease. We're hugely grateful to Kevin Brennan MP for

the time he has taken to put forward these questions and for working so closely with us to put Kawasaki Disease "on the map" in Parliament.

Societi has continued to pursue a programme of Political engagement with the support of Lexington Communications, including writing to key Government Ministers and to each party leader and election candidate during the General Election.



# 10. Working with Ladies Circle

Societi Foundation was extremely fortunate and delighted to be named as presidential charity of the year, by Lindsay Pickard, Ladies Circle president 2019 – 2020. The Ladies Circle is a vast network of thousands of wonderful women covering the whole of the UK – all of whom have worked tirelessly throughout the year to support Societi, raise awareness of Kawasaki Disease and raise much needed

#### funds.

From fashion shows to head shaves, we were blown away time and time again by the ingenuity and enthusiasm of the members of this brilliant organisation. The powerful partnership between Ladies Circle and Societi has helped to get the #1 cause of acquired heart disease in our children known - Thank you!



#### societí Our Work - Awareness Raising





# societí Our Work - Awareness Raising

11. World Heart **Day 2019** 

29 September, World Heart Day is one of the biggest days in the Societi calendar, second only to International Kawasaki Disease Awareness Day.

We spent the weeks and days leading up to World Heart Day raising awareness of Kawasaki Disease and taking advantage of the opportunity to have a global voice with our partners around the world, to get Kawasaki Disease known. We also promoted the launch of our annual World Heart Day Societi Virtual Run and Fun Mile which turned out to be a huge success and our biggest World Heart Day virtual event to date, raising over a staggering £6,100!!

12. The creation of 'Societi Active' Over the last 3 years, the Societi virtual running group has grown from strength to strength. This community, that we are SO PROUD of, is not just for runners - but for ANYONE wanting to take part in ANY activity for Societi. Our volunteer running Committee have worked so hard to make

this group a huge success and now they have become 'Societi Active' with their new dedicated Facebook page. We are so grateful to volunteers Vikki, Hayley, Gayle and Lucy for all their dedication, effort and enthusiasm developing ideas and planning events for Societi Active community.





# **societí** Our Work - Awareness Raising



# societí Our Work - Awareness Raising



#### 13. Clear **Channel UK's Malls Live** network

Societi was given an extraordinary opportunity – UK wide advertising space to support our mission to protect children's hearts - at no cost. We're hugely grateful to Clear Channel UK for donating very valuable space for a Kawasaki Disease campaign on their digital screens - across the Malls Live network in the UK's leading

shopping malls nationwide. We were able to reach a whole new audience with our Kawasaki Disease awareness raising message - something that, without the generosity of Clear Channel, we just could not have done. The incredible team at Clear Channel provided all the help and advice needed to create an effective campaign.

Societi

Societi

# 14. Young **People's Portal**

Societi has started work developing our exciting new information service for children and young people affected by Kawasaki Disease. We want to provide trusted answers to young people's questions about Kawasaki Disease and about their future too by creating a

dedicated online space which is relevant to their needs.

We've already made huge progress towards developing the portal for an expected launch date of 26 January 2021 -International Kawasaki Disease Awareness Day.









#### 15. Veswas Gala

Societi Foundation was privileged to be one of two charities supported by Veswas at their spectacular Charity Gala Ball in November 2019 - a truly sensational

The Veswas directors - Depesh, Rahul and Gary were determined to make a difference by giving a HUGE boost to two

charities, making a MASSIVE difference to their work. And that's exactly what they did - with a PHENOMENAL donation of £19,000 being given to Societi. A truly transformational sum - the largest single donation our young charity has received. their immense generosity.

We are deeply grateful to all at Veswas for

16. International Kawasaki Disease **Awareness Day** 2020

Throughout the whole of January 2020, thanks to the incredible work of #TeamSocieti supporters from right across the UK, we encouraged thousands of people to THINK Kawasaki Disease for International Kawasaki Disease Awareness Day 2020. #TeamSocieti worked non-stop on awareness raising projects throughout

the month to get Kawasaki Disease known. Our campaign, supported by hundreds of fantastic Societi Supporters, was one of the biggest across the globe. The Impact Statement over the page shares just some of #TeamSocieti's achievements from our 2020 Awareness Day campaign.



# THINK Kawasaki Disease



Kawasaki Disease ...let's get it known!

Societi

# International Kawasaki Disease Awareness Day 2020

# Impact Statement



#### **THINK Kawasaki Disease!**

Throughout the whole of January 2020, thanks to the incredible work of #TeamSocieti supporters from right across the UK, we encouraged simply thousands of people to THINK Kawasaki Disease for International Kawasaki Disease Awareness Day 2020. #TeamSocieti worked non-stop on awareness raising projects throughout the month to get Kawasaki Disease known. Once more, we surpassed our previous Awareness Day achievements, reaching record numbers of people with our awareness messages. Our campaign, supported by hundreds of fantastic Societi Supporters, was one of the biggest across the globe. This Impact Statement shares just some of #TeamSocieti's achievements from our 2020 Awareness Day campaign.

#### Impacts across the UK

Getting Kawasaki Disease known by 'just' 65 million people, that's everyone in the UK, is our aim. And Awareness Day is a very important milestone in our calendar as we work to make this a reality. #TeamSocieti today is growing fast with many new and long-standing supporters. YOUR work in holding activities and events to raise awareness in YOUR communities about Kawasaki Disease for awareness day will make sure we really do get Kawasaki Disease known. Made possible with funds raised by #TeamSocieti, throughout January, Societi HQ sent out THOUSANDS of leaflets, posters, wallet cards, schools packs, GP packs and other awareness raising resources to help get Kawasaki Disease known. Whole communities now

know how important it is to THINK Kawasaki Disease - through cake sales, non-uniform days, wear red days, school mail outs, coffee mornings, workplace awareness and even community treasure hunts! The reach of #TeamSocieti grows stronger and further each year, and Awareness Day gets bigger and better – thanks to YOU!

We are hugely grateful to all our Supporters for making Awareness Day 2020 such a massive success. Not only by raising awareness but also by raising much needed funds for Societi. As well as funds raised at events up and down the country on Awareness Day, we received nearly 50 separate donations through supporters Virgin Money Giving and Just Giving pages too! Money raised will contribute directly to awareness raising throughout the rest of the year. THANK YOU SO MUCH to everyone who contributed to raising awareness and funds - YOU power our work!

## **Our Digital Footprint**

We created over 50 new awareness raising pictures and animated gifs to post on Facebook, Twitter, Instagram and Linkedin for our 2020 campaign. We posted over 100 Kawasaki Disease awareness raising posts on our social media

channels throughout January, resulting in our BIGGEST online campaign to date. Once again #TeamSocieti was outstanding and played an

absolutely CRITICAL role, sharing Societi posts, retweeting and liking our Insta pics – to reach THOUSANDS of people. Together, we directly reached over 100,000 people – with engagement with posts at an all-time high too! Thanks to Societi partners like Master Cardiology on Insta, even single posts by those with already HUGE followings reached tens of thousands more people. So we know that the indirect reach of our work together was EVEN BIGGER – and potentially millions of people will now have heard of Kawasaki Disease. WOW!

As well as amazing coverage throughout the UK, Awareness Day was truly international for Societi too. With your help we reached supporters from as far away as USA, Australia, Philippines, Italy, Germany, India, Canada, Mexico, Singapore, Norway, France & New Zealand!



2020 has been by far the most successful International Kawasaki Disease Awareness Day yet for Societi. Combined efforts from everybody at #TeamSocieti have meant that tiny hearts across the UK and far beyond can be protected from Kawasaki Disease.

We can't thank YOU, the members of #TeamSocieti enough - whether you shared or liked a Facebook post, held a cake sale, a non-uniform day or a coffee morning - or whether you had a Kawasaki Disease conversation. Our impact is only possible with the input of every single member of #TeamSocieti. We are truly grateful for each and every action that helps to get Kawasaki Disease known. TOGETHER we have made a huge difference. Because of OUR impact thousands of children's hearts will be protected from Kawasaki Disease!



post reach

3,900 A Sign 321 likes



51,500 + Profile Twitter

34 New Twitter 51



100s of donations received from Societi Supporters

















Kawasaki Disease is the leading cause of acquired heart disease in children in the UK. It's time we changed that...







# 1. FOI Research shaping our focus and delivery

Societi continued its Freedom of Information research contacting Trusts and Health Boards throughout the whole of the UK, requesting information spanning from 2006 until 2018. The FOI request sought data regarding Kawasaki Disease hospital admissions spanning from 2006 until 2018. 138 Trusts and Health Boards

throughout the UK provided information on nearly 7,500 Kawasaki Disease hospital admissions. The resulting database is at an unprecedented scale and subsequent analysis undertaken by Societi provides a unique insight into Kawasaki Disease within the UK and is a powerful tool helping to shape and inform our work.

# Aberystwyth Swansea CARL FF Southampton Singston upon Hull Kingston upon Hull Kingston upon Hull Liverpoon Sheffield Lincoln Camadge Leices OX ONDO Britingham Camadge Ipswich Gloub ster OX ONDO Britingham Camadge Ipswich Swansea CARL FF Southampton Britingham A Portsmouth

# 2. Supporting BPSU PIMS-TS study

Societi provided support to a phase two application for a BPSU study 'Multisystem inflammatory syndrome temporally associated with COVID-19 in children the United Kingdom'.

Societi is now working with the BPSU to provide PPI support associated with the study and is further supporting the study

through input into to the development of protocol; review of any lay material produced and assisting in disseminating the information to patient groups. Societi will also signpost the study on our website and share study information across our active social media platforms.



Societi

# societí Our Work - Clinical Research







# 3. Development for clinical trial

Beginning with a meeting our Founder called in May 2016, Societi catalysed and advanced the development of a clinical trial for Kawasaki Disease treatments. The trial titled KDCAAP (Kawasaki Disease Coronary Artery Aneurysm Prevention) will investigate the potential for better acute treatments for Kawasaki Disease which may reduce the heart damage

children can experience when affected by Kawasaki Disease. This pan-European trial received funding in April 2019 from Connect4Children. Societi is a partner in the trial team and will be involved throughout, leading the work with families, creating patient information and clinical awareness resources.



4. Societi
leads Public
and Patient
Involvement
(PPI) for
Europe-wide
clinical trial

Having been the catalyst for the KDCAAP trial, back in May 2016, Societi was asked to play an ongoing role in the delivery of the largest Kawasaki Disease clinical trial of its type to ever take place – by leading the PPI elements. Societi sits as part of the Trial Management Group and Trial Steering

group too – with an important part to play making sure the views of families and patients are represented. Our work includes ensuring the profile of the trial is raised and the information families need, as they consider taking part in the trial, is available in user friendly formats.



Societi

# societí Our Work - Clinical Supervision



# societí Our Work - Clinical Supervision



# 1. Shaping National Guidelines

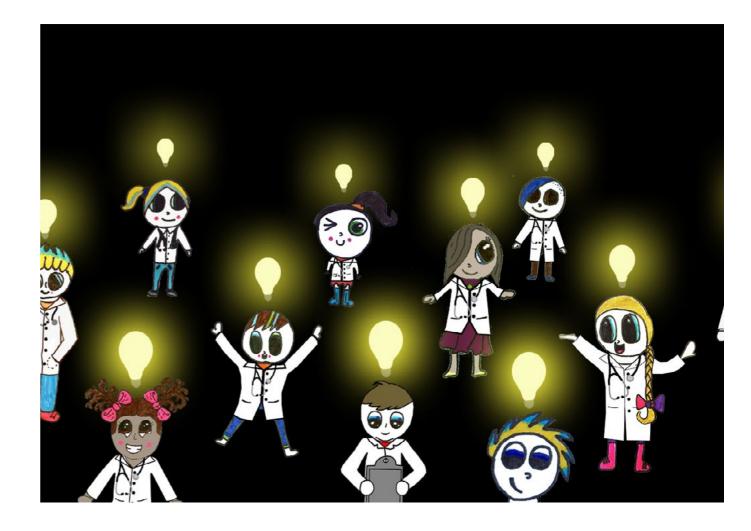
Societi Founder Rachael, was involved in a NICE Committee looking at the guidance on fever in the under 5's age group, particularly Kawasaki Disease and was able to contribute directly to the work of this very important committee.

NICE - the National Institute for Health and Care Excellence have now published revised guidance for public consultation, based on the evidence reviewed by – and experience of – their appointed committee. The resulting changes to the guidance are highly significant and urge clinicians to think about Kawasaki Disease in all children who have a fever lasting 5 days or longer, even when no additional features are present.

2. Development of E-learning module with RCGP

In February 2020 the culmination of a partnership between Societi and the Royal College of General Practitioners (RCGP) - the professional body for UK GPs resulted in the long anticipated release of our Kawasaki Disease e-learning module. Designed to raise awareness and build knowledge of Kawasaki Disease amongst GPs, Societi produced and developed a variety of content and resources to be used within the module. Funded by Societi with donations from Veswas Ltd and Alsford Timber, and authored by then Societi Trustee, Dr Louise Tulloh the module is now available to over 100,000 UK healthcare professionals as part of their continued professional development.





# societí Clinical Supervision



# Clinical Supervision



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# 3. Lifetime cardiac management guidance

Hugely important and much needed UK lifetime cardiac management guidance, for those who have had Kawasaki Disease with heart damage was published in December 2019. The guidance sets out in detail the lifetime clinical care needs of those who suffer lasting heart damage. Leading experts in Kawasaki Disease, paediatric

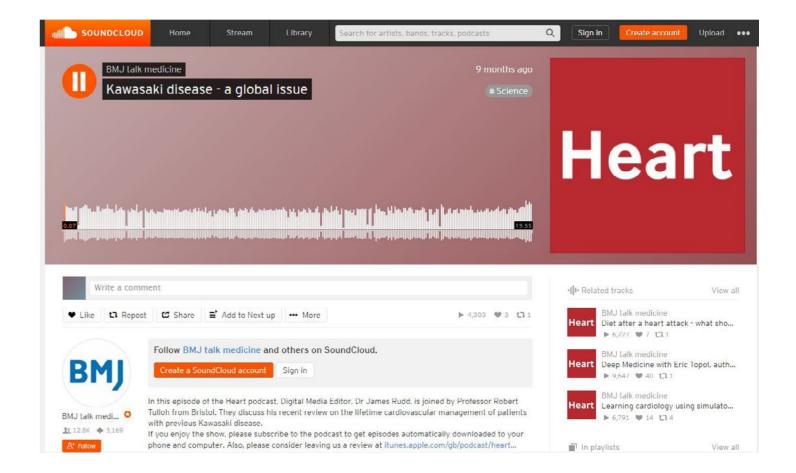
cardiology and adult cardiology contributed to this critical paper. NHS England National Clinical Directors Prof Huon Gray CBE and Dr Jackie Cornish OBE chaired the work of the group. And the RCPCH and BCS have lent their support too meaning key groups of doctors will get important access to this TRANSFORMATIONAL paper.



# 4. Interview with BMJ Heart Journal

Societi Trustee and Kawasaki Disease expert, Professor Robert Tulloh gave an interview with BMJ Heart Journal in connection with the new released lifetime guidance published by Heart BMJ. In the interview which is recorded and available on the BMJ Talk Medicine Soundcloud channel as a podcast,

Professor Tulloh gave an overview of the Lifetime cardiovascular management of patients with previous Kawasaki Disease Paper. This podcast is an extremely useful resource for clinicians and has been viewed thousands of times.



#### societí Our Work - Clinical Supervision



# societí Our Work - Clinical Supervision



#### 5. UK Kawasaki Disease **Steering Group**

Societi continues to chair the UK Kawasaki Disease Steering Group - a UK wide partnership group comprising key national leaders and influencers who can act together as a catalyst for positive change around Kawasaki Disease - for awareness, for knowledge sharing and to encourage best practice in clinical care across the UK.

During 2019/2020 our work included progress and discussions around our lifetime cardiac management paper, Societi research study on hospital admissions, a patient registry, Awareness Raising, the KDCAAP clinical trial and the terms of reference and membership of the Group.

Societi

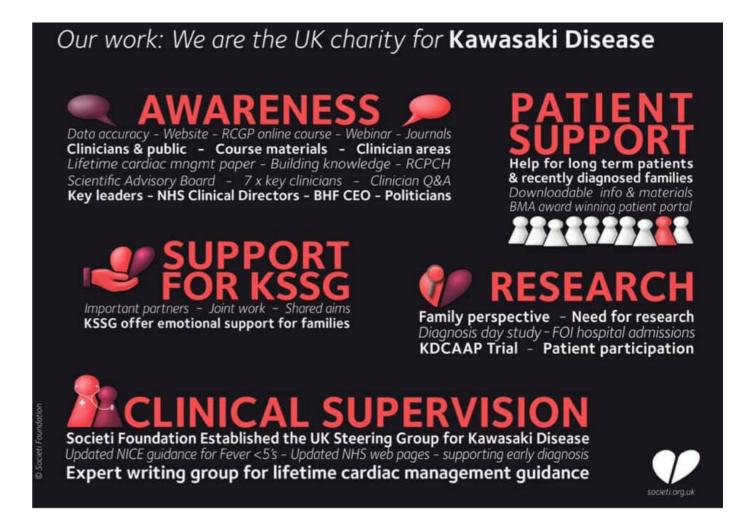
Societi

6. Presenting to the London **Symposium** on Kawasaki Disease

Societi were hugely privileged to have been asked to present to the London Symposium on Kawasaki Disease, run by the fabulous team at Great Ormond Street Hospital. Founder, Rachael presented to almost 100 key doctors from all over London and had the chance to summarise some of what Societi does and talk about what we know - from families and our own research - and

what needs to change. It was an incredible opportunity to meet so many wonderful clinicians who want to get Kawasaki Disease known, want to learn from the experts and who are determined to now THINK Kawasaki Disease!





# societí Our Work - Clinical Supervision



# societí Our Work - Clinical Supervision



# 7. Updating and reviewing our clinicians information

Societi has a dedicated space on our website for clinicians which includes Learning information and resources, links to useful Kawasaki Disease research, papers on Kawasaki Disease Management and a clinician Q&A which has been created following many of the discussions

we have had with clinicians during events, conferences and webinars. The information in our clinicians area is well used and is regularly reviewed and updated with new information added constantly.

#### Learning information and resources for clinicians

#### Clinical Resource Pack

This information pack is intended for Primary Care staff and includes posters, which are suitable for display in clinic and waiting areas and a handy Myths & Facts sheet to share with colleagues, current NICE guidance on Fever Under 5's and Kawasaki Disease – and our information leaflets which are endorsed by the Royal College [...]

Clinician's Information Poster Clinician's Information Poster

Understanding some of the possible longer term issues

A leaflet written for parents and carers of children who have been affected by Kawasaki Disease.

TEMPERS! Awareness Raising Leaflet

We are working to make Kawasaki Disease memorable! Download our TEMPERS leaflet to help us do this - and raise awareness of Kawasaki Disease.

More resources and downloads for clinicians »

#### Kawasaki Disease Research

#### Kawasaki Disease: a prospective population survey in the UK and Ireland from 2013 to 2015

#### August 2018

Kawasaki Disease is an increasingly common vasculitis with risk of coronary artery aneurysms. The last UK survey was in 1990. Current epidemiology, treatment patterns and complication rates are unknown. The aim of this study, undertaken across the UK and Ireland, was to address this knowledge gap.

Kawasaki disease: New info to enhance our index of suspicion

May 2018

Every clinician needs a high index of suspicion. This paper contains new information to enhance it.

How to spot zebras – Kawasaki Disease May 2018

'When you hear hoofbeats, think of horses not zebras' – the old adage is well-known to GPs but what should you do when faced with a zebra, not a horse?

More research articles and links for clinicians »

#### Kawasaki Disease Management

#### Lifetime cardiovascular management of patients with previous Kawasaki Disease

Increasing numbers of patients who suffered Kawasaki Disease in childhood are transitioning to the care of adult services where there is significantly less awareness and experience of the condition than in paediatric services. The aim of this document is to provide guidance on the long-term management of patients who have vascular complications of Kawasaki Disease [...]

Understanding some of the possible longer term issues

A leaflet written for parents and carers of children who have been affected by Kawasaki Disease.

Utility of Coronary Computed Tomography Angiography in the Diagnosis and Management of Acute-Phase Adult-Onset Kawasaki Disease

A Japanese paper describing the use of CCTA to support Kawasaki Disease diagnosis.

More resources about Kawasaki Disease Management »

# 8. Distribution of GP and hospital information packs

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Societi has created and distributes GP information packs and hospital information packs to ensure that doctors have the information they need to make a Kawasaki Disease diagnosis quickly.

Even though work to create and distribute the packs has needed to be temporarily halted due to Covid-19 national restrictions, a total of 500 packs have still been distributed throughout this period. Work has also taken place to create and distribute the packs electronically and a program of electronic distribution has already begun.





# Our Work - Support for the Support Group



# societí Our Work - Support for the Support Group

#### 1. Hosting and updating the **KSSG** website

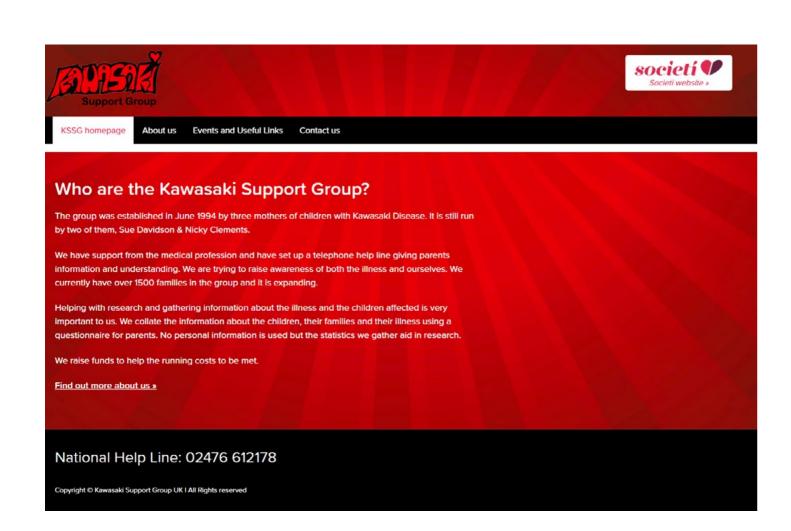
The KSSG website gives vital contact information for families who are affected by Kawasaki Disease and need to connect with the Support Group. Societi host the Support Group's website within its own site and completes updates as and when required. The national helpline promoted

through our website and elsewhere, allows families to speak to a friendly, knowledgeable and experienced team, and have questions answered in a sympathetic and supportive way.

2. Reviewing and updating the KSSG **Parent Guide** 

The KSSG Parent Guide was originally developed by KSSG. Societi fully updated and expanded the KSSG parent quide on behalf of KSSG in 2018 which was reviewed by Societi Trustee, Professor Tulloh. The guide which sits on the Societi Family Portal is intended to help families

understand more about Kawasaki Disease and explain some of the common issues raised by parents of children who are diagnosed. These pages of our website are reviewed regularly by Societi to ensure the information is as up to date as possible.





#### **Parent Guide**

This guide was originally developed by Sue Davidson, one of the founders of the Parent Support Group KSSG, with clinical input from Professor Robert Tulloh and Dr Colin Michie - whilst at Guy's and St Thomas' Hospital Trust and Ealing Hospital respectively.

It has since been fully updated and expanded by Societi Foundation (December 2017) and reviewed for accuracy by Professor Robert Tulloh (Societi Foundation Trustee and Chair of the Societi Scientific Advisory Board) for use on our Family Resource Portal. It was last reviewed by Societi in April 2019.

The original version of this guide was funded by a kind donation from West Malling Golf Club for which KSSG were extremely grateful, also to the family who nominated them for the funds. Thanks to donors and Societi fundraisers, we have been able to review, revise and expand this guide for families affected by Kawasaki Disease. We will periodically review this and if you'd like to make a donation to support our work, please click here.

#### Introduction

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This guide is intended to help you understand more about Kawasaki Disease. It may not answer all your questions but it does help to explain some of the common issues raised by parents of children who are diagnosed with Kawasaki Disease. We hope you find the facts useful and are not worried by them. We discuss lots of aspects of Kawasaki Disease in this section including a number of possible







If you have any feedback or comments on the Family Resource Portal we'd love to hear from you!



# Our Work - Support for the Support Group



# Our Work - Support for the Support Group

3. KSSG Members raising awareness Working with KSSG, batches of TEMPERS leaflets and 'wallet cards' - all containing invaluable Kawasaki Disease information have been sent out to tens of homes across the UK, to families wanting to raise awareness in their communities. KSSG promotes access to Societi resources

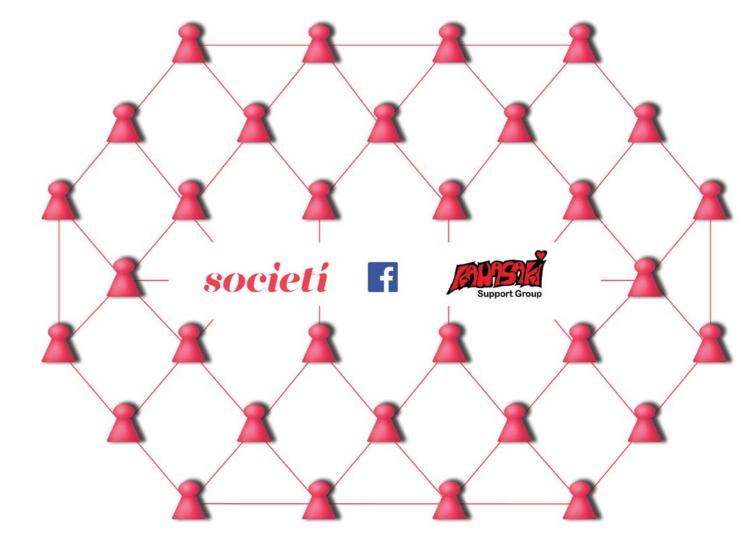
through their closed Facebook group and ensures that, by working together, our materials are able to reach pharmacies and school / nursery settings which otherwise it would not have been possible for us to reach.

# 4. Social Media Partners

KSSG support their members throughout the year, via a Facebook group for directly affected families. Supporting this work, Societi developed and KSSG then shared and promoted a series of information posts to this closed group so that families had access to up-to-date information, through a familiar channel.

KSSG supported dialogue and discussion by families on topics such as raising awareness and the impact of Covid-19 on Kawasaki Disease. Feedback from KSSG continues to help Societi to shape information and materials for families.





# Financial Position

### Reserves Policy

At the year end, the charity had total reserves of £53,501 (2019: £40,034) composed of unrestricted funds of £53,501 (2019: £40,034) and restricted funds of £nil (2019: £nil).

#### Context

Societi Foundation (Societi) has established a reserves policy to protect its activities by providing a financial comfort zone against an unpredictable environment and to make sufficient provision for future cash flow requirements to sustain our charitable activities. The policy also provides the framework for future strategic planning and decision-making. The development of an effective reserves policy will reduce the impact of financial risks upon the continuing operations of Societi.

The reserves policy and the establishment of ranges is based upon an annual risk assessment of the internal and external operating environment, as well as having a due regard for the nature of activities under taken by Societi for our beneficiaries.

#### Scope

This policy relates to Societi Foundations operation as a charity with four strategic aims – to raise awareness, enhance clinical supervision, enable clinical research and support the UK Support Group. In setting this policy Trustees are aware that, as a newly established organisation our reserves policy will need to be under regular review and be adjusted appropriately to reflect growth in our organisation.

#### Reserves

Societi Foundation holds unrestricted reserves derived from fundraiser income or

donations that can be spent at the discretion of the Trustees in furtherance of any of Societi's objectives.

#### **Range of Reserves Held**

The target range for reserves has been set by Trustees at no less than £40,000. This policy remains under informal review (annually) and formal review (every 3 years) to ensure that, as a new charity with a rapidly changing financial environment (due to positive growth and an increasing supporter/fundraiser base) our reserves policy remains relevant and continues to act to appropriately safequard the future operation of Societi. At the year end the charity had reserves of £53,501 which is above the minimum level per the reserves policy of £40,000. Due to the uncertain economic climate the trustees feel it prudent to have a figure above the minimum level.

#### Approach to Reserves

The work of our charity is both planned and reactive. As well as planned works, such as the development and delivery of Societi-led projects, opportunities can be presented - or circumstances arise which demand an immediate response or a new approach. New funding opportunities also arise which may require match funding and in order to ensure we are well placed to take advantage of these, and through these address the challenges presented to UK children by Kawasaki Disease, reserves are held by Societi.

As a newly established organisation, at the time of the development of this policy we have no paid staff so continuity planning for such costs, in challenging circumstances are not allowed for in the reserves. However it is

# Reserves Policy cont.

foreseen that with growth, this position will change and our reserves policy will need to change to reflect this. Similarly, only minimal costs are incurred by Societi currently in respect of its organisational overheads and as we grow, Trustees recognise that these will increase and again, our reserves position will need to be amended to reflect the need to ensure operational continuity.

Trustees have considered operational costs when setting the reserves policy, current and planned commitments and 'seed-corn' funding requirements which may be needed.

Our current modest reserves level (whilst relatively high in percentage terms) reflects:

- the low turnover of the organisation

   from which a modest sum must be
   identified as reserves, and this translates
   as a higher relative percentage as
   presently, income is low.
- the need to continue our primary operations - awareness raising - in the face of financial pressures. Trustees have satisfied themselves that these can be continued with the modest financial provisions described in this policy.
- 3. experience of establishing and growing Societi as a new organisation Trustees have a proven track record of delivering the work of the charity within a very small budget having started the charity without grants or access to donations/fundraising

#### **Management of Reserves**

Any reserves held in excess of the target percentage will be reviewed by Societi Foundation Trustees on a regular basis and an appropriate range of options will be considered, which might include releasing the funds to enhance delivery of Societi's objectives. As we grow as a charity this reserves policy could be updated to include provisions such as investment of funds, to generate further income and allow the expansion of Societi's work. As a young organisation our current focus is on actions to deliver against our objectives and grow our

The movement of funds to and from the reserves identified above will be at the discretion of the Trustees.

#### **Reviewing our Policy**

The Charity Commission recommends that charities develop their reserves policy and their planning at the same time, recognising that strategic and financial planning informs the development of reserves policies and vice versa. Trustees recognise the importance of setting our operational budgets to identify peaks or troughs in cash flow and the reserves policy must ensure the troughs in funding can be met from reserves held.

Our reserves policy will be regularly reviewed in light of the changing funding and financial climate and other emerging risks. We publish our assessment of the risks that we are facing as part of our statutory accounts/annual report.

This policy will also be amended in line with UK Government quidance, as amended.



# Structure, governance and management

## societí

# Structure, governance and management

# **Governing Document**

Recruitment and appointment of new trustees

The legal form of the charity is that of a Charitable Incorporated Organisation (CIO) which is controlled by its governing document, its constitution dated 10 July 2017

#### **Selecting Trustees - Preparations**

Prior to mapping out our selection process for Trustees joining Societi Foundation, Trustees are alerted to, and informed of existing and new rules regarding eligibility and automatic disqualification of charity Trustees. Any amendments to these provisions are circulated automatically to Trustees, and the most up to date guidance will be consulted at each point a recruitment process is considered (and always before commencement).

Trustees are aware of the need for a balance of skills and abilities on our Board – as well as the need for available capacity in all Trustees if we are to achieve our objectives as a charity. A "hands-on" role is expected from all Trustees as we guide and grow our organisation. In determining the need for additional Trustees therefore we consider current skills, abilities and capacity – as well as horizon scanning for the skill sets and capacity we will need in order to achieve current and future plans.

#### **Process to Appoint Trustees**

The procedures for electing or appointing new Trustees is set out in overview in our Constitution. Section 10 of the Societi Foundation Constitution notes:

(1) Apart from the first charity Trustees, every trustee must be appointed for a term of three years by a resolution passed at a properly convened meeting of the charity Trustees.

(2) In selecting individuals for appointment as charity trustees, the charity Trustees must have regard to the skills, knowledge and experience needed for the effective administration of the CIO.

We acknowledge that we are quorate with five Trustees but we recognise that, for a strong organisation, our aim is always to exceed this minimum number of Trustees and that our Trustee cohort should bring breadth of reach, capacity and energy, to ambitiously drive our organisation.

#### **Recruiting Trustees**

As the requirements for Trustees within our growing charity are changing rapidly – mirroring the growth we experience and plan to continue to achieve, it is essential that Trustees joining Societi Foundation can be selected to meet these changing needs. Equally, it is essential that new Trustees are able to join the organisation and bring strong, positive contributions – and in doing this they must match and exceed the level of ambition for our organisation as demonstrated by our current Trustees.

We will work to recruit Trustees not simply when vacancies occur, but when needs are identified. We will recruit through informal and formal processes – as may be needed and best suited to the Trustee position(s) which we have identified to fill.

#### **Appointment**

Information on prospective Trustees including professional biographies and/or the findings from formal recruitment processes and/or references taken up will inform the appointment process. Trustees will make a majority decision on the appointment of any new Trustee(s) at a formally convened

# Induction and training of new trustees

# meetings may be called to confirm the appointment of a Trustee if needed. Induction

We recognise that an appropriately organised induction for all new Trustees is vital. It is a gateway for both new trustees – helping them to get up to speed with the role, the organisation and their legal responsibilities.

meeting of the Board of Trustees – whether

within or outside of the cycle of planned

meetings. This recognises that additional

Trustees are alert to the need for a strong induction which ensures we can provide evidence that the people in our organisation have an awareness and understanding of our ambitions and aims -but also, essentially, key policies and procedures such as health and safety and data protection. Our Trustee induction programme includes a variety of activities over a period of time, including:

- Meetings and introductions to other Trustees, beneficiaries, service users etc
- Invitations to events, meetings and presentations
- A Trustee induction pack
- · Buddying or coaching

## Registered Charity number 1173755

#### **Principal address**

Victoria Court Holme Lane Winthorpe Newark Nottinghamshire NG24 2NU

#### Trustees

R Tulloh
R E A Greenwood
R D Greenwood
L Tulloh (resigned 1.6.20)
G Higgins
Professor P Brogan (appointed 10.9.20)

#### **Independent Examiner**

Wright Vigar Limited
Chartered Accountants & Business Advisers
15 Newland
Lincoln
Lincolnshire
LN1 1XG

Approved by order of the board of trustees on O7 April 2021 and signed on its behalf by:

C greennow.

# Reference and administrative details

# Independent Examiner's Report to the Trustees of Societi Foundation

# Thank you

Our annual report is an important document for us as a charity. But it serves to do much more than that by helping anyone who reads it to get to know a little more about Societi and Kawasaki Disease than they did before.

For me, that's a truly valuable outcome to have achieved. 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 our annual report. The time you've invested in understanding more about out work means such a lot.

With my very best wishes,

Reesel

Rachael McCormack, Founder for Societi Foundation

## Independent Examiner's Report to the Trustees of Societi Foundation

#### Independent examiner's report to the trustees of Societi Foundation

I report to the charity trustees on my examination of the accounts of Societi Foundation (the Trust) for the year ended 30 June 2020.

#### Responsibilities and basis of report

As the charity trustees of the Trust you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the Trust's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

#### Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

- 1. accounting records were not kept in respect of the Trust as required by section 130 of the Act; or
- the accounts do not accord with those records; or
- 3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Paul Colcomb FCCA Wright Vigar Limited Chartered Accountants & Business Advisers 15 Newland Lincoln Lincolnshire LN1 1XG

Date: 15 April 2021

Societi

# Statement of financial activities for the year ended 30 June 2020

# societi Balance sheet 30 June 2020

	Notes	Unrestricted funds £	Restricted funds £	2020 Total funds £	2019 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies		79,417	-	79,417	69,772
Other trading activities	2	843	-	843	95
Other income		356	-	356	405
Total		80,616		80,616	70,272
<b>EXPENDITURE ON</b> Raising funds		6,081	-	6,081	2,183
Charitable activities					
Kawasaki disease awareness		61,068	-	61,068	77,493
Total		67,149		67,149	79,676
NET INCOME/(EXPENDITURE)		13,467	-	13,467	(9,404)
RECONCILIATION OF FUNDS					
Total funds brought forward		40,034	-	40,034	49,438
TOTAL FUNDS CARRIED FORWARD		53,501		53,501	40,034

	Notes	Unrestricted funds	Restricted funds £	2020 Total funds £	2019 Total Funds £
FIXED ASSETS					
Intangible assets	6	272	-	272	943
CURRENT ASSETS					
Stocks	7	2,445	-	2,445	3,103
Debtors	8	202	-	202	166
Cash at bank		<u>59,686</u>		<u>59,686</u>	44,872
		62,333	-	62,333	48,141
CREDITORS					
Amounts falling due within one year	9	(9,104)	_	(9,104)	(9,050)
NET CURRENT ASSETS		53,229	-	53,229	39,901
TOTAL ASSETS LESS CURRENT		53,501	-	53,501	40,034
LIABILITIES					
NET ASSETS		53,501		53,501	40,034
FUNDS	10				
Unrestricted funds				53,501	40,034
					<u> </u>
TOTAL FUNDS				53,501	40,034

The financial statements were approved by the Board of Trustees and authorised for issue on O7 April 2021 and were signed on its behalf by:

R E A Greenwood - Trustee



## Notes to the Financial Statements for the Year Ended 30 June 2020

## societí

# Notes to the Financial Statements - continued for the Year Ended 30 June 2020

#### 1. Accounting **Policies**

#### Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities can be measured reliably. Expenditure is preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

The charity is a Charitable Incorporated Organisation (CIO) registered with the Charity Commission in England and Wales.

#### Financial reporting standard 102 reduced disclosure exemptions

The charity has taken advantage of the following disclosure exemptions in preparing these financial statements, as permitted by FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland':

the requirements of Section 7 Statement of Cash Flows.

#### Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Donations in kind are valued at the market rate of the services donated.

#### **Expenditure**

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

#### Intangible assets

Amortisation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Website - 33% on cost

#### **Stocks**

Stocks are valued at the lower of cost and net realisable value, after making due allowance for obsolete and slow moving items.

The charity is exempt from tax on its charitable activities.

#### Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Societi

2. Other trading activities	Merchandise income		2020 £ 843	<b>2019 £</b> 95
3. Support costs		Other	Governance costs £	Totals £
	Kawasaki Disease awareness	24,504	300	24,804
4. Independent			£	£
examination	Independent examination fee		300	300

#### 5. Trustees' renumeration & benefits

There were no trustees' remuneration or other benefits for the year ended 30 June 2020 nor for the period ended 30 June 2019.

#### Trustees' expenses

There were no trustees' expenses paid for the year ended 30 June 2020 nor for the period ended 30 June 2019.

#### 6. Intangible fixed assets

	Website £
COST	
At 1 July 2019 and 30 June 2020	2,034
AMORTISATION	
At 1 July 2019	1,091
Charge for year	671
At 30 June 2020	1,762
NET BOOK VALUE	
At 30 June 2020	272
At 30 June 2019	943

Notes to the Financial Statements - continued for the Year Ended 30 June 2020

**societí** Notes to the Financial Statements - continued for the Year Ended 30 June 2020

7. Stocks			2020 £	2019 £
	Stocks		2,445	3,103
8. Debtors: amounts falling due			2020 £	2019 £
within one year	Prepayments and accrued income		202	166
9. Creditors: amounts falling due			2020 £	2019 £
within one year	Other creditors		9,104	9,050
10. Movement in funds		At 01.07.19 £	Net movement in funds £	At 30.06.19 £
	Unrestricted funds			
	General fund	40,034	13,467	53,501
	Total funds	40,034	13,467	53,501
	Net movement in funds are as follows:			
		Incoming resources £	Resources expended £	Movement in funds £
	Unrestricted funds			
	General fund	80,616	(67,149)	13,467
	TOTAL FUNDS	80,616	(67,149)	13,467

#### 10. Movement in funds continued

#### Comparatives for movement in funds

	At 1/7/18 £	Net movement in funds £	Transfers between funds £	At 30/6/19
<b>Unrestricted funds</b>				
General fund	40,138	11,596	(11,700)	40,034
Restricted funds				
SOBI	9,300	(21,000)	11,700	-
TOTAL FUNDS	49,438	(9,404)	_	40,034

#### Comparatives for movement in funds , included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	70,272	(58,676)	11,596
Restricted funds			
SOBI	-	(21,000)	(21,000)
TOTAL FUNDS	70 272	(70,676)	(0.404
TOTAL FUNDS	70,272 ======	(79,676) =======	(9,404

The fund arose following a donation from SOBI, an international rare disease company. This donation is to be used to fund clinical resources. The expenditure in the period related to the production of a Clinical eLearning film.

# Notes to the Financial Statements - continued for the Year Ended 30 June 2020

#### 11. Related party disclosures

During the period, the Charity received donated services of £7,512 (2019: £7,512) from Lanarca Limited, a company of which trustee R E A Greenwood and R D Greenwood are directors.

Additionally salaries for the year of £28,017 (2019: £17,024) have been recharged from Lanarca Limited at cost and with no uplift for the secondment of a Design and Research staff member.

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# Detailed Statement of Financial Activities for the Year Ended 30 June 2020

INCOME AND ENDOWMENTS	2020 £	2019 £
Donations and legacies		
Donations	71,905	62,260
Donated services	7,512	7,512
	79,417	69,772
Other trading activities		
Merchandise income	843	95
Other income		
Other Income	<u>356</u>	405
Total incoming resources	80,616	70,272
EXPENDITURE		
Raising donations and legacies		
Fundraising costs	2,665	1,916
Other trading activities		
Opening stock	3,103	-
Purchases	2,758	3,370
Closing stock	(2,445)	(3,103)
	3,416	267
Charitable activities		
Subscriptions	82	179
Advertising	206	125
Travel and subsistence	112	1,999
Resource Films	-	3,000
Donated services	7,512	7,512
Kawasaki Course Development	-	18,000
Staff Costs	28,017	17,024
Raising Awareness Costs	335	2,484
	36,264	50,323
Support costs		
Other		
Postage and stationery	5,004	10,013
Insurance	185	185
Accountancy	804	734
Office costs	7,550	14,916
Sundries	677	351
Administrative staff costs	9,613	-
Computer software	<u>671</u>	671
	24,504	26,870
Governance costs		
Independent Examination	300	300
Total resources expended	67,149	79,676
Net (expenditure)/income	13,467	(9,404)

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# Kawasaki Disease Symptoms

# If a child has a **PERSISTENT FEVER** and two or more of these symptoms

# **THINK KAWASAKI DISEASE!**









Swollen fingers/toes







