

societì

*Societi
Foundation
Annual Report*

2018/2019



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



Persistent fever



**Cracked lips/
'strawberry' tongue**



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands

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Bloodshot eyes

Swollen glands

Swollen fingers/toes

About Kawasaki Disease

About Kawasaki Disease

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 Once thought of as a rare disease, this now outdated idea, wrongly held on to by some, leads to delayed diagnosis and with this, increased risk of serious heart damage for children.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.

About Societi Foundation

About Societi

Societi was established to raise awareness of Kawasaki Disease. Societi is 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 both 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.

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 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 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.

Significant Activities

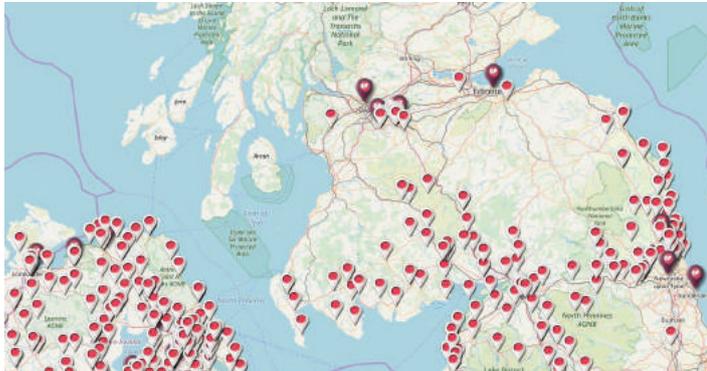
In setting our objectives and planning our activities our Trustees have given careful consideration on the Charity Commission's guidance on public benefit. On the pages which follow our delivery and impact during 2018/2019 is set out.

Our Work
Awareness Raising





1. GP & hospital information packs



From 1 July 2018 until 30 June 2019, Societi Foundation sent out over 1000 GP and hospital Kawasaki Disease information packs. The packs which contain posters, leaflets and vital information on Kawasaki Disease were created to ensure that doctors have the information they need to make a Kawasaki Disease diagnosis quickly. Our project to send GP and hospital packs to every GP and hospital in the UK is ongoing. Below is an image of our interactive map which can be found on our website and is updated with every pack that is sent out. Societi supporters have been directly involved in this important work, volunteering to create packs and fundraising to meet the cost of packs.

2. Developing our hardworking Societi Kids



Our 'Societi Kids' are a really important part of our charity. Created and developed by our Junior Artist, Societi Kids help us to portray Kawasaki Disease as a children's Disease and Societi Foundation as a children's charity whilst upholding our policy for the protection of children's privacy. Our Societi Kids work hard for us and are part of our brand identity. It's important that as our organisation grows and builds upon its work, we develop our Kids to fulfil our needs. We have been delighted with the way in which our supporters have taken Societi Kids to their heart, and actively support growing awareness by promoting Societi Kids PLUS respecting our policy to protect the identity of children as we grow Kawasaki Disease awareness.

3. Our website and award winning Family Resource Portal



With the help of a very valued financial contribution from KSSG, the Societi Family Resource Portal was created to provide families of children affected by Kawasaki Disease with useful, up to date and UK relevant information regarding Kawasaki Disease. It is vital that the information available on the Portal and on our website remains up to date and relevant to ensure families affected by Kawasaki Disease have the most reliable resources available to them. Our Family Resource Portal won a Patient Information Award from the BMA in September 2018. Throughout the year, our website was periodically and regularly updated to ensure the info families need was current and accurate. Feedback from families has been so positive on how they value this trusted source of online support.

4. Helping our supporters raise awareness



Societi Foundation was established to raise awareness of Kawasaki Disease. There is only so much that Societi Foundation can do as an organisation - BUT with an army of Societi Supporters (#Team Societi) ready and willing to raise awareness of Kawasaki Disease, our reach penetrates the whole of the UK. We are constantly developing and supplying awareness raising materials to our supporters to enable them to achieve the very best results from their awareness raising. From 1 July 2018 until 30 June 2019 Societi posted 342 parcels to #TeamSocieti containing awareness and fund raising materials, including a large amount of materials to KSSG for their onward distribution to families.



5. Developing Societi merchandise



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6. Reviewing and updating our resources



Making information, resources and posters available for #TeamSocieti as they undertake awareness work in their communities has been a focus during the year. New posters, downloadable information, flyers, leaflets and more have all been added to our website, allowing supporters to shape and run their own awareness campaigns. We've responded too, throughout the year, to a range of requests for bespoke posters, stickers and letters - so that really tailored awareness raising has been possible, where our volunteers feel in control and supported with *exactly* the 'supplies' they need.

7. Developing a new long term issues leaflet



With the help of a very valued financial contribution from KSSG, the Societi Family Resource Portal was created to provide families of children affected by Kawasaki Disease with useful, up to date and UK relevant information regarding Kawasaki Disease. It is vital that the information available on the Portal and on our website remains up to date and relevant to ensure families affected by Kawasaki Disease have the most reliable resources available to them. Our Family Resource Portal won a Patient Information Award award from the BMA in September 2018. Throughout the year, our website was periodically and regularly updated to ensure the info families need was current and accurate. Feedback from families has been so positive on how they value this trusted source of online support.

8. Creating new awareness films



Societi Foundation commissioned the creation of two new short films during the year that tell the stories of two people affected by Kawasaki Disease - Jasmine and Massoud. Jasmine and her family share their experiences of fighting a long and desperate battle against Kawasaki Disease - ultimately receiving a life saving heart transplant. Massoud, a doctor himself, share his story of unknowingly having Kawasaki Disease and suffering a heart attack as a consequence. Both stories and their Kawasaki Disease awareness messages are truly powerful. The films are available to view on our Family Resource Portal and Youtube channel.



9. Societi's Virtual 10k



Societi kicked off World Heart Day 2018 with a Virtual 10k open to all Societi Supporters from the end of September until the end of October. The Virtual 10k was led by Societi's Running Committee who drove every aspect of the project and provided expert training advice too. The Running Committee built an international community of 120 supporters all of whom were involved in the event. Needless to say the event was a huge success with many participants all over the UK and internationally too. The event raised an impressive £2,300 and a huge amount of global awareness for Kawasaki Disease! Our volunteer running committee made this remarkable event possible!

10. Collaborating with the NHS to update UK information



Societi Foundation worked closely with NHS England and NHS Choices, guided by Societi Trustee and Kawasaki Disease expert, Professor Tulloh, to comprehensively update all the information on the NHS Choices website about Kawasaki Disease. As such a 'go-to' resource for health information, we were delighted to have had the full support of the fabulous team at NHS Choices as we worked together to jointly create current page content for Kawasaki Disease. Fully updated, and once again holding accurate information about Kawasaki Disease, these pages are also a source of referrals to the Societi website, which is linked to the NHS Choices page for access to both doctor and family resources.

11. Working with Partners Reddico



Societi specialist and influential partners, Reddico, an award winning digital marketing company offered to support Societi to help us reach more people with our Kawasaki Disease awareness raising message. Reddico analysed our use of social media and provided professional advice and information on how to make the most of the resources available to us to extend our reach, ensuring our awareness raising efforts obtained maximum impact! We're hugely grateful to Reddico for the very valuable advice they gave Societi.

12. Working Internationally with Sister Organisations



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17. Working with Ladies Circle



Societi Foundation was named as the Ladies Circle Presidents charity of the year in May 2019, by the newly installed President Lindsay Pickard. Ladies Circle is a huge organisation with groups across the UK – and has thousands of members, all of them active in their local communities for many great causes. Societi attended the Ladies Circle AGM where the partnership was revealed and Societi was able to provide Circlers with specially designed Kawasaki Disease information and resources to help them on their way to raising awareness and funds for Kawasaki Disease throughout the presidential year.

18. #VSS365 & 'Every day in January'



Led by Societi Supporter Andy, Societi took part in a Twitter story writing campaign to raise awareness of Kawasaki Disease 'every single day' through #vss365 (very short story everyday) in January. It was part of our "Month of Awareness" during January, building up to International Kawasaki Disease Awareness Day on 26 January. The Twitter based campaign was an inspired way to reach a whole new audience, telling them about Kawasaki Disease. The impact was huge. We were overwhelmed with the support in writing, tweeting and retweeting. Over 350 people got involved throughout January sending a staggering 2,400 tweets raising awareness of Kawasaki Disease – tweets which were seen up to 3 million times!

19. Vaccines information



Societi Foundation released a statement in October 2018 on Kawasaki Disease and vaccines. Prompted by conversations about this topic – which many parents over a number of years have raised questions about, we joined forces with Government agency partners at Public Health England and the Medicines and Healthcare products Regulatory Agency to issue a statement which was also supported by our Scientific Advisory Board. The statement was well received and continues to be a popular page on the Societi website as it addresses the questions many parents have and uncouples fact from fiction.

20. Facebook, Instagram & Twitter



Societi posts Kawasaki Disease awareness raising material across our social media pages on a daily basis. The number of followers we have on each platform has steadily and organically grown over time. We work hard to create content which has a consistent message and that is reliable and original – something that our followers will want to share to raise Kawasaki Disease awareness even further. It is only with the incredible support of now thousands in #TeamSocieti, across our social media channels, that we can continue to grow our reach and impact.



21. Political engagement thanks to Lexington Communications



Societi has benefited from immense support from an expert team of Public Affairs specialists from Lexington Health, a recognised leader in the field of communications and engagement, developing plans to reach UK policymakers, politicians and wider stakeholders. Societi has been directly in touch with the offices of dozens of MPs and the Prime Minister during the year – with a view to meetings, discussion and more. Societi attended Westminster where we spoke about the need for a patient registry, the increasing incidence of Kawasaki Disease and the serious damage it causes for far too many children. We’ve talked about the need for awareness – and the need for investment to support UK led research and knowledge building across our medical community.

22. International Awareness Day 2019



Kawasaki Disease International Awareness Day 2019 was by far the biggest and most far reaching awareness campaign ever held in the UK for Kawasaki Disease. Societi Foundation worked in the run up to, and throughout January on wide ranging projects to get Kawasaki Disease known. We Collaborated with significant national partners including the Royal College for Paediatrics and Child Health and NHS, as well as hundreds of Societi Supporters, to ensure our Kawasaki Disease awareness raising messages reached as far as possible. The summary statement over the page gives an overview of the activities and achievements of the campaign.

International Kawasaki Disease Awareness Day 2019
Impact Statement

Theme: Kawasaki Disease - EXPECT to see it - be READY to treat it!

This year, Awareness Day became Awareness month! #TeamSocieti worked throughout January on wide ranging projects to get Kawasaki Disease known. And our impact together was significant – with Awareness Day 2019 being by far the biggest and most far reaching awareness campaign ever held in the UK for Kawasaki Disease. Collaborating with significant national partners as well as hundreds of Societi Supporters, this summary statement shares a few of the achievements from our campaign.

Creating Powerful Conversations
With simply fantastic support from many long term fundraisers and donors, we were able to provide an extensive range of materials, packs and downloadable resources for Societi Supporters to use to power their Kawasaki Conversations. Parcels full of everything from TEMPERS to t-shirts, posters to pin badges and more besides were sent to over 100 supporters right across the UK – double the number of supporters getting involved in this way compared to 2018.

Over 30,000 TEMPERS leaflets were shared with Societi Supporters as well as in GP and Hospital information packs – with these going into schools, pharmacies, offices, community centres, coffee shops and many more places too.

The dedicated page on our website for Awareness Day was significantly expanded for 2019 with the addition of a host of new downloads and resources for growing Kawasaki Conversations. We created social media frames to download, share and raise awareness – over 1,000 website users downloaded resources!

Building Awareness
#TeamSocieti were busy – innovative and creative with their plans to raise awareness! From talks, to spreading the word on social media, films, coffee mornings and cake sales, “wear red” and non uniform days... whilst others put up posters and shared TEMPERS – handed out wallet cards and sent a teddy bear armed with info on his Kawasaki travels! And with offices ‘going red’, whole buildings going red – and Kawasaki Conversations growing across community events, every single Societi Supporter involved created powerful, lasting impact – growing knowledge which will directly protect children from Kawasaki Disease.

Fantastic Fundraisers! Determined Donors!
Whilst awareness is our primary aim in January – our Supporters know that without their fundraising support, we can’t grow awareness throughout the year. Many took on the challenge to fundraise in January for us – one of the hardest months in which to fundraise and we’re hugely grateful! Thanks too, to our growing army of donors, together you’ve made Societi’s financial start to 2019 so strong, giving us the confidence to plan for and commit to projects in the months ahead.

Schools Packs, GP Packs and Hospital Packs
Thanks to key fundraisers, partners and sponsors – including SKLP Cardiff and KSSG, over 50 Societi Hospital information packs were sent in January and over 250 GP packs linked to Awareness Day have also been posted. Each one contains key info, posters and leaflets so that doctors and staff teams can get to know Kawasaki Disease. Over 420 information packs were sent to schools too – with many taking part in activities on Awareness Day!

Strategic Stakeholder Support
As in 2018, we worked with the RCPCH and BPSU, the World Heart Federation and the British Heart Foundation, all key and longstanding Societi partners, to reach national and international audiences. Our joint media release was posted on the WHF and BHF websites – and this year we had huge support on social media from RCPCH, PCO, many hospitals, CCG’s and Trusts too, building lasting knowledge across clinical and medical communities. Our 2019 campaign also had great support from Lexington Health to reach a host of MPs; and from Roche Diagnostics who brought their considerable influence to raise Kawasaki Disease awareness.

Social Media Messaging – #ShareIfYouCare
Simply outstanding support from partners and supporters on social media meant we reached many hundreds of thousands of people, through Twitter, LinkedIn, Facebook and Instagram. Together with partners we made a huge impact. We have to mention some simply brilliant individuals too who gave up time – not just on the day but throughout all of January to get creative, write (#vss365!) and really power our messages with reposts, shares, tweets – and retweets –over 2,400 posts (on Twitter alone!) by over 350 people created absolutely phenomenal impact. Facebook and Instagram support was huge too – with over 45,000 accounts reached from our top posts. Wow! Societi supporters care!

Thank You...

Throughout 2018 as fundraisers – and through EVERY day in January 2019, Societi supporters and fundraisers directly helped make Awareness Day the best campaign yet. To all our wonderful fundraisers a HUGE THANK YOU! And to everyone who got actively involved during January – investing time and energy – please know – that TOGETHER we have made a difference. YOU have contributed to protecting children’s hearts from Kawasaki Disease.



THANK YOU!

Our Impact

- Over 3,000,000 potential Twitter reads
- 250+ GP information packs sent
- 30,000 TEMPERS distributed
- 420 information packs sent to schools
- 100+ Societi supporters actively raising awareness with events and local campaigns
- 15 Strategic partners supporting Societi
- 50 Societi hospital packs sent
- 1,000+ downloads of website resources
- 350 Twitter supporters joining #vss365
- 299 shares on our most popular Facebook post!
- 2,400 tweets in January
- 24,000 people reached with our top Facebook post



TOGETHER – our impact was simply huge!
#ForOurChildren

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

...Together we will!



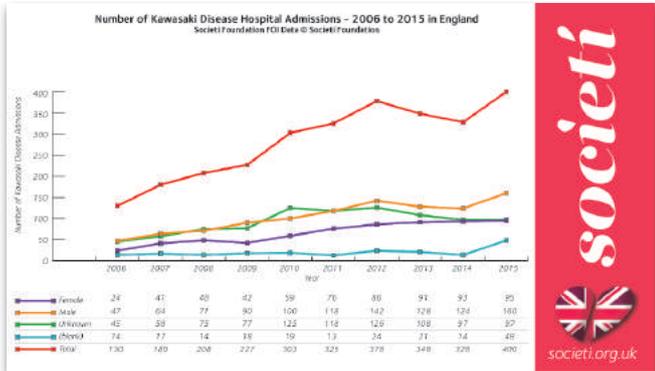
societi.org.uk

Our Work
Clinical Research





1. FOI Research shaping our focus and delivery



In 2016, Societi contacted every NHS Trust in England with a Freedom of Information request relating to Kawasaki Disease. We captured essential data regarding Kawasaki Disease hospital admissions spanning 10 years, between 2006 and 2015. Building on this previous research, Societi has planned a new Freedom of Information research request contacting Trusts and Health Boards throughout the whole of the UK, requesting information spanning from 2006 until 2018. The resulting database of Kawasaki Disease information is at an unprecedented scale and will be a powerful tool to help shape and inform our work around Kawasaki Disease.

2. Questions of the Heart

Questions of the Heart
Fundraising for Kawasaki Disease Research

Our Activity Timeline

- 2016: Societi launched a fundraising campaign for UK based research into Kawasaki Disease.
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- 2020: Societi launched a fundraising campaign for UK based research into Kawasaki Disease.
- 2021: Societi launched a fundraising campaign for UK based research into Kawasaki Disease.
- 2022: Societi launched a fundraising campaign for UK based research into Kawasaki Disease.
- 2023: Societi launched a fundraising campaign for UK based research into Kawasaki Disease.
- 2024: Societi launched a fundraising campaign for UK based research into Kawasaki Disease.
- 2025: Societi launched a fundraising campaign for UK based research into Kawasaki Disease.

Funding Goals

- £10,000
- £20,000
- £30,000
- £40,000
- £50,000
- £100,000
- £150,000

Many of the longer term effects of Kawasaki Disease are not yet fully understood or well enough known. Many families have questions which, if we could find or share answers could improve long term care for those affected. Societi launched a fundraising campaign for UK based research into Kawasaki Disease, designed to find answers to key questions. Research questions are to be selected by working closely with families, together with clinicians, focusing on areas which will help improve long term outcomes for those affected by Kawasaki Disease. The project is currently in the planning stage.

3. Development for clinical trial

Research Investment!

connect4children

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

societi.org.uk

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 we'll be involved throughout, leading the work with families, creating patient information and clinical awareness resources.

4. Diagnosis Day research

Word cloud containing terms such as: Severe Eczema, Unknown Infection, Measles, Herpes simplex, Bacteria in blood, Swine flu, Irritable hip, Adenovirus, Mumps, Rocky Mountain Fever, Hand foot and mouth, Lymphadenitis, Allergic reaction, Scarlet Fever, UTI, Sepsis, Severe Anaemia, Slapped Cheek, Kawasaki Disease suspected and ruled out, Moraxella, Pneumonia, Chest infection, Meningitis, Tonsillitis, Conjunctivitis, Ear Infection, Measles, Glandular Fever, Eye infection, Flu, Flesh eating disease, Strep Throat, Atypical pneumonia, Rheumatoid Arthritis, Bronchiolitis, Rubella.

With an apparent increase in reports from families of issues arising around diagnosis, and no current UK data on what was occurring in the diagnosis environment, Societi Foundation undertook to evaluate the picture with a mini poll of parents. Working with KSSG who also promoted the study to parents, the study aimed to highlight some of the issues around Kawasaki Disease diagnosis and treatment times. Information from the study was analysed in April 2018 and found growing delays across the UK in Kawasaki Disease diagnosis, no increase in Kawasaki Disease awareness, continued confusion around Kawasaki Disease symptoms and a potentially significant increase in risk to our children in terms of acquired heart disease from Kawasaki Disease in the UK.

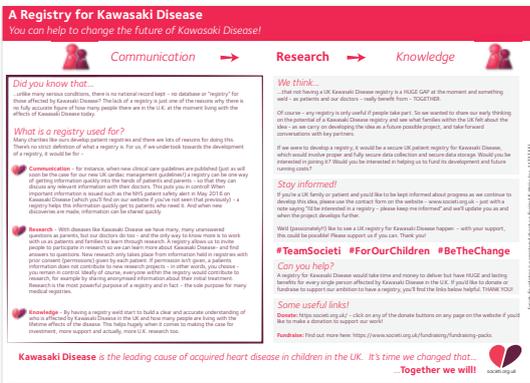
Our Work

Clinical Supervision



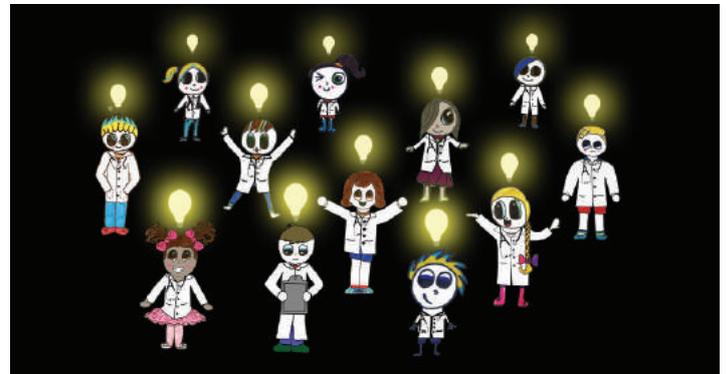


1. Planning a Kawasaki Disease registry



Societi Foundation prepared and made available a Kawasaki Disease awareness raising newsletter article for use by Supporters. It has been prepared so that it can be included in local newspapers, school newsletters, community or church magazines. The simple article has been publicised on our social media sites is available on our website to be downloaded and emailed directly to local news desks, raising valuable awareness within local communities. Thanks to the wonderful work of our supporters, this article has appeared in church, community and village magazines and has also been shared on social media.

2. Development of E-learning module with RCGP



In February 2019 we announced a partnership between Societi and the Royal College of General Practitioners (RCGP) - the professional body for UK GPs to develop a 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 and authored by Societi Trustee, Dr Louise Tulloh the module will become available to over 100,000 UK healthcare professionals as part of their continued professional development. Work advanced during 2019 to create course content, led by Societi.

3. Working with Paediatric Care Online



Working with the Paediatric Care Online (PCO) team, part of the Royal College of Paediatrics and Child Health, we helped directly in the development of updated pages on their clinical decision support system app. Previously, Societi worked with PCO staff to include Kawasaki Disease in a host of the "Key Practice Points" (clinician information pages) on their app - an online resource available to over 18,000 members of the College. The updated pages, including one on "Pyrexia of unknown origin" - or fever with unknown cause, now highlights information on Kawasaki Disease.

4. Attendance at the annual RCPCH conference



Societi ensured huge visibility for Kawasaki Disease with clinicians attending the RCPCH annual conference in Birmingham. With support from KSSG, Societi spent time having many Kawasaki conversations with hundreds of interested clinicians and handing out thousands of items of Kawasaki Disease information over the three days. Societi Trustee, Professor Robert Tulloh ran a 90 minute training workshop at the conference which we worked together with BPSU to promote. The workshop was oversubscribed and extremely successful with fantastic participation and lots of engagement.



5. UK Kawasaki Disease Steering Group



Societi chairs 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. Advocacy in all these areas is the remit of our group. The group meets twice yearly and works to advance focus areas such as research, knowledge sharing, awareness raising and encouraging and enabling best practice in clinical care. During 2018/2019 our work included directing the delivery of the ground breaking ‘Lifetime cardiovascular management of patients with previous Kawasaki Disease’ paper.

6. Producing guidance - Lifetime cardiovascular management of patients with previous Kawasaki Disease



With the UK Kawasaki Disease Steering Group having identified the priority to develop lifetime guidance for Kawasaki Disease, Societi coordinated the establishment of an expert writing group to produce much needed new UK. lifetime cardiac management guidance. The guidance is for those who have been affected Kawasaki Disease and this has resulted in lasting heart damage. During the year the group are consulted widely and expanded its membership to include experts in Kawasaki Disease, paediatric cardiology and adult cardiology from across the UK and USA. The guidance will set out in detail definitive lifetime clinical care needs of those who suffer lasting heart damage.

7. Shaping national guidance



Societi founder, Rachael McCormack, was appointed in May to the “Fever under 5’s” Committee of the National Institute for Health and Care Excellence (NICE). The work of the national Committee is to review and consider updates to clinical guidelines for fever in the under 5’s. NICE describe the purpose of the guideline as “This guideline is designed to assist healthcare professionals in the initial assessment and immediate treatment of young children with fever presenting to primary or secondary care.” With a focus on Kawasaki Disease, we recognised the huge importance of updating these guidelines so that more children could be correctly and quickly diagnosed, when affected by Kawasaki Disease.

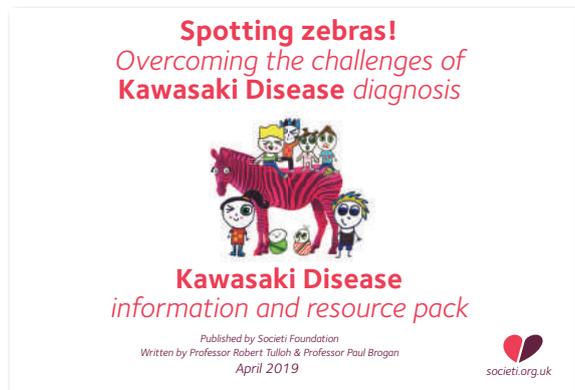
8. RCPCH webinar on Kawasaki Disease diagnosis and management



Together with leading UK experts in Kawasaki Disease, Professor Robert Tulloh and Professor Paul Brogan and enabled by the British Paediatric Surveillance Unit, Societi created a clinician’s webinar which was run by the Royal College of Paediatrics and Child Health. The webinar highlighted how out-dated information about Kawasaki Disease is hampering best practice for affected children and presented recent research findings on incidence (UK and Ireland) – including revealing data on lifetime heart damage caused. This has been the most popular webinar developed by the RCPCH and continues to get high viewing figures.



9. Spotting zebras - detailed clinician resource pack



Societi created an information and resource booklet for use by clinicians as an addition to Kawasaki Disease workshops and webinars. The booklet was designed to help clinicians understand diagnosis considerations, increase knowledge of differential diagnosis issues, increase awareness of urgency of treatment and disease severity and abandon prevailing 'myths' around Kawasaki Disease. As well as use with webinars and workshops the booklet is an excellent aid for all clinicians wishing to increase their knowledge around Kawasaki Disease.

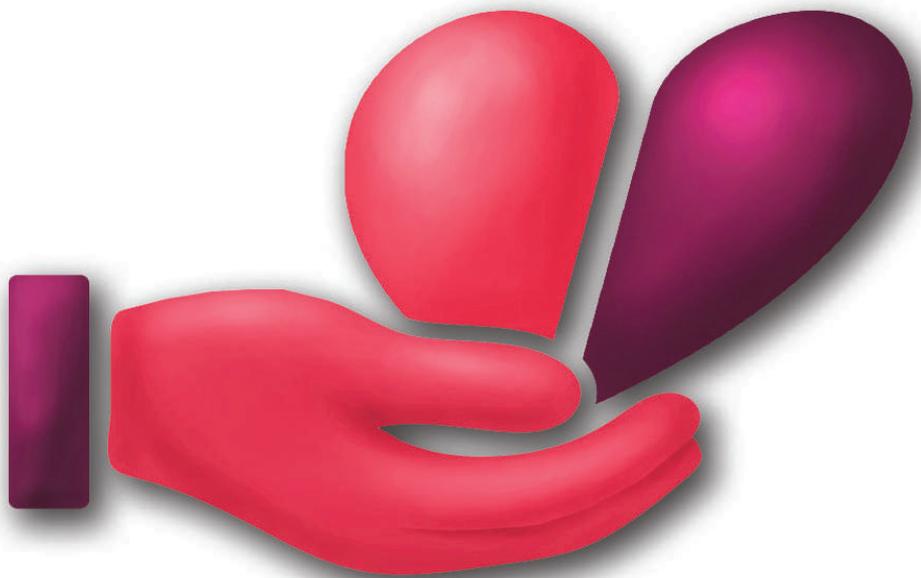
10. Recruitment to our Scientific Advisory Board



Kawasaki Disease can have many effects on a child and as such a multi-disciplinary approach to research/care is needed for this disease. Societi is therefore supported by a Scientific Advisory Board – a phenomenal group of Kawasaki Disease experts. Throughout the year, we have recruited to our Scientific Advisory Board to ensure Societi has access to the clinical expertise needed in our work. After recruitment, the Board now comprises the experts and field leaders as shown below.

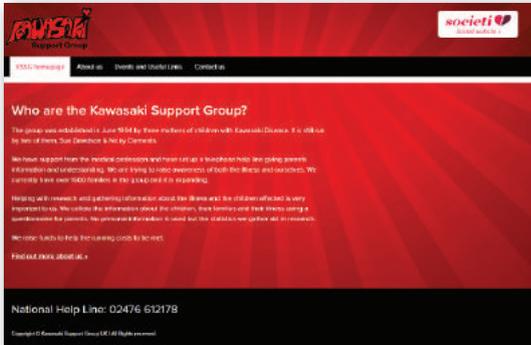
Our Work

**Support for the
Support Group**



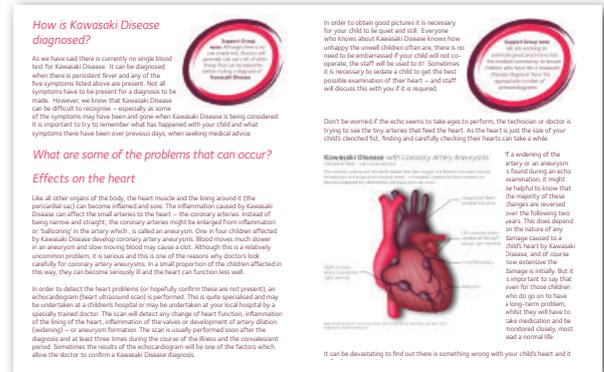


1. Hosting and updating the KSSG website



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. Updating the KSSG Parent Guide



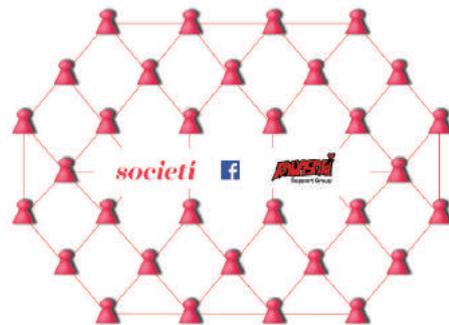
The KSSG Parent Guide was originally developed by KSSG. Societi fully updated and expanded the KSSG parent guide on behalf of KSSG which was reviewed by Societi Trustee, Professor Tulloh. We re-designed it too, making sure information is set out in a clear and user-friendly way. The guide is intended to help families understand more about Kawasaki Disease and explain some of the common issues raised by parents of children who are diagnosed. The guide now also sits on the Societi Family Resource Portal and within the KSSG pages of our website and is reviewed regularly to ensure the information is as up to date as possible.

3. KSSG Members raising awareness



Working with KSSG, batches of TEMPER'S 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 led an awareness campaign, supported by Societi materials. KSSG promoted access to Societi resources through their closed Facebook group and ensured that, by working together, our materials were able to reach pharmacies and school / nursery settings which otherwise it would not have been possible for us to reach.

4. Social Media Partners



Together with leading UK experts in Kawasaki Disease, Professor Robert Tulloh and Professor Paul Brogan and enabled by the British Paediatric Surveillance Unit, Societi created a clinician's webinar which was run by the Royal College of Paediatrics and Child Health. The webinar highlighted how out-dated information about Kawasaki Disease is hampering best practice for affected children and presented recent research findings on incidence (UK and Ireland) - including revealing data on lifetime heart damage caused. This has been the most popular webinar developed by the RCPCH and continues to get high viewing figures.



5. Patient-led content



Throughout the year, Societi have worked with KSSG in the creation and development of materials, to ensure that KSSG and their members have access to a comprehensive range of trusted resources. This is a two-way process however, with KSSG guidance and input helping to shape content, refine material and ensure that together the resources we produce are helpful to and tailored for the families that we support, across both Societi and KSSG. We are grateful for the continued support of KSSG in so many areas of our work.

6. Raising awareness of KSSG



Societi promote the work of KSSG where ever possible with our supporters and partners and vice versa. KSSG attended the RCPCH conference alongside Societi in May 2019, providing much welcome support over the 3 day event. The conference provided KSSG with the fantastic opportunity to speak to clinicians from across the UK and to raise awareness of the Family Support Group to this key group of people. At the conference, KSSG were able to inform clinicians of their work offering emotional support and advice to families affected by Kawasaki Disease.

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



Persistent fever



**Cracked lips/
'strawberry' tongue**



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands

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