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societi.org.uk



We are the
UK Foundation for
Kawasaki Disease

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1 January 2022 – 31 December 2022
Registered charity number 1173755



About Kawasaki Disease

Kawasaki Disease symptoms



Persistent fever



Rash



Cracked lips/
'strawberry'
tongue



Bloodshot eyes



Swollen glands



Swollen fingers/toes

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

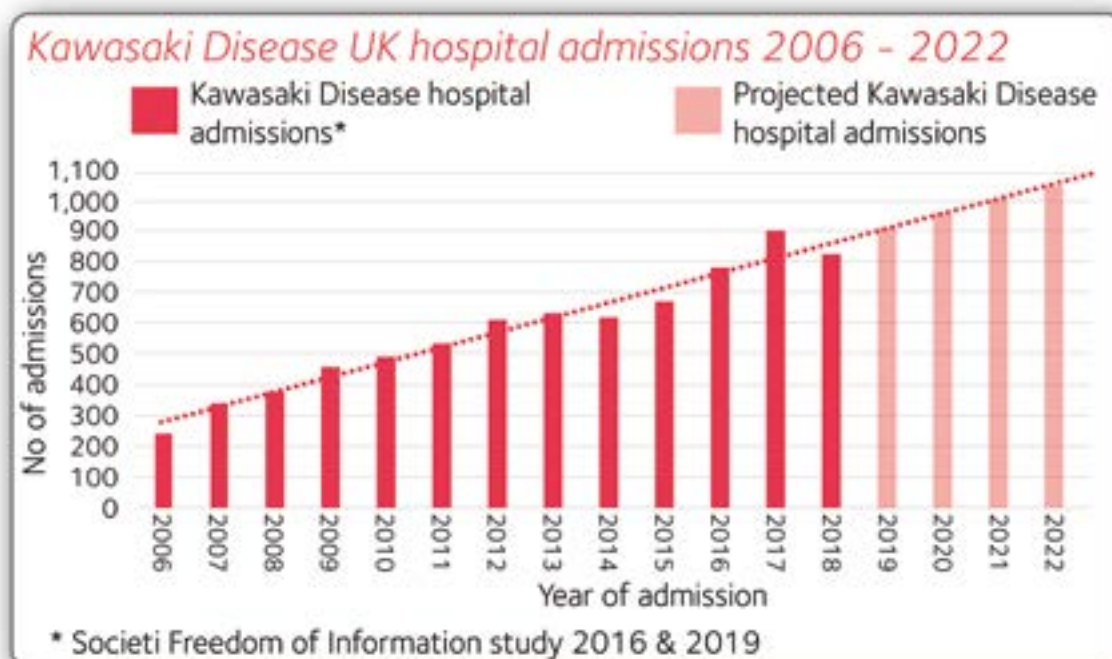
It is a type of vasculitis that mainly affects young children but it can affect people of any age. Its impact can be most serious in the very young, particularly infants. Identified in 1967 in Japan by Dr Tomisaku Kawasaki, the cause of Kawasaki Disease is still unknown. The illness presents with several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

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 damage to the blood vessels in the heart, and leads to acquired heart disease in about one in five affected children.

Children with 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. Research has shown that the risk of heart damage grows with increasing delay.

Kawasaki Disease is increasingly common. The graph below, based on Societi's study on hospital admissions for Kawasaki Disease shows there are up to 1,000 hospital admissions in the UK every year. 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.



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About Societi Foundation

What we do

Societi was established in 2015 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 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, in any child with a persistent fever.

We enable urgently needed research and pursue change to 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.

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.

Our Objectives and Activities:

- 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.

Our significant activities:

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



Awareness raising - We raise awareness of Kawasaki Disease to improve prompt diagnosis - through a dynamic multi media campaign, reaching GPs, paediatric clinicians, health professionals and parents.



Clinical research - We work to identify funds and 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 UK families - Keep a sustained focus on support for families affected by Kawasaki Disease by way of development and maintenance of Kawasaki information to help support informed decision making. Provide opportunities for affected families to share experiences and to access advice and emotional support.

Our Values:



Priority - We work with others to enable them to recognise Kawasaki Disease as a priority



Pace - We act quickly with a momentum that comes from our motivation to succeed



Partnership - We forge strong and lasting, partnerships with organisations who share our determination to transform the environment around Kawasaki Disease in the UK, and beyond.

Our Vision - We want 'just' 66 million people - the entire UK population to know Kawasaki Disease

Our Mission

To ensure that every clinician, parent, carer and every person in the UK knows to THINK Kawasaki Disease in a child with a persistent fever and has access to accurate information and support. To champion best practice clinical care for those with Kawasaki Disease.

Our People

#TeamSocieti
Trustee Board
UK Kawasaki Disease
Steering Group
Scientific Advisory Board
Staff members

Our Aims

Awareness raising
Clinical research
Clinical supervision
Support for UK families

Our Values

Priority
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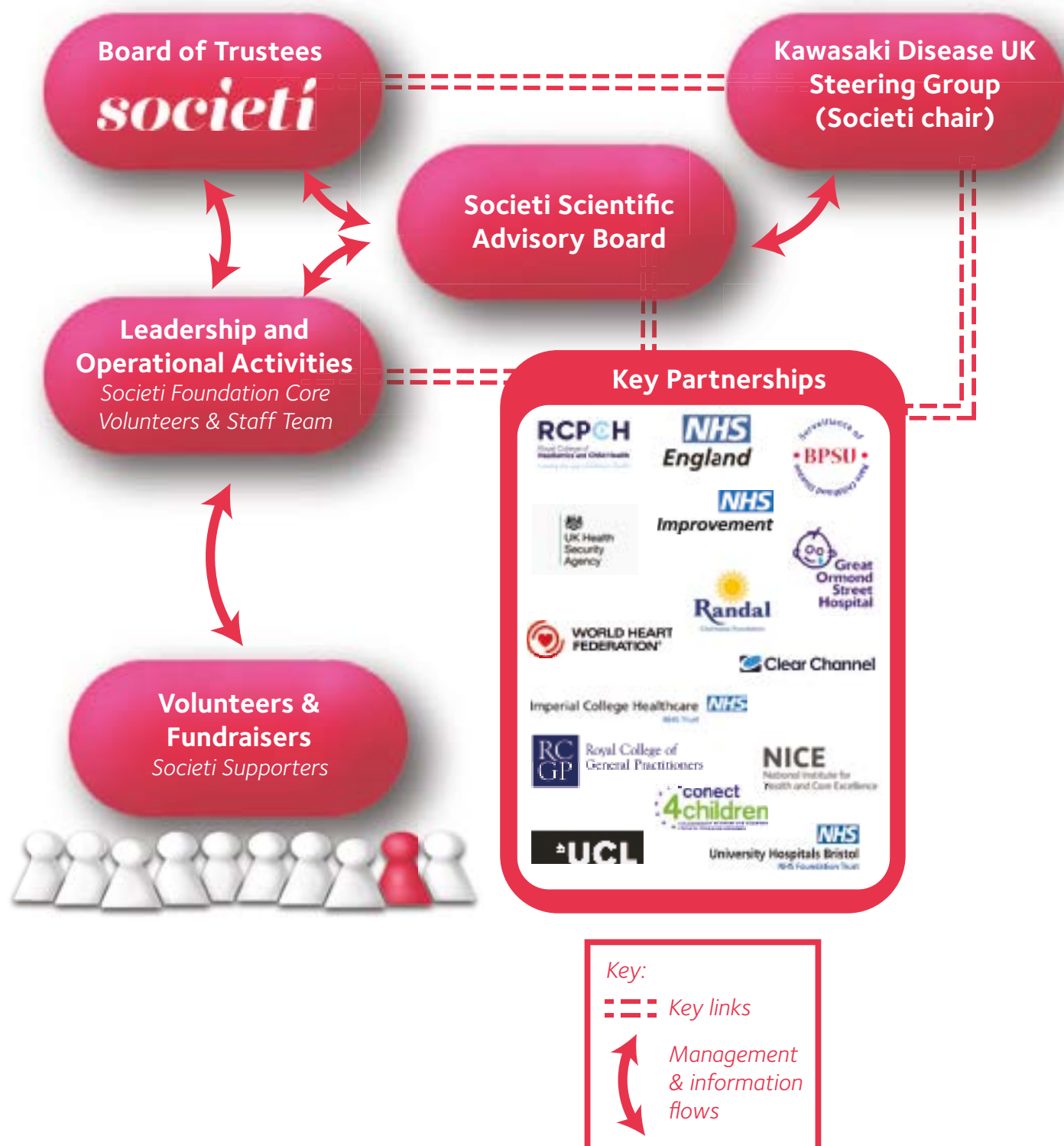
About Societi Foundation

Our Organisational Structure

We work with pace, passion and through partnership to create high visibility for Kawasaki Disease and bring about the transformation our children deserve in their care. We aim to increasingly enable correct care for the thousands of children, young people and adults previously affected by Kawasaki Disease to stem the rising number of children carrying a lifelong legacy of heart damage.



Societi Foundation Organisational Structure



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About Societi Foundation

Our Trustee Board

Societi is governed and supported by six Trustee Board Members, Ms Rachael McCormack, Prof Robert Tulloh, Prof Paul Brogan, Mr Roger Greenwood, Mr Gerry Higgins and Mr Peter Ware. Together our trustees bring together a strong combination of skills and expertise to drive and direct the work of our charity.



Rachael McCormack FCMI FInstLM

Rachael is the Founder of Societi Foundation and was inspired to create our charity after her family was affected by Kawasaki Disease. She'd found support lacking, and facts few and far between and so undertook to create our charity to support other affected families facing. Rachael has experience across the third, public and private sectors, and leads a consultancy firm she established in 2003. Rachael holds post graduate qualifications in management, is an active researcher and together with our Board, sets the tempo for our growing organisation.

Professor Robert Tulloh

Rob, MA DM FRCPCH Honorary Professor of Congenital Cardiology and pulmonary hypertension (retired), is an internationally recognised expert in Kawasaki Disease. Rob led the largest Kawasaki Disease clinic in the UK and the only Adult Kawasaki Disease clinic. He is an active researcher and teacher, and has supported Societi since before its formal establishment. Today, as a Trustee, Rob brings a wealth of expert clinical knowledge and broader oversight for our organisation.

Professor Paul Brogan

Paul is Professor of Vasculitis and Honorary Consultant Paediatric Rheumatologist at Great Ormond Street Hospital (GOSH). An expert in Kawasaki Disease, Paul leads a successful clinical and academic programme of work dedicated to the developing field of paediatric vasculitis and auto-inflammatory diseases, including Kawasaki Disease. He is also Chair of the Vasculitis Consortium, and Clinical Lead for Auto-inflammatory Disease at GOSH – and contributes to both the clinical and strategic trajectory of our charity.

Roger Greenwood FLI

Roger is a Landscape Architect and master planner by profession, and has been a businessman throughout his career with diverse sector experience. He was the Chief Examiner for his industry professional body for seven years and has been mentor to a vast community of emerging professionals to support them as they developed their practice. He is also, most importantly, a parent of a child affected by Kawasaki Disease. This immensely valuable experience combination of experience and knowledge brings scrutiny, wide ranging skills and support to our charity.

Gerry Higgins

Gerry is Managing Director of the Social Enterprise World Forum CIC – a fast growing global organisation which he founded and leads, proactively enabling the development of a global social impact economy. With a BA in Education and a MSc in Business Studies and decades of experience working in, establishing and supporting third sector organisations, Gerry brings in depth expertise in recognising and addressing the challenges of third sector organisational sustainability and leadership to Societi.

Peter Ware

Peter is Partner and Head of the Government Sector at Browne Jacobson LLP, specialising in complex procurement, shared services, PFI, outsourcing and public sector joint ventures. His extensive knowledge and his time leading major projects has given him a wealth of experience across sectors. He is also Finance and Membership Secretary of the Procurement Lawyers Association, on the editorial board of CIPFA's TISOnline, on the editorial Board for Lexis Nexis Local Government and a regular public speaker.

Our Board is also supported by:

Paul Colcomb, Independent Examiner

Paul is a Partner at Wright Vigar, the retained financial specialists and accountants for Societi Foundation – bringing extensive expertise in charitable organisation structures and financial matters. Paul supports both the team and the Board in financial reporting, annual reporting and Charity governance requirements.

Report of the Trustees

The trustees present their report with the financial statements of our charity for the year ended 31 December 2022. 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)

Public benefit – In setting our objectives and planning our activities our Trustees have given careful consideration to the Charity Commission's guidance on public benefit. In the pages which follow our delivery and impact during January 2022 – December 2022 is set out.

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Acknowledging our partners

By working in partnership, we can achieve our stated aims and those shared aims of our partners and stakeholders. In partnership we can have greater impact, work with increased pace and reach; and create the urgently needed step change for Kawasaki Disease.



The issues we face are huge and we know we simply can't tackle them alone. That's why we place huge importance on partnership and relationships. If we are to make real progress for our children – if we are to protect tiny hearts from the serious threat of Kawasaki Disease – and if we are to learn and share much more about this serious and enigmatic disease – we need strong partnerships.

Our partners, stakeholders and organisations we are in dialogue with are many and varied – and we are so

grateful to those who support us by bringing influence, helping us make impact – and those who support us financially.

We are extremely grateful to receive support from many organisations including The Randal Charitable Foundation, the Chemical Business Association, Clear Channel, Lanarca, and many more who have expedited the work of Societi in a way that otherwise would not be achievable by our young charity.



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Shortly after Societi Foundation was established, we led the development of the first ever UK Strategy for Kawasaki Disease in 2016. This important document successfully directed the focus of the first five years of work by our charity. In that time much has been achieved, working through partnerships and creating change across the landscape of Kawasaki Disease.

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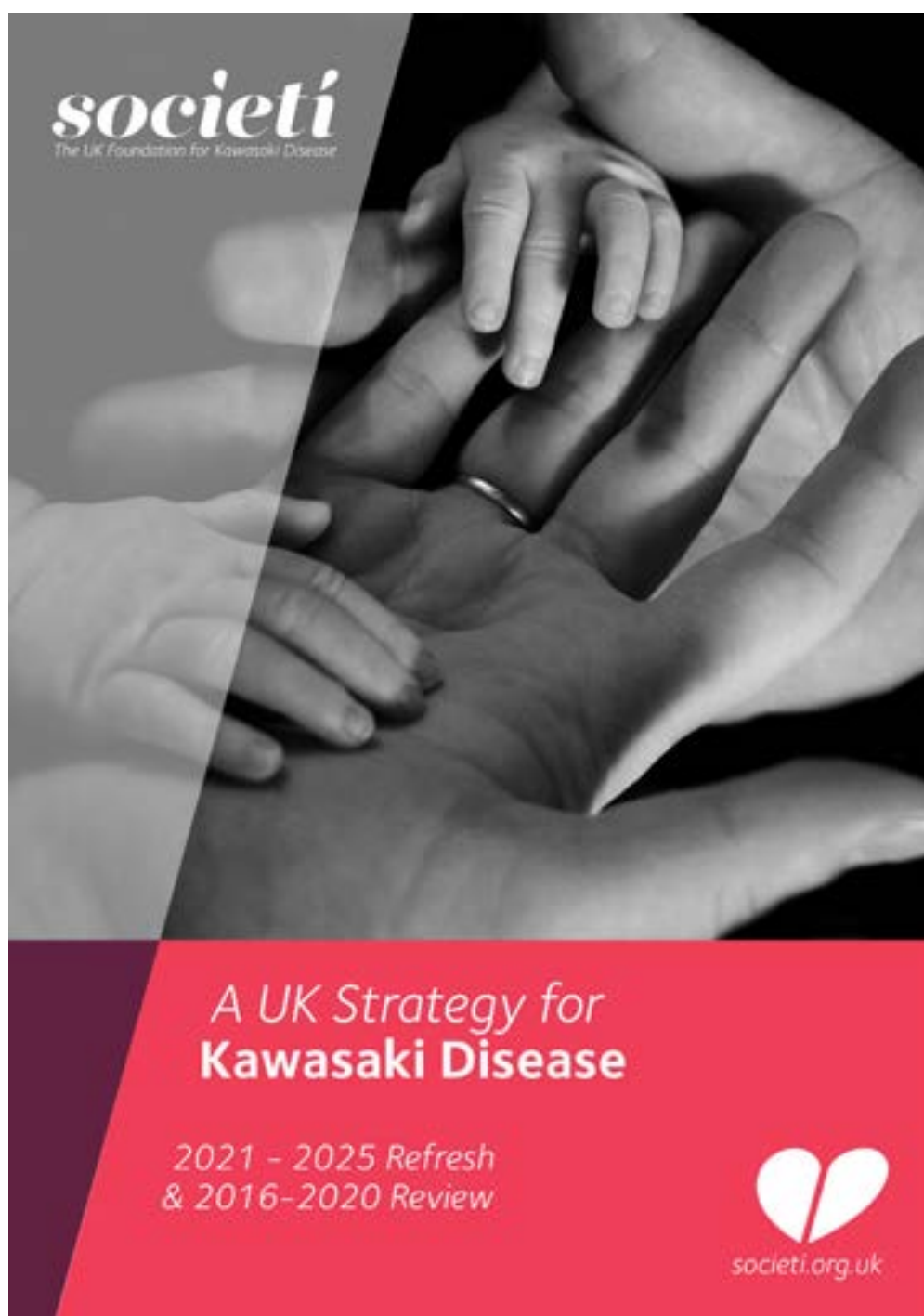
Our future plans

Our aim to tackle the leading cause of acquired heart disease in children in the UK remains the same. Our UK National Strategy which was originally created in 2016 and reviewed and updated for 2021 - 2025 defines ambitious targets and the focus areas for our work, going forward.



The strategy was refreshed in 2021, and shapes our work up to 2025. Our strategy is a starting point from which to engage with partners to discuss mutual opportunities to address the challenges we collectively face and to drive the work of Societi Foundation.

To read our National Strategy for 2021 - 2025 click [here](#).



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We raise awareness of Kawasaki Disease to improve diagnosis and treatment times and reduce the risk of heart damage in our children. Through multi media campaigns, we aim to reach 'just' 66 million people – the entire UK population!



Clear Channel helping to Get Kawasaki Disease known!

Clear Channel continued in its tremendous support for Societi Foundation throughout 2022, enabling us to raise awareness of Kawasaki Disease in a way that otherwise, would just not be possible.

As part of their 'Platform for Good' campaign, Clear Channel donated advertising space to Societi over BOTH our main campaign periods, International Kawasaki Disease awareness day in January and World Heart Day in September.

Societi's campaigns were displayed to MILLIONS of people on Clear Channel's Adshel and Malls Live digital screen network in shopping centres, on busy streets and in city centres across the whole of the UK.

The generosity and kindness that Clear Channel has shown Societi is truly overwhelming, and their commitment and support has been just phenomenal and simply transformational.



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Our brand new awareness animation is launched!

Launched on International Kawasaki Disease Awareness Day, this fantastic 90 second video, starring our much-loved Societi Kids, provides Societi with an engaging and practical way to share important Kawasaki Disease information.

Working with creative experts, The Animation Guys, we set out to create an animation that would give people key information about Kawasaki Disease. We wanted the animation to centre around our well known Societi

Kids, and give a fresh feel to our awareness raising, while keeping true to our trusted brand.

It is a valuable resource that supporters' donations and fundraising have made possible. The animation will work hard for us being used as an information resource in hospitals and at events as well as on social media. We've received some brilliant feedback on the animation since its launch. If you'd like to watch the animation you can do so on Societi's YouTube channel [here](#).



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Chemical Business Association luncheon

Societi were extremely grateful to be invited to attend the Chemical Business Association (CBA) Annual Lunch in April 2022 in London by Chair Kate Mingay.

As the Chair's nominated charity, we had the opportunity to get our message out to association members and their guests – all 900 people in the room. Our 10-minute presentation included a speech by Founder, Rachael McCormack, our new awareness animation and our parent voice film.

Donations were collected following the presentation, and we broke the fundraising record for the 99 year old association –

the membership donated almost £16,000 including Gift Aid to Societi Foundation. This is testament to the power of our voice and the absolute importance of the messages we can, and do, convey.

The full Societi team attended the event and we also exhibited a stand full of Kawasaki Disease awareness items for attendees to browse and take home. Funds from the luncheon were invested in close discussion with the CBA and were distributed towards our new family films – [see page 37](#) and our new Parent and Carer Kawasaki Disease Guide – [see page 38](#).



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Raising awareness with partners - presenting to NHS Blood and Transplant

Societi presented to NHS Blood and Transplant (NHSBT) colleagues to raise awareness of Kawasaki Disease at their stakeholder forum.

IVIG - the main treatment for Kawasaki Disease is produced using blood plasma collected by NHSBT and they therefore wanted to understand more about Kawasaki Disease.

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The stakeholder forum was a well-attended focused group of partners and employees with the objective to learn more about partner organisations and NHSBT updates. Societi presented for 10 minutes and showed our brand-new awareness animation which was very well received and praised highly. We continue to grow our partnership with NHSBT and work together to raise awareness of Kawasaki Disease and vital blood and plasma donations.

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Campaigning and awareness raising online

Societi's social media channels are essential to our work in raising awareness of Kawasaki Disease throughout the UK. It is one of the most efficient and effective ways to get our message to as many people as possible including parents, carers and clinicians.

We continue to work to expand the reach we have through daily posts and campaigns on Facebook, Twitter Instagram and LinkedIn. Our content is constantly refreshed, ensuring

our messaging continues to engage our followers and gets them thinking about Kawasaki Disease.

As our social media following continues to grow, we are able to achieve greater levels of engagement, consistently furthering our reach.

We will continue to invest in our online campaigns and work hard to raise awareness via effective digital marketing initiatives.

Click on the logos below to visit our social media platforms and take a look at our online awareness raising work:



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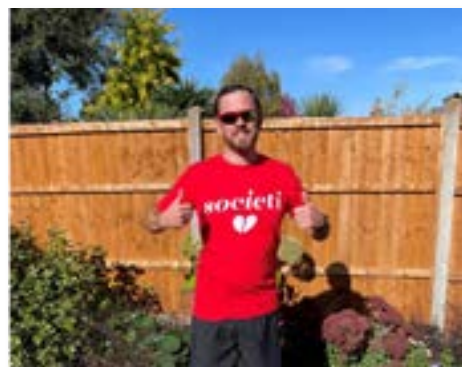
Supporting our Supporters

The simply astounding support and absolute dedication from #TeamSocieti continued to astonish us throughout 2022.

Families – often those who have been affected by Kawasaki Disease themselves – businesses, organisations and others who have been inspired by the work of our charity got involved with some amazing events.

Throughout 2022, our FABULOUS supporters took on some fantastic challenges, raising much needed funds and raising awareness of Kawasaki Disease.

Click on the images below to what just some of our supporters have been up to in their fabulous fundraising and awareness raising activities:



Our activities – awareness raising

Our activities around raising awareness of Kawasaki Disease

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#TeamSocieti showed new and ingenious ways of raising awareness and funds for Kawasaki Disease from marathons to pantomimes and everything in between!

We work hard to help our supporters in their awareness and fundraising efforts in every way we can. Our gratitude to every single member of #TeamSocieti for their unrelenting effort and their show of support is endless.

Below are just some of the things our supporters got up to throughout 2022.

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The Societi newsletter

Societi produces a regular newsletter with updates about our work that is distributed directly to our supporters.

Our newsletters keep our supporters informed about everything we are doing throughout the year and also include everything they have been up to, to raise awareness of Kawasaki Disease and to Support Societi too.

We love to hear all about what our supporters are up to and we hope they like to hear about what we are doing just as much! It is so important that we let our supporters

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know about the work our organisation does. After all, it is their support that drives us and helps us to achieve our objectives for Kawasaki Disease in the UK.

As well as information about our latest projects and activities and invitations to supporters to help us in our work, our newsletters also draw attention to the incredible hard work and achievements of #TeamSocieti.

Click [here](#) to read our 2022 summer newsletter and [here](#) to read our 2022 Christmas newsletter.



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Societi Active

Fabulous volunteers, Hayley, Vikki, Gayle and Lucy continued to lead Societi Active to encourage our supporters to get active for Kawasaki Disease.

The team supported our marathon runners, led our 'Just Move' event for International Kawasaki Disease Awareness Day and our Virtual 10K for World Heart Day, inspiring everyone with their infectious energy and enthusiasm.

Societi Active provided the information needed to start fundraising for Societi Foundation and suggested ways to promote challenges and raise awareness of Kawasaki Disease. They also provided training advice and tips from a qualified sports and running coach, offered bespoke training plans for runners, shared ideas, books, music, podcasts and lots of other inspiration.

We're really grateful to the team for everything they do and for keeping #TeamSocieti active!



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Just move

For Kawasaki Disease International Awareness Day 2022, our wonderful volunteer group, Societi Active, kicked off their 'Just Move' for Kawasaki Disease awareness challenge.

Societi Active asked supporters to commit to moving every day for the whole month, starting from Wednesday 26th January. Supporters could pledge to do ANYTHING - 10 sun

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salutations, running 1 mile, 50 press-ups, walking the kids to school instead of driving - the possibilities were endless.

Thank you to organisers, Societi Active and to everyone who got involved, helping to raise awareness of Kawasaki Disease in and around their local communities.

We are extremely grateful to everyone who took part.



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Societi Active's Virtual 10K

Going into its 4th year, Societi Active's Virtual 10K returned for World Heart Day thanks to our fabulous volunteers Hayley, Vikki and Gayle. And once again it was a resounding success – bringing together those most physically active in our community, connecting old friends and forging new links. Incredible achievements in these things alone, but this years 10K went further – with a truly inspiring fundraising effort which went along with it. Huge thanks must go to our

Our activities – awareness raising

Our activities around raising awareness of Kawasaki Disease

We raise awareness of Kawasaki Disease to improve diagnosis and treatment times and reduce the risk of heart damage in our children. Through multi media campaigns, we aim to reach 'just' 66 million people – the entire UK population!



supporters for their hugely successful fundraisers and to their friends, family and colleagues too who sponsored them so generously. In total, the Virtual 10K raised an extraordinary £2,220.

We are very grateful to everyone who took part in the Virtual 10K and helped protect tiny hearts. A huge amount of Kawasaki Disease awareness was raised in communities throughout the UK by our participants, all in their Societi running jackets, t-shirts and running vests.

Let's protect tiny hearts... from Kawasaki Disease!

societi
World Heart Day 2022

societi ACTIVE 10K
for World Heart Day!

Be a part of our Societi Active World Heart Day Virtual 10K and help us raise awareness of **Kawasaki Disease**!

Starting on 29 September 2022 – **WORLD HEART DAY**, you'll have until 31st October to run or walk your virtual 10K.

Standard entry is £10

Exclusive entry is £40 and includes an ****exclusive**** Societi running jacket to help you raise vital awareness of Kawasaki Disease whilst completing your walk/run in your community.

All participants will receive a medal and a special 50% discount code to use in our Societi shop on either a t-shirt or running vest – or both!

AND free entry into a lucky dip for a chance to win prizes including wristbands, stationery and a Societi hoodie!

To enter simply scan or click the QR code to **COMPLETE THE REGISTRATION FORM** and follow the link to pay your entry fee.

facebook.com/SocietiActive

societi
The UK Foundation for Kawasaki Disease

societi.org.uk

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Expanding and promoting our Societi merchandise

We are always thinking of new and innovative ways to enable our supporters to raise awareness of Kawasaki Disease and Societi's merchandise is a brilliant way to do just that.

Some popular additions to our online shop throughout the year were our Societi swim caps and our thermal mugs

– helping our supporters to raise awareness of Kawasaki Disease and protect tiny hearts every sip of the way!

Each piece of Societi merchandise is a fantastic opportunity to raise both funds and much needed awareness of Kawasaki Disease. We continue to make our merchandise available to our supporters on our website and promote it through social media.



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Lighting up for Kawasaki Disease awareness

Landmarks in towns and cities across the UK – from Weymouth to Inverness – lit up red for International Kawasaki Disease Awareness Day 2022. Thanks to the hard work and dedication of #TeamSocieti, eleven landmarks shone brightly to raise awareness of Kawasaki Disease.

The illuminations were a catalyst for many news stories about Kawasaki Disease appearing online and in local newspapers up and down the country, spreading valuable awareness of Kawasaki Disease to thousands of people in their communities.

Local press coverage is an incredibly powerful way to raise awareness and we were absolutely delighted to have had stories published that included lots of useful and accurate information about Kawasaki Disease, reaching whole new audiences.

We are so grateful to everyone who got personally involved to make this happen – and to everyone who contacted their local landmarks. The support Societi received from these magnificent and iconic regional landmarks that shone a light on Kawasaki Disease and shared our information was just phenomenal!



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Raising Kawasaki Disease Awareness through National Political Engagement

Highlighting where action needs to be taken by Government, Societi wrote to the UK Prime Minister, the Scottish First Minister and the Welsh First Minister, together with the leader of the UK Labour Party - bringing their attention to for the urgent need to get Kawasaki Disease known.

Our activities – awareness raising

Our activities around raising awareness of Kawasaki Disease

We raise awareness of Kawasaki Disease to improve diagnosis and treatment times and reduce the risk of heart damage in our children. Through multi media campaigns, we aim to reach 'just' 66 million people – the entire UK population!



The letters sent highlighted the issues surrounding Kawasaki Disease in the UK, urging ministers to prioritise children's health and asking that this remains high on the political agenda.

Through our past engagement with Government, Societi has a number of committed MP's dedicated to getting Kawasaki Disease known. We are grateful for their support which is significant in building a voice and powerful presence for Kawasaki Disease in UK parliament.

Building political momentum for KAWASAKI DISEASE



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Our World Heart Day campaign

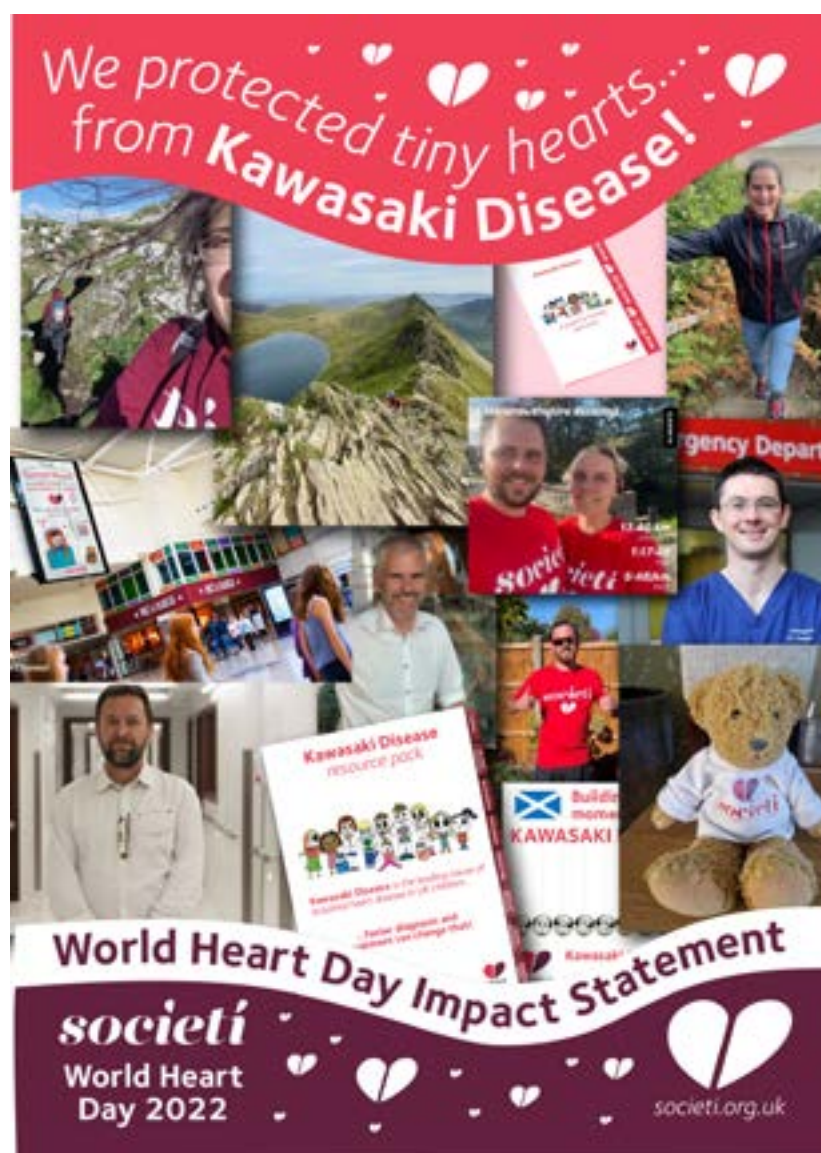
29 September – World Heart Day – is a hugely important date in our calendar and 2022 was just phenomenal! Working with our partners at the World Heart Federation once again, we had the fantastic opportunity to also work alongside our wonderful supporters and many more exceptional partners, as we raised awareness of Kawasaki Disease and children's heart health.

Right from the start of September, our World Heart Day campaign focused on 'Protecting Tiny Hearts', getting Kawasaki Disease known by families, carers, clinicians – just about EVERYONE, as we work to protect tiny hearts.

Together we shared awareness raising messages, hosted a UK-wide outdoor advertising campaign, distributed clinical training and patient information resources across the UK and Europe, highlighted our ongoing KD-CAAP clinical trial work, released an expert-led podcast for our clinical audience, shared our World Heart Day Statement, highlighted Kawasaki Disease to UK Government leaders and held our Virtual 10K community running event.

All these brilliant projects and many more highlighted Kawasaki Disease and the urgent action needed to prevent heart damage in our children.

To read our World Heart Day impact statement click [here](#).



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Our International Kawasaki Disease Awareness Day campaign

Our KNOW Kawasaki Disease campaign for International Kawasaki Disease Awareness Day 2022 was an overwhelming success. And that's thanks to our supporters '#TeamSocieti', and the HUGE commitment of time, effort and energy both our supporters and our partners gave throughout January.

Our work together to raise Kawasaki Disease awareness included many supporters getting involved with magnificent projects designed to highlight issues, start

Our activities – awareness raising

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conversations and make sure everyone was able to get to KNOW Kawasaki Disease!

We are very grateful to everyone who has got behind what we think has been the biggest and best awareness day campaign ever delivered for Kawasaki Disease!

All of the activities from the launch of our new awareness animation to our campaign being displayed to millions across the UK, to wear red days – all of which led to such an amazing day are highlighted [here](#) in our impact statement!

International Kawasaki Disease Awareness Day 2022



Our KNOW Kawasaki Disease campaign for International Kawasaki Disease Awareness Day 2022 was an overwhelming success. And that's thanks to YOU – #TeamSocieti, and the HUGE commitment of time, effort and energy both our supporters and our partners give, not just through January but all through the year. Our work together to raise Kawasaki Disease awareness included so many of you getting involved with magnificent projects designed to highlight issues, start conversations and making sure everyone you know was able to get to KNOW Kawasaki Disease! A MASSIVE THANK YOU to everyone who has got behind what we think has been the biggest and best awareness day campaign ever delivered for Kawasaki Disease! Every single person who gets to know Kawasaki Disease through our work together is a precious achievement. Why? Because that knowledge could protect a tiny heart from life long heart disease. It doesn't get much more precious than that. Just some of #TeamSocieti's extraordinary achievements which led to such an amazing day are highlighted here in our impact statement!



Launching our brand new awareness animation!

We were absolutely delighted to be able to launch our brand new Kawasaki Disease awareness animation this International Kawasaki Disease Awareness Day. This fantastic 90 second video, starring our much loved Societi Kids, provides Societi with an engaging and practical way to share important Kawasaki Disease information. It is a valuable resource for us at Societi Foundation that will work hard for us, spreading our vital message, that EVERYONE needs to know Kawasaki Disease. Societi were only able to create this fantastic awareness raising resource due to the amazing support we receive from #TeamSocieti for our charity. Your donations and fundraising have made this possible! Thank you to EVERYONE that shared our awareness animation and for all the incredible feedback we have received. You can see the animation on Societi's YouTube channel [here](#). Please take a look and share with your friends, family and wider community – let's get everybody to KNOW Kawasaki Disease. Knowing Kawasaki Disease could save a child's heart!



Continued valuable support from Clear Channel!

Clear Channel has continued in its tremendous support for Societi Foundation, enabling our small charity to raise awareness of Kawasaki Disease in a way that otherwise, would just not be possible. At an even bigger scale than ever before, Societi's campaign was displayed on Clear Channel's spectacular Adshel and Malls Live digital screen network. Our Kawasaki Disease awareness raising message was displayed across the whole of the UK, in shopping centres, on busy streets and in city centres. Thank you to all our supporters who sent us photos and videos of the campaign displays – from Brighton Seafront, to Tottenham Court Road, to Doncaster's Frenchgate shopping centre, to the Inverness Eastgate shopping centre – and EVERYWHERE (!!!) in between – we were extremely excited to see them all! The generosity and kindness that Clear Channel has shown Societi is truly overwhelming and their commitment and support has been just phenomenal. Thank you Clear Channel, we really are very grateful indeed.



Lighting up across the UK

Landmarks in towns and cities across the UK – from Weymouth to Inverness – lit up red for International Kawasaki Disease Awareness Day. Thanks to the hard work and dedication of #TeamSocieti, eleven landmarks shone brightly to raise awareness of Kawasaki Disease. A really special thank you to everyone who got personally involved to make this happen – and to everyone who contacted a local landmarks too...We were quite simply blown away by the support from these magnificent and iconic regional landmarks and we want to say THANK YOU, for shining a light on Kawasaki Disease and for sharing our information tool. It's not too early to get in touch with your local council to ask if they can light up your local town hall, cathedral, or landmark for Kawasaki Disease Awareness Day next year – and get THOUSANDS of people in your area talking about Kawasaki Disease!



Local press coverage highlights Kawasaki Disease

News stories about Kawasaki Disease appeared in online and in local newspapers up and down the country, spreading valuable awareness of Kawasaki Disease to thousands of people in their communities. Local press coverage is an incredibly powerful way to raise awareness and we were absolutely delighted to have had stories published that included lots of useful and accurate information about Kawasaki Disease, reaching whole new audiences. THANK YOU so much to all of our supporters who approached their local press asking them to publish stories for International Kawasaki Disease Awareness Day. We just couldn't have done this without you!

Societi Active launch JUST MOVE!

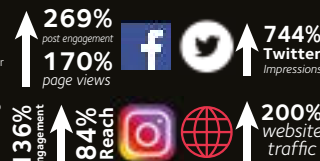
Starting on International Kawasaki Disease Awareness Day, our wonderful volunteer group, Societi Active, kicked off their 'Just Move' for Kawasaki Disease awareness challenge. Societi Active asked supporters to commit to moving every day for the whole month, starting from Wednesday 26th January. Supporters could pledge to do ANYTHING – 10 sun salutations, running 1 mile, 50 press-ups, walking the kids to school instead of driving – the possibilities were endless. Thank you to organisers, Societi Active and to everyone who has gotten involved, helping to raise awareness of Kawasaki Disease in and around your local communities.

JUST MOVE!



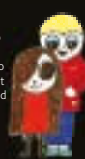
Super Social!

Social media shares, likes and comments have been phenomenal throughout the whole of January! Thank you to EVERYONE that shared our KNOW Kawasaki Disease posts. We had our busiest Awareness Day ever on social media including resharing resources like MySocieti and our KD-CAAP podcast! Your likes and shares go a long way. Thank you too, to everyone who ran their own Kawasaki Disease awareness campaign. The creative, hard hitting impact of your campaigns worked hard to help us get Kawasaki Disease known! There was a huge leap in our website traffic with people learning about our KD-CAAP research, getting to our Family Portal and much more besides.



Wearing red for awareness!

A HUGE thank you must go to all the schools and nurseries that held a 'Wear Red Day' for International Kawasaki Disease Awareness Day – a great way to raise awareness! We are extremely grateful to all the parents who worked to make this happen and to the schools that took part, raising much needed funds and sharing our awareness materials including our brand new awareness raising animation! THANK YOU for helping to get Kawasaki Disease known!



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

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Leading Public and Patient (PPI) Activities for the KD-CAAP Trial

Throughout 2022, Societi continued to lead the PPI elements as part of the Trial Management Group and Trial Steering Group for the delivery of KD-CAAP (Kawasaki Disease Coronary Artery Aneurysm Prevention), the largest Kawasaki Disease clinical trial of its type to ever take place.

As part of our role, Societi ensures that the views of families and patients affected by Kawasaki Disease are

Our activities – clinical research

Our activities around 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. Click on the buttons below to find out about our activities around clinical research:



represented. Our work includes ensuring the profile of the trial was raised and the information families need, as they consider taking part in the trial, is available in user friendly formats. Trial specific web pages created and updated by Societi can be viewed on our website [here](#).

Societi was the catalyst for the clinical trial which is investigating the potential for better acute treatments for Kawasaki Disease which may reduce the heart damage children can experience when affected by Kawasaki Disease.



KD-CAAP – PPI

KD-CAAP – single greatest opportunity for transformation in patient care, improving outcomes in **Kawasaki Disease**, in a generation

Our role:

- Co-ordination – Public / patient involvement programme – proactive; social media
- Technical/admin – including family liaison – online/reactive
- Senior lead (PPI team) – leadership and overview, finance and programme management
- Collateral – design, development
- Information distribution, evaluation and feedback
- Website
- Information management
- Group work
- Participant and centre updates



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Raising awareness of the KD-CAAP trial

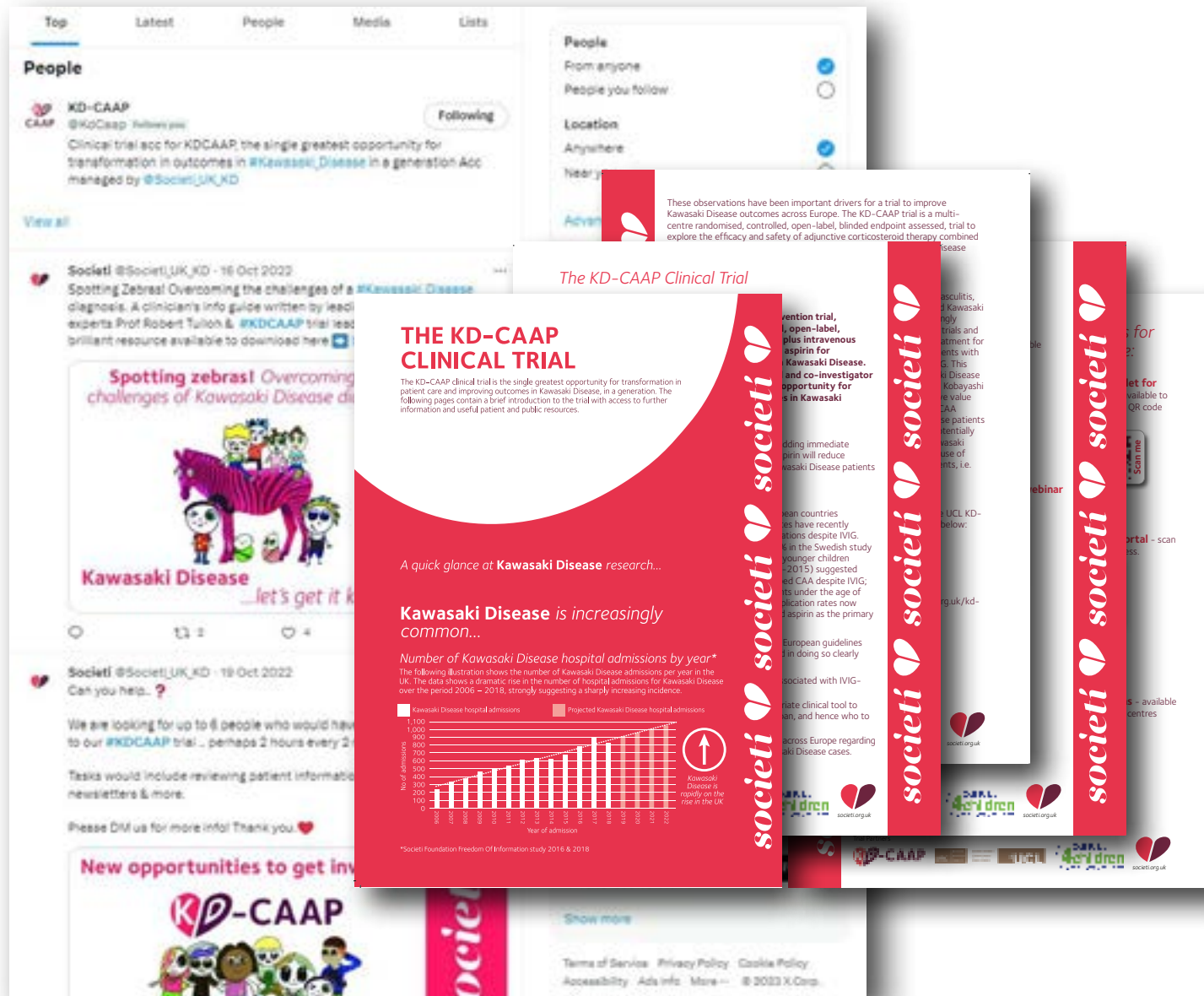
Societi raises awareness of the KD-CAAP clinical trial to clinicians and to the public as part of our role.

Our new Kawasaki Disease resource folder, developed for our Children's Hospital Partnership Programme included a section about the trial and was distributed to all partner and KD-CAAP hospitals. Societi also developed a Kawasaki Disease awareness poster specifically highlighting the KD-CAAP trial for use in trial centres.

A KD-CAAP Twitter account dedicated to promoting awareness of the KD-CAAP trial continued to post during 2022 and followers continue to grow in numbers. Societi cross-posts to the Societi Twitter account which has a regular, active following of over 1,250.

Societi's Facebook page, which has an international following of over 2,000, continues to promote and explain the trial and highlight its focus.

Societi also draws attention to the work of the trial using LinkedIn via the Societi Foundation account.



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Contributing to Kawasaki Disease incidence research

Societi contributed to research led by Dr Fiona Pearce of the University of Nottingham, into incidence of Kawasaki Disease using hospital admissions data for England 2006–2021.

Contributing to its development throughout 2022, Societi were co-authors of the paper which identified all cases in hospital episode statistics using data obtained from the National Congenital Anomaly and Rare Disease Registration Service (NCARDS). The paper calculated incidence rate ratios, assessing the influence of age, sex, ethnicity and index of multiple deprivation.



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Continuing our Diagnosis Day research poll

During 2022, Societi undertook to collect information as part of an important update to a research project first conducted in 2018.

The Diagnosis Day research poll seeks our supporters experience of Kawasaki Disease to understand more about just what is happening when our children are first being diagnosed.

Societi will use the anonymised information gathered through the poll to highlight any ongoing challenges families are facing and if diagnosis is being delayed or confused with other illnesses.

Work on the poll and the analysis of the information collected was ongoing throughout 2022. Once published, the paper will enable Societi to highlight diagnosis issues and focus training about Kawasaki Disease to help overcome problems being faced.



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Our activities – clinical supervision

Our activities around 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. Click on the buttons below to find out about our activities around clinical supervision:



Children's Hospital Partnership Programme

2022 was the first year of our three year Children's Hospital Partnership Programme generously funded by the Randal Charitable Foundation.

















Extensive work went into the development of Kawasaki Disease educational materials and resources to support our efforts in forming strategic partnerships with major children's hospitals.

Key contacts with UK children's hospitals were identified and relationships developed. Societi also worked to

build on relationships with KD-CAAP centres (those participating in the clinical trial Societi is involved with) across Europe, to enable us to share extended resources and clinical training information online.

Societi attended targeted events including the RCPCH annual conference to enable further knowledge exchange and identification of additional Ambassadors. A Societi web page [here](#) provides more detailed updates on progress against each of our programme milestones to date.

Interim progress against year 1 specified milestones

Specified milestones	Work to date	Progress
Digital resources  Deliver digital clinical information and resources to all UK NHS Trusts and Health boards and all KD-CAAP centres across Europe	Societi's Kawasaki Disease digital clinical information resources have been reviewed and updated in line with our hard copy resources. Contact data for NHS Trusts and Health boards and all KD-CAAP centres across Europe has been gathered and work will begin shortly to issue resources accordingly.	
Establishing key contacts  Establish key contacts/PGME relationships with 15 major UK children's hospitals, identifying a named Kawasaki Disease Ambassadors	Key contacts with major UK children's hospitals and KD-CAAP centres have been identified. Work has been undertaken to establish key relationships through which to disseminate Kawasaki Disease information, resources and training.	
RCPCH conference  Attendance at RCPCH conference with a goal to identify 10 further hospitals with which to develop relationships and potential Kawasaki Disease Ambassadors.	A large 4x4m stand at the RCPCH conference in Liverpool, 28-30 June 2022 has been acquired and preparations to ensure Societi's impact at the event are well underway.	
Research informed targeting  Identify a further 10 hospitals from FOI and other research data in Kawasaki Disease 'hot spot' areas with which to build key contacts/PGME relationships.	After relationships with key children's hospitals have been firmly established, work will be undertaken to identify 10 hospitals from FOI and other research data in Kawasaki Disease 'hot spot' areas. Contact with these hospitals and contacts acquired from RCPCH identified hospitals will commence after the end of June.	
Hard copy information  Deliver hard copy clinical information to all identified key hospital contacts/PGMEs.	Production of a new hard copy Kawasaki Disease clinical resource is now complete. This comprehensive resource will ensure vital Kawasaki Disease information is available to clinical staff within targeted hospitals. Issuing of the hard copy resource will commence in June 2022.	
Training proposals  Deliver a training proposal to all key hospital contacts assessing needs and identifying additional resources required.	A baseline training proposal is currently being prepared and will be developed on a hospital by hospital basis when relationships with key hospital contacts are firmly established. This will allow needs of individual hospitals to be properly assessed and additional resources that are required to be identified.	
Kawasaki Disease symposium  Deliver a Kawasaki Disease symposium to be recorded and shared online to all UK NHS Trusts and Health boards and all KD-CAAP centres across Europe.	Societi has been in discussion with doctors from Great Ormond Street Hospital who have agreed to assist in delivering a Kawasaki Disease symposium. The symposium which will take place on site at GOSH, is planned for later in the year and will be recorded and shared with UK NHS Trusts and Health boards and KD-CAAP centres.	
Assessing impact  Undertake monitoring and research to assess impact, building on FOI and BPSU data, creating baseline information and deliver a clinically backed report including impact achieved	Quantitative baseline data has been gathered which includes Societi FOI data, BPSU data and collaboration with Nottingham University's on a study into Kawasaki Disease incidence. Societi has also updated our Diagnosis Day study which now includes data from nearly 80 families. We are currently looking to publish the report which provides qualitative baseline information.	



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Developing our doctor training film - Kawasaki Disease – Acute Management – An expert led discussion

Working with the Animation Guys, during 2022 work was undertaken to develop a new doctor training film – Kawasaki Disease – Acute Management – An expert led discussion.

Created by doctors for doctors, Dr Jethro Herberg and Dr Harsita Patel from Imperial College London discuss how to spot and treat Kawasaki Disease in this expert led training

film. We are extremely grateful to Dr Herberg and Dr Patel for the time and expertise they so generously shared to ensure the film is as useful to other clinicians as possible.

The film will prove a valuable resource for clinicians enabling them to diagnose Kawasaki Disease and treat promptly.

Filming took place in November 2022 with the training film due for release on International Kawasaki Disease Awareness Day, 26 January 2023.



Our activities – clinical supervision

Our activities around 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. Click on the buttons below to find out about our activities around clinical supervision:



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Attendance at the RCPCH Conference

Societi had an exceptional three days exhibiting at the Royal College of Paediatrics and Child Health annual conference in June 2022. The interest in our work was incredible and the conversations we had showed huge appetite for Kawasaki Disease learning resources.

Many resources were taken away from conference by clinician's including our new resource folder funded by Randal Charitable Foundation, Spotting Zebras clinician training booklet, clinical guidelines for long term care,

awareness posters & clinician posters, NICE guidance, research papers on Kawasaki Disease, our new research postcard and much, much more.

We made a huge impact and seized the opportunity to speak to hundreds of clinicians from all over the UK, Europe and further afield too. We had great success recruiting new Ambassadors to our Children's hospital Partnership Programme and drew a lot of attention from all attendees with our Kawasaki Disease notepads, post-its, pens, fridge magnets, love heart sweets and chocolates.



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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. Click on the buttons below to find out about our activities around clinical supervision:



Creating our new Kawasaki Disease resource folder

In September as part of our World Heart Day campaign, Societi brought UK leading clinical voices together, to focus on getting Kawasaki Disease known by doctors and healthcare professionals.

Experts Professor Damian Roland, University Hospitals Leicester, Professor Paul Brogan, Great Ormond Street Hospital and Professor Simon Kenny, NHSE Clinical Director worked with us to take part in an interview and

record a 'for doctors' podcast, to make sure Kawasaki Disease stays high on the radar of doctors.

The experts covered topics around spotting Kawasaki Disease, differentiating between Kawasaki Disease and other illnesses and a national perspective on NHS priorities and programmes, underpinning delivery of better outcomes for our children.

The podcast can be listened to [here](#).

Societi Foundation World Heart Day Kawasaki Disease podcast



Professor Damian Roland



Professor Paul Brogan



Professor Simon Kenny

Let's protect tiny hearts...
from Kawasaki Disease!

societi
World Heart
Day 2022



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Working with our Scientific Advisory Board

Kawasaki Disease has many effects on a child and as such a multi-disciplinary approach to research/care is needed for this disease.

Societi is supported by the phenomenal clinical expertise of our Scientific Advisory Board – UK leading medical experts who guide and underpin our work as a charity.

We work with the Scientific Advisory Board on a regular basis to ensure our output is reviewed by experts, meaning our supporters can rely on the information and facts we share.

During 2022, our Scientific Advisory Board input into many aspects of our work including, our Covid-19 vaccines for children statement, expert podcasts, our parent and carer Kawasaki Disease guide, our Kawasaki Disease resource folder and much, much more.



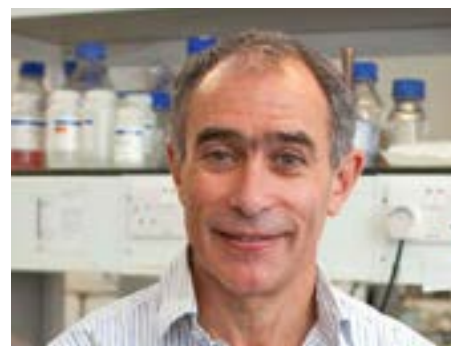
Prof Despina Eleftheriou

Paediatric Rheumatologist, Great Ormond Street Hospital and Institute of Child Health



Prof Paul Brogan

Professor of Vasculitis and Honorary Consultant Paediatric Rheumatologist, Great Ormond Street Hospital



Prof Michael Levin

Professor of Paediatrics & International Child Health, Imperial College London



Dr Tom Johnson

Consultant Cardiologist, Bristol Heart Institute



Prof Damian Roland

Consultant and Honorary Associate Professor in Paediatric Emergency Medicine, University Hospitals, Leicester



Dr Owen Miller

Consultant in Paediatric and Fetal Cardiology, Clinical Director, Congenital Heart Network, Evelina London Children's Hospital



Dr Filip Kucera

Paediatric Cardiologist, Great Ormond Street Hospital



Dr Jethro Herberg

Clinical Reader in Paediatric Infectious Disease, Imperial College London

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UK Kawasaki Disease Steering Group

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

During 2022, the group focused on standardising lifetime clinical care and adoption of published lifetime guidance, the challenges that remain with lifetime care with many children being prematurely discharged and lost to follow up, and the approach to transitioning patients from paediatric services to adult care.



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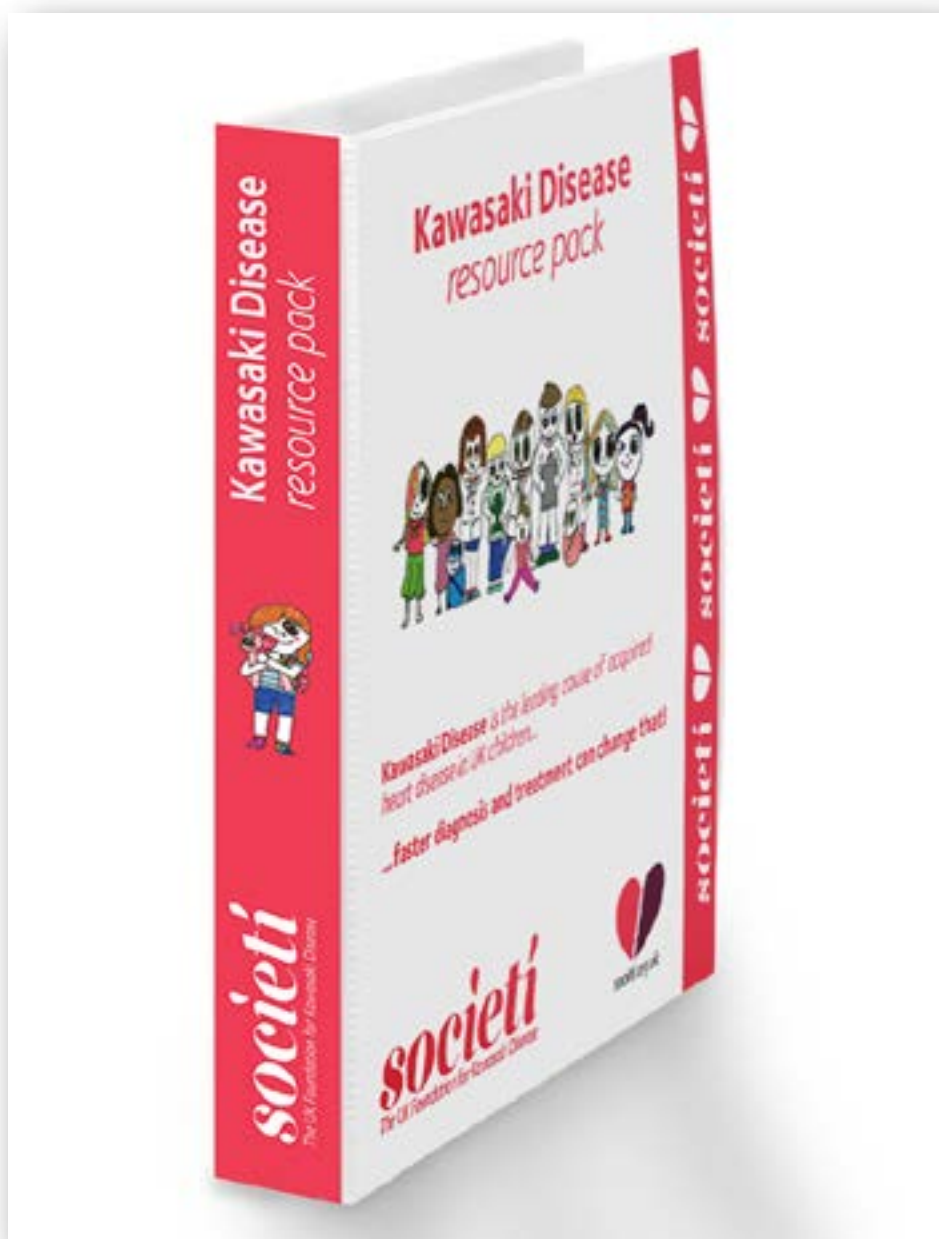
Creating our new Kawasaki Disease resource folder

As part of our Hospital Partnership Programme, Societi created Kawasaki Disease resource folders for clinicians to use and share with their teams.

Developed with generous support from the Randal Charitable Foundation, the packs draw together really useful Kawasaki Disease educational resources. These include our Spotting Zebras booklet, NICE guidance, new long-term guidance, Kawasaki Disease myths and facts

and clinician's Q&A to name a few.

The resource folders have been distributed across the UK to Children's Hospital Partnership Programme Ambassadors and have also been converted to digital format. The digital version of this useful resource was distributed to every NHS trust and health board throughout the UK as part of our World Heart Day campaign – with an estimated potential reach of over 3,750 paediatric clinicians.



Our activities – clinical supervision

Our activities around clinical supervision

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Reviewing and republishing 'Spotting Zebras'

"Spotting Zebras! Overcoming the challenges of Kawasaki Disease Diagnosis" is an information pack based on a [RCPCH training webinar](#) by Professor Robert Tulloh and Professor Paul Brogan.

In 2022, with the help of our Scientific Advisory Board members, Societi re-published (including on our website and within our new resource packs) and updated our

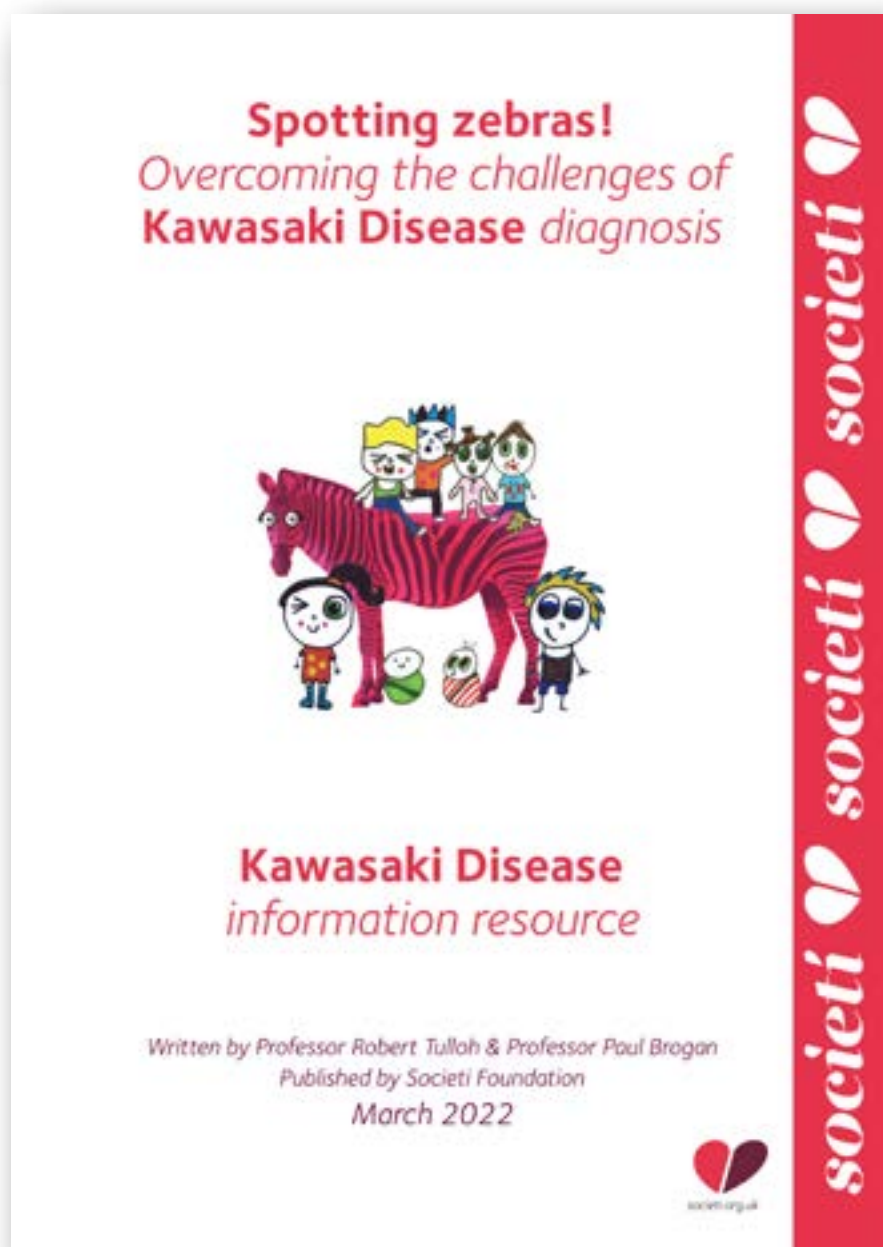
comprehensive, expert clinician-led "Spotting Zebras!" booklet to ensure that the most accurate and detailed information is available to clinicians likely to see children with Kawasaki Disease. It was extremely well received by supporters on Twitter, our Partnership Hospital Partners and at the RCPCH annual conference.

You can view our "Spotting Zebras!" booklet [here](#).

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Social media for clinicians

Societi regularly engages with clinicians through our various social media channels and employs a focused approach to knowledge sharing and awareness raising.

Work continued during 2022 with a focused approach and increase in reach across our social media platforms. Our communications are regularly reaching thousands

of healthcare providers on Twitter, Facebook, Instagram and LinkedIn – promoting key awareness messages and other important information. Societi also continues to host and manage a separate KDCAAP Twitter account raising awareness of the research trial with clinicians and cross posting Kawasaki Disease awareness posts with the main Societi account.

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Updating and reviewing our website clinician's area

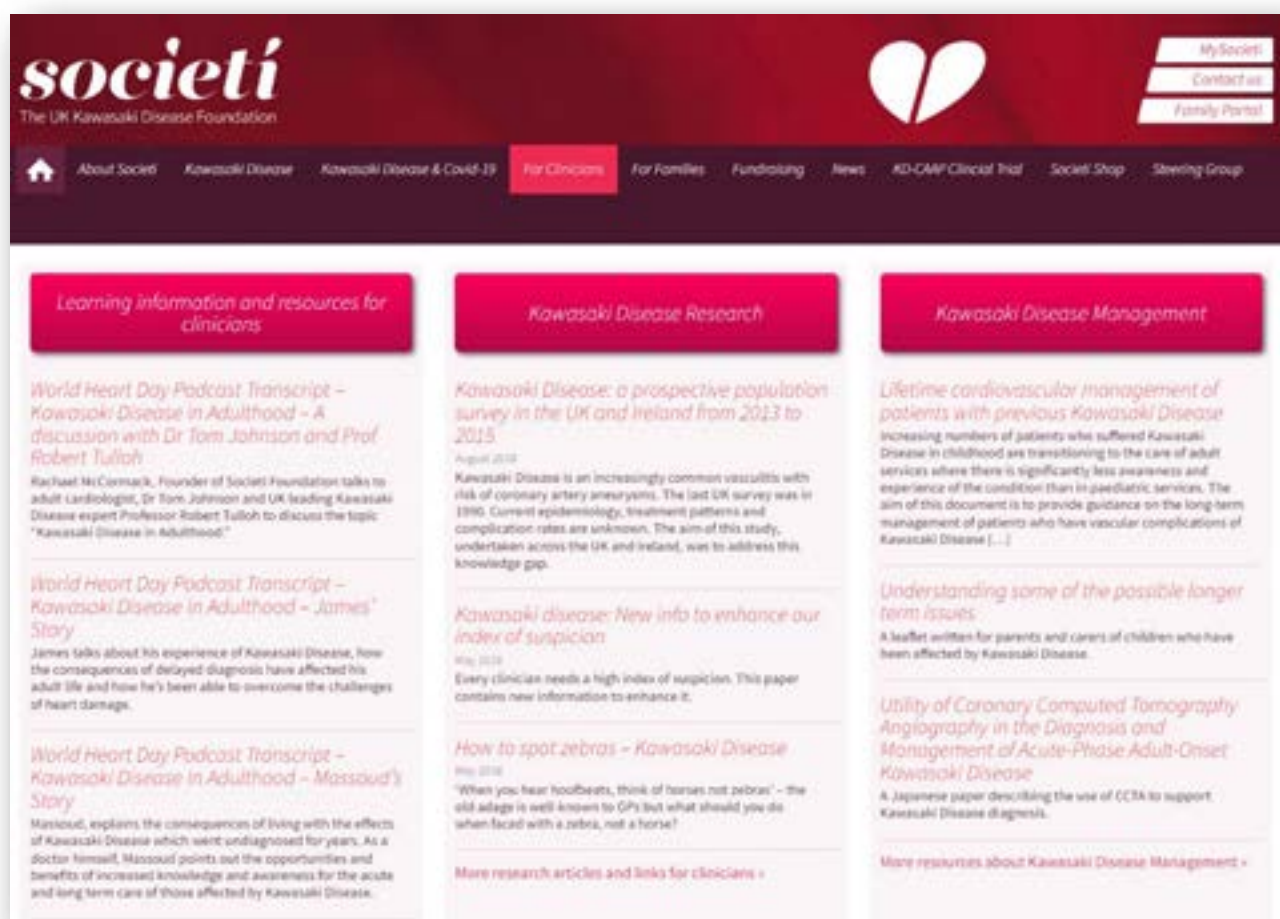
Societi makes information available to clinicians interested in Kawasaki Disease through a dedicated space on our website.

The information within this space 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 being added constantly.

To view the clinician's area of our website, click [here](#) or on the image opposite.



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Our activities – support for UK families

Our activities around support for UK families

We recognise that when faced with a diagnosis of Kawasaki Disease, support, expert backed information and helpful resources are of vital importance to families. Our work enables a sustained focus on family support. Click on the buttons below to find out about our activities around supporting UK families:



Working to create our family story films

Working with the Animations Guys (who also created our animated awareness film earlier in 2022), work began to produce a new suite of family story films.

Four fabulous volunteers – Alister, Manda, Olivia and Laura each generously contributed their time and their incredible stories to help other families going through similar situations.

The films will provide families affected by Kawasaki Disease with valuable information and reassurance derived from the familiarity of our supporters' similar experiences.

Filming took place in November 2022 with the family films due for release on International Kawasaki Disease Awareness Day, 26 January 2023.



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Creating our Kawasaki Disease guide for parents and carers

During 2022 we created our Family and Carer's Kawasaki Disease Guide in response to the extremely difficult and distressing time that families given a Kawasaki Disease diagnosis can face. Having access to reliable and trusted information, to help better understand a Kawasaki Disease diagnosis, can help to alleviate some anxiety.

The guide was shaped by our supporters through our parent survey and our panel of parent reviewers. We are extremely grateful for all the input we received to help make this guide as useful as possible to families facing a Kawasaki Disease diagnosis.

Our activities – support for UK families

Our activities around support for UK families

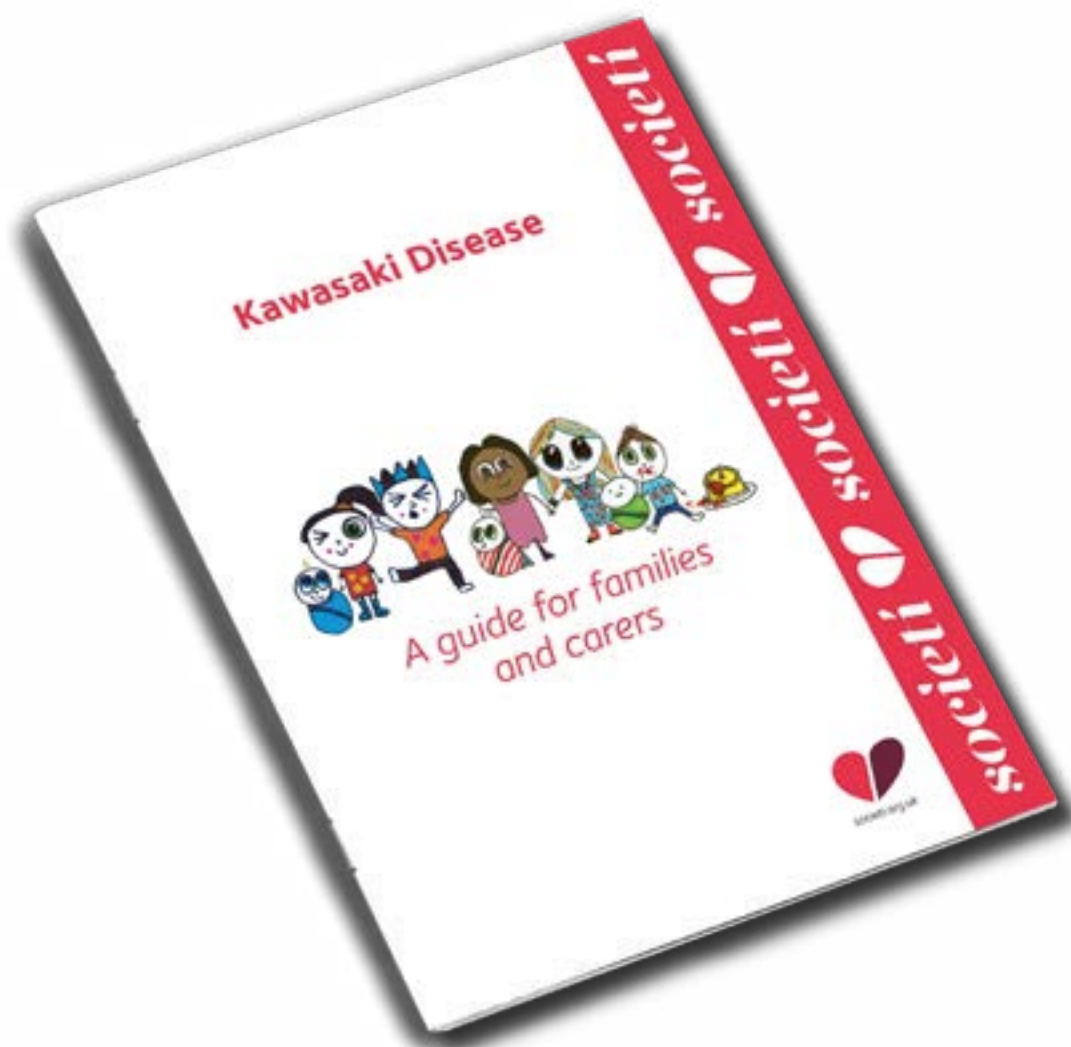
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We're are also very grateful to our Scientific Advisory Board members for contributing to and reviewing all content of this guide, ensuring clinical accuracy.

Many thanks must go to our generous funders for enabling us to create this important resource. The development of the guide was made possible by generous funding received from the Randal Charitable Foundation in relation to our Children's Hospital Partnership Programme. Funding received from the fabulous members of the Chemical Business Association also enabled the printing and distribution of hundreds of copies of the guide.

To view the resource on our website, please [click here](#).



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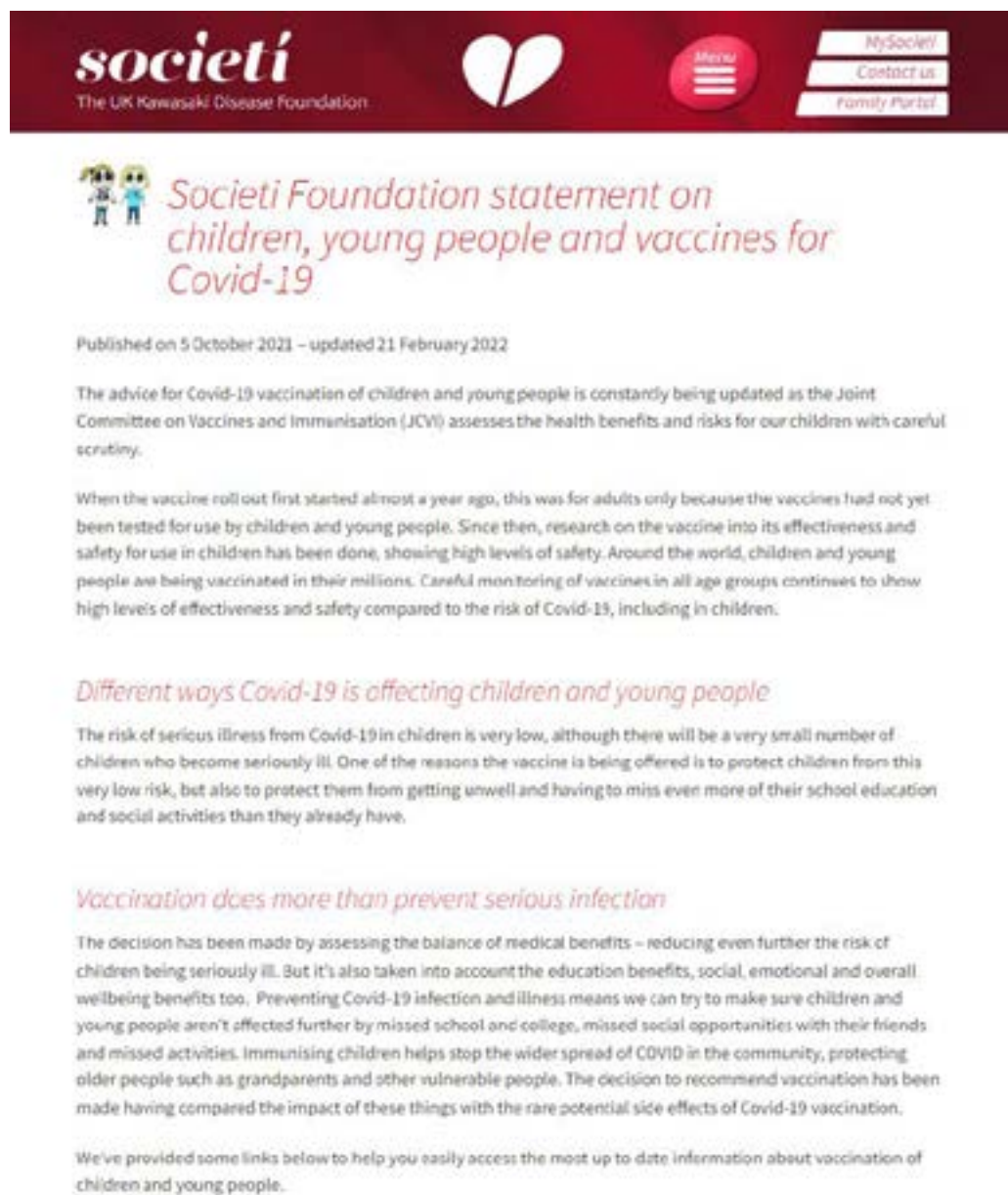
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Updating our statement on children, young people and vaccines for Covid-19

Societi received questions early in 2022 from our supporters regarding Covid-19 vaccines for children. As the Joint Committee on Vaccines and Immunisation (JCVI) assessed the health benefits and risks for our children with careful scrutiny and new guidance emerged, supporters sought advice and reassurance from Societi about children

who had been affected by Kawasaki Disease receiving a Covid-19 vaccine.

Our existing statement on children, young people and vaccines for Covid-19 was reviewed with close guidance from our Scientific Advisory Board members and the statement was updated and also directed to JCVI and RCPCH statements. The statement is available to view [here](#) on our website.



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Revisiting our Heart-to-Heart virtual round table

In 2020 Societi released our Heart-to-Heart video – a round table discussion with experts from our Scientific Advisory Board, answering questions about Kawasaki Disease put to them by our supporters.

During 2022, this unstoppable conversation, talking through topics like long term issues, aspirin and lifetime care – vital information for families affected by Kawasaki

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Disease – was re-purposed and re-released as a podcast.


Sharing expert, up-to-date and FACT-based knowledge with families and carers of children affected by the all-too-often devastating consequences of Kawasaki Disease, remains at the top of our agenda. Giving our existing information and resources a new lease of life and making them more accessible, means that even more families affected by Kawasaki Disease will benefit from them.

Listen to our **Kawasaki Disease**
Heart-to-Heart!



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

societi



societi.org.uk

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Updating and promoting our website and online resources

Societi has many assets and resources available for families who have experienced a diagnosis of Kawasaki Disease.

Our information filled website, Family Resource Portal and children's and young people's portal are all extremely helpful resources and can be a lifeline for families experiencing a Kawasaki Disease diagnosis.

We constantly review, update and promote our website and portal content, including our downloadable leaflets and information, to ensure that the most up to date and accurate information is available to users.

Feedback received from supporters suggests that our resources are invaluable tools for those affected by Kawasaki Disease and their families.

Visit our website [here](#).



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Developing our Societi calendar with our community

Societi worked closely with our supporters to create a calendar which, as well as highlighting key dates in the year (like Awareness Day on 26 Jan!), Also included the birthdays of the people who are part of our Kawasaki Disease community!

Inclusion of supporter's birthdays, or their child's birthday

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was free and offered on a first come, first served basis. The calendar was a huge success with a huge amount of supporters requesting to be involved in the project.

Families who are affected by Kawasaki Disease can often feel isolated. Our calendar serves as a reminder to these families that their circumstances are similar to many others and they are not alone in their Kawasaki Disease journey.



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Support for the Kawasaki Disease Support Group (KSSG)

KSSG are an organisation run by parents of children who have been affected by Kawasaki Disease. They have an invaluable role in providing a listening ear and emotional support for Families affected by Kawasaki Disease.

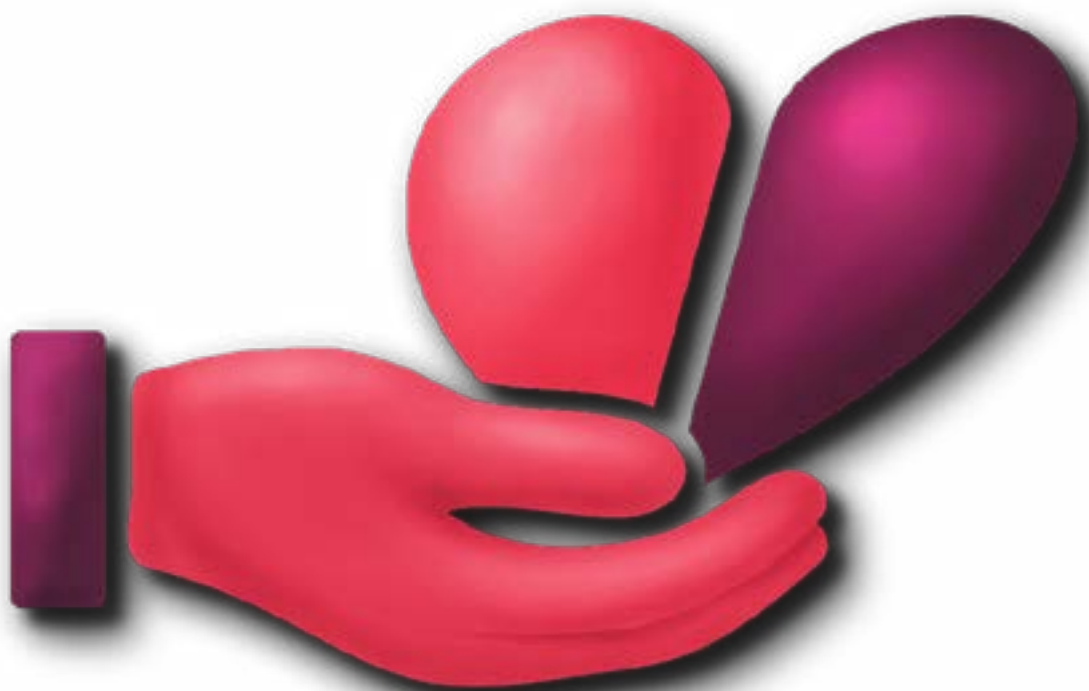
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Societi hosts the Support Group's website within its own site and completes updates as and when required. Families who are in need of emotional support are signposted to KSSG. Societi also has an open offer of support financially to KSSG.



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Financial position

At the period end, the charity had total reserves of £100,156 (2021: £123,247) composed of unrestricted funds of £100,156 (2021: £103,247) and restricted funds of £nil (2021: £20,000).



Reserves Policy

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 £80,000. 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 safeguard the future operation of Societi. At the year end the charity had unrestricted reserves of £100,156 which included functional fixed assets of £2,803. The 'free reserves available to the charity was £97,353, which is above the minimum level per the reserves policy of £80,000.

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.

Societi is a young organisation and we endeavour to maintain a careful rate of growth and development. Trustees recognise that as we grow and incur greater running costs and overheads, our reserves position will need to be reviewed regularly to reflect present circumstances and other extenuating factors to ensure stability and operational continuity for our organisation.

Our current reserves level reflects:

1. the modest turnover of the organisation – from which a sum in the region of 6–9 months typical operating cost is identified as reserves.
2. 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. Societi, which is still a young and developing organisation. Our Trustees have a proven track record of delivering the work of the charity within a 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 reach.

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

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At the period end, the charity had total reserves of £100,156 (2021: £123,247) composed of unrestricted funds of £100,156 (2021: £103,247) and restricted funds of £nil (2021: £20,000).

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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 guidance, as amended.

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Governing document

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.



Recruitment and appointment of new trustees

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 meeting of the Board of Trustees – whether within or outside of the cycle of planned meetings. This recognises that additional meetings may be called to confirm the appointment of a Trustee if needed.

Induction and training of new trustees

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.

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



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Structure, governance and management

Governing document

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.



Reference and administrative details

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
G Higgins
Professor P Brogan
Professor M W Danson (appointed 6.2.23)
P T Ware (appointed 22.6.22)

Independent Examiner

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

Approved by order of the board of trustees on
23 October 2023 and signed on its behalf by:

R E A Greenwood - Trustee

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 our work means such a lot.

With my very best wishes,

Rachael McCormack, Founder
for Societi Foundation

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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 31 December 2022.

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
2. 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: 23.10.2023



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Statement of financial activities for the Year Ended 31 December 2022



	Notes	Unrestricted funds £	Restricted funds £	2022 Total funds £	2021 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies		82,841	-	82,841	182,965
Other trading activities	2	14,223	-	14,223	2,242
Other income		<u>5,095</u>	<u>-</u>	<u>5,095</u>	<u>10,234</u>
Total		<u>102,159</u>	<u>-</u>	<u>102,159</u>	<u>195,441</u>
EXPENDITURE ON					
Raising funds		31,765	4,250	36,015	33,614
Charitable activities					
Kawasaki Disease awareness		<u>73,485</u>	<u>15,750</u>	<u>89,235</u>	<u>83,365</u>
Total		<u>105,250</u>	<u>20,000</u>	<u>125,250</u>	<u>116,979</u>
NET INCOME / (EXPENDITURE)		(3,091)	(20,000)	(23,091)	78,462
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>103,247</u>	<u>20,000</u>	<u>123,247</u>	<u>44,785</u>
TOTAL FUNDS CARRIED FORWARD		<u>100,156</u>	<u>-</u>	<u>100,156</u>	<u>123,247</u>

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	Notes	Unrestricted funds £	Restricted funds £	2022 Total funds £	2021 Total Funds £
FIXED ASSETS					
Intangible assets	7	2,681	-	2,681	5,980
Tangible assets	8	<u>122</u>	<u>-</u>	<u>122</u>	<u>360</u>
		2,803	-	2,803	6,340
CURRENT ASSETS					
Stocks	9	2,346	-	2,346	1,388
Debtors	10	713	27,881	28,594	136,075
Cash at bank		<u>99,610</u>	<u>-</u>	<u>99,610</u>	<u>43,049</u>
		102,669	27,881	130,550	180,512
CREDITORS					
Amounts falling due within one year	11	<u>(5,316)</u>	<u>(27,881)</u>	<u>(33,197)</u>	<u>(63,605)</u>
NET CURRENT ASSETS		<u>97,353</u>	<u>-</u>	<u>97,353</u>	<u>116,907</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>100,156</u>	<u>-</u>	<u>100,156</u>	<u>123,247</u>
NET ASSETS		<u>100,156</u>	<u>-</u>	<u>100,156</u>	<u>123,247</u>
FUNDS	12				
Unrestricted funds				100,156	103,247
Restricted funds				<u>-</u>	<u>20,000</u>
TOTAL FUNDS				<u>100,156</u>	<u>123,247</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 23 October 2023 and were signed on its behalf by:

R E A Greenwood - Trustee

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Notes to the Financial Statement for the Year Ended 31 December 2022



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 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 can be measured reliably. Expenditure is 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

Tangible fixed assets

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

Computer equipment - 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.

Taxation

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.

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2. OTHER TRADING ACTIVITIES

	2022 £	2021 £
Fundraising events	12,317	-
Merchandise income	1,906	2,242
	<u>14,223</u>	<u>2,242</u>

3. SUPPORT COSTS

	Other £	Governance costs £	Totals £
Kawasaki Disease awareness	<u>28,566</u>	<u>1,032</u>	<u>29,598</u>
Support costs, included in the above, are as follows:		2022 Kawasaki Disease awareness £	Total activities £
Postage and stationery		2,716	526
Insurance		185	186
Accountancy		577	562
Office costs		9,886	5,074
Administrative staff costs		11,665	6,595
Amortisation of intangible fixed assets		3,299	3,164
Depreciation of tangible fixed assets		238	235
Independent Examination		<u>1,032</u>	<u>1,200</u>
		<u>29,598</u>	<u>17,542</u>
		£	£
Independent examination fee		<u>900</u>	<u>300</u>

4. INDEPENDENT EXAMINATION

5. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 December 2022 nor for the year ended 31 December 2021.

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 December 2022 nor for the year ended 31 December 2021.

6. STAFF COSTS

	2022 £	2021 £
Wages and salaries	48,564	54,600
Social security costs	1,260	16
Other pension costs	<u>1,150</u>	<u>1,264</u>
	<u>50,974</u>	<u>55,880</u>

No employees received employee benefits over £60,000.

The average monthly number of employees during the year was as follows:

	2022	2021
Administration	<u>2</u>	<u>2</u>

No employees received emoluments in excess of £60,000.

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7. INTANGIBLE FIXED ASSETS

COST

At 1 January 2022 and 31 December 2022

AMORTISATION

At 1 January 2022

Charge for year

At 31 December 2022

NET BOOK VALUE

At 31 December 2022

At 31 December 2021

Website £

-

11,932

5,952

3,299

9,251

2,681

5,980

8. TANGIBLE FIXED ASSETS

COST

At 1 January 2022 and 31 December 2022

DEPRECIATION

At 1 January 2022

Charge for year

At 31 December 2022

NET BOOK VALUE

At 31 December 2022

At 31 December 2021

713

353

238

591

122

360

9. STOCKS

Stocks

2022 £

2,346

2021 £

1,388

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

Prepayments and accrued income

2022 £

28,594

2021 £

136,075

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

Taxation and social security

Other creditors

2022 £

613

2021 £

847

32,584

33,197

62,758

63,605

12. MOVEMENT IN FUNDS

Unrestricted funds

General fund

Restricted funds

Randal Charitable Foundation

TOTAL FUNDS

At 1.1.22 £

103,247

20,000

123,247

Net movement in funds £

(3,091)

(20,000)

(23,091)

At 31.12.22 £

-

100,156

-

100,156

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12. MOVEMENT IN FUNDS CONTINUED

Net movement in funds, included in the above are as follows:

Unrestricted funds

	Incoming resources £	Resources expended £	Movement in funds £
General fund	102,159	(105,250)	(3,091)

Restricted funds

Randal Charitable Foundation	-	(20,000)	(20,000)
------------------------------	---	----------	----------

TOTAL FUNDS

	102,159	(125,250)	(23,091)
--	---------	-----------	----------

Comparatives for movement in funds

At 1.1.21
£

Net
movement
in funds £

Transfer between
funds £

At 31.12.21 £

Unrestricted funds

General fund	36,477	(18,726)	85,496	103,247
--------------	--------	----------	--------	---------

Restricted funds

Young Person's Portal	8,308	-	(8,308)	-
-----------------------	-------	---	---------	---

Randal Charitable Foundation	-	20,000	-	20,000
------------------------------	---	--------	---	--------

KD CAAP Trial	-	77,188	(77,188)	-
---------------	---	--------	----------	---

TOTAL FUNDS

	8,308	97,188	(85,496)	20,000
--	-------	--------	----------	--------

	44,785	78,462	-	123,247
--	--------	--------	---	---------

Comparative net movement in funds, included in the above are as follows

Unrestricted funds

	Incoming resources £	Resources expended £	Movement in funds £
General fund	88,353	(107,079)	(18,726)

Restricted funds

Lanarca fund	9,900	(9,900)	-
--------------	-------	---------	---

Randal Charitable Foundation	20,000	-	20,000
------------------------------	--------	---	--------

KD CAAP Trial	77,188	-	77,188
---------------	--------	---	--------

TOTAL FUNDS

	107,088	(9,900)	97,188
--	---------	---------	--------

	195,441	(116,979)	78,462
--	---------	-----------	--------

Young Person's Portal Fund - The fund arose following a grant from The Foyle Foundation. This grant is to be used to fund the creation of a Children's and Young People's Online Information Portal about Kawasaki Disease.

Lanarca Fund - This fund was a donation from Lanarca towards the staff costs of the charity.

Randal Charitable Foundation Fund - Randal Charitable Foundation Fund

KD-CAAP Trial - The fund arose from an agreement for provision of resources with University College London (UCL) as part of a larger grant arrangement. The agreement specifies the expenditure must be spent on delivering the project and any variation needs to be approved by UCL.

13. RELATED PARTY DISCLOSURES

During the period, the Charity received donated services of £10,517 (2021: £35,256) from Lanarca Limited, a company in which trustees R E A Greenwood and R D Greenwood are directors.

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Detailed Statement of financial activities for the Year Ended 31 Dec 2022



INCOME AND ENDOWMENTS

Donations and legacies

Donations	40,004	48,232
Gift aid	2,389	2,289
Grants	29,931	97,188
Gifts in kind	<u>10,517</u>	<u>35,256</u>
	82,841	182,965

Other trading activities

Fundraising events	12,317	-
Merchandise income	<u>1,906</u>	<u>2,242</u>
	14,223	2,242

Other income

Other Income	<u>5,095</u>	<u>10,234</u>
--------------	--------------	---------------

Total incoming resources

102,159 195,441

EXPENDITURE

Raising donations and legacies

Wages	24,282	27,300
Social security	630	-
Pensions	575	632
Fundraising costs	<u>7,569</u>	<u>84</u>
	33,056	28,016

Other trading activities

Opening stock	1,388	3,296
Purchases	3,917	3,690
Closing stock	<u>(2,346)</u>	<u>(1,388)</u>
	2,959	5,598

Charitable activities

Wages	24,282	27,300
Social security	630	16
Pensions	575	632
Subscriptions	278	295
Advertising	54	168
Travel and subsistence	2,161	-
Resource Films	21,140	5,900
Donated services	10,517	7,512
Recharged Staff Costs	<u>-</u>	<u>24,000</u>
	59,637	65,823

Support costs

Other		
Postage and stationery	2,716	526
Insurance	185	186
Accountancy	577	562
Office costs	9,886	5,074
Administrative staff costs	11,665	6,595
Computer software	3,299	3,164
Computer equipment	<u>238</u>	<u>235</u>
	28,566	16,342

Governance costs

Independent Examination	<u>1,032</u>	<u>1,200</u>
-------------------------	--------------	--------------

Total resources expended

125,250 116,979

NET (EXPENDITURE)/INCOME

(23,091) 78,462

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We are the
UK Foundation for
Kawasaki Disease

**Societi Foundation is a
registered charity in England &
Wales, number 1173755**

*Societi Foundation
Victoria Court, Holme Lane
Winthorpe, Newark
NG24 2NU*

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