

Societi Foundation

Annual Report & Accounts

1 January 2021 - 31 December 2021

Registered charity number 1173755





**Annual
Report**



*Independent
Examiner's Report*

About Kawasaki Disease

About Societi Foundation



Our Activities -
Awareness Raising



Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



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.**

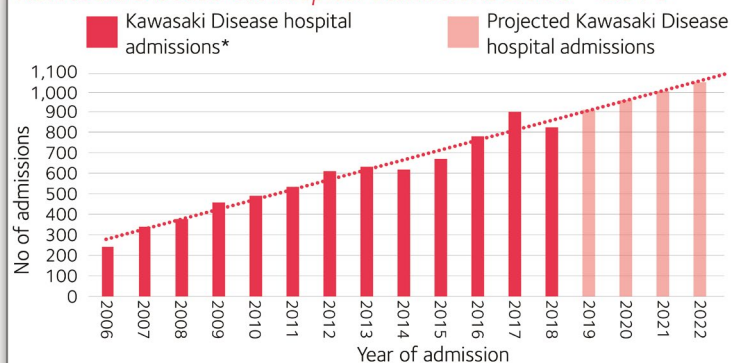
It is a type of vasculitis that mainly affects young children but it can affect people of any age – and its impact can be most serious in the very young, particularly infants. Identified in 1967 in Japan by Dr Tomisaku Kawasaki, the cause of Kawasaki Disease is still unknown. The illness presents with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

Kawasaki Disease UK hospital admissions 2006 - 2018



* Societi Freedom of Information study 2016 & 2019

Kawasaki Disease is increasingly common. The above graph, 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.

Societi Foundation

Annual Report and Accounts

January 2021 - December 2021



Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation

Our Activities -
Awareness Raising



Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



About Societi Foundation

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

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.

Report of the trustees - The trustees present their report with the financial statements of our charity for the year ended 31 December 2021. 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 2021 - December 2021 is set out.

Societi Foundation and Covid 19 - In setting out this report, whilst much has been achieved during the year to December 2021, it must be recognised that this has been once again with the very challenging

backdrop of Covid 19 which has restricted us, like so many organisations. Limits on staff coming together have had an impact on our team, virtual and online Trustee meetings have shifted the dynamic too -and most significantly, the constraints faced by families during lockdowns and the far reaching impact of Covid 19 has limited fundraiser activities, awareness work and more.

We have faced these challenges with resolve and with bold choices by our trustees, to continue our urgent work with unrelenting determination. Trustees recognise too that the impact of Covid 19 will be lasting, and our continued growth as an organisation and future success will depend on continued strong leadership from our trustees, support from influential partners and the growth of our amazing community of supporters who volunteer and carry out so much of our work.

Societi Foundation

Annual Report and Accounts

January 2021 - December 2021



Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation

Our Activities -
Awareness Raising



Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



About Societi Foundation

Societi was established in 2015 as an organisation to raise awareness of Kawasaki Disease – a disease which affects hundreds of children in the UK each year. Societi is an influencing and policy shaping organisation which works through partnerships to drive transformational change in awareness across the UK, about Kawasaki Disease.



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.

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 will work with others to enable them to recognise Kawasaki Disease as a priority

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

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



Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation

Our Activities -
Awareness Raising



Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



About Societi Foundation

Our five Trustee Board Members, Ms Rachael McCormack, Prof Robert Tulloh, Prof Paul Brogan, Mr Roger Greenwood, and Mr Gerry Higgins bring together a strong combination of skills and expertise to drive and direct the work of our charity.



Our Trustee Board

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 families facing, and living with this illness. Rachael has experience across the third sector, 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 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 autoinflammatory diseases, including Kawasaki Disease. He is also Chair of the Vasculitis Consortium, and Clinical Lead for Autoinflammatory 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.

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.



Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation

Our Activities -
Awareness Raising



Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management

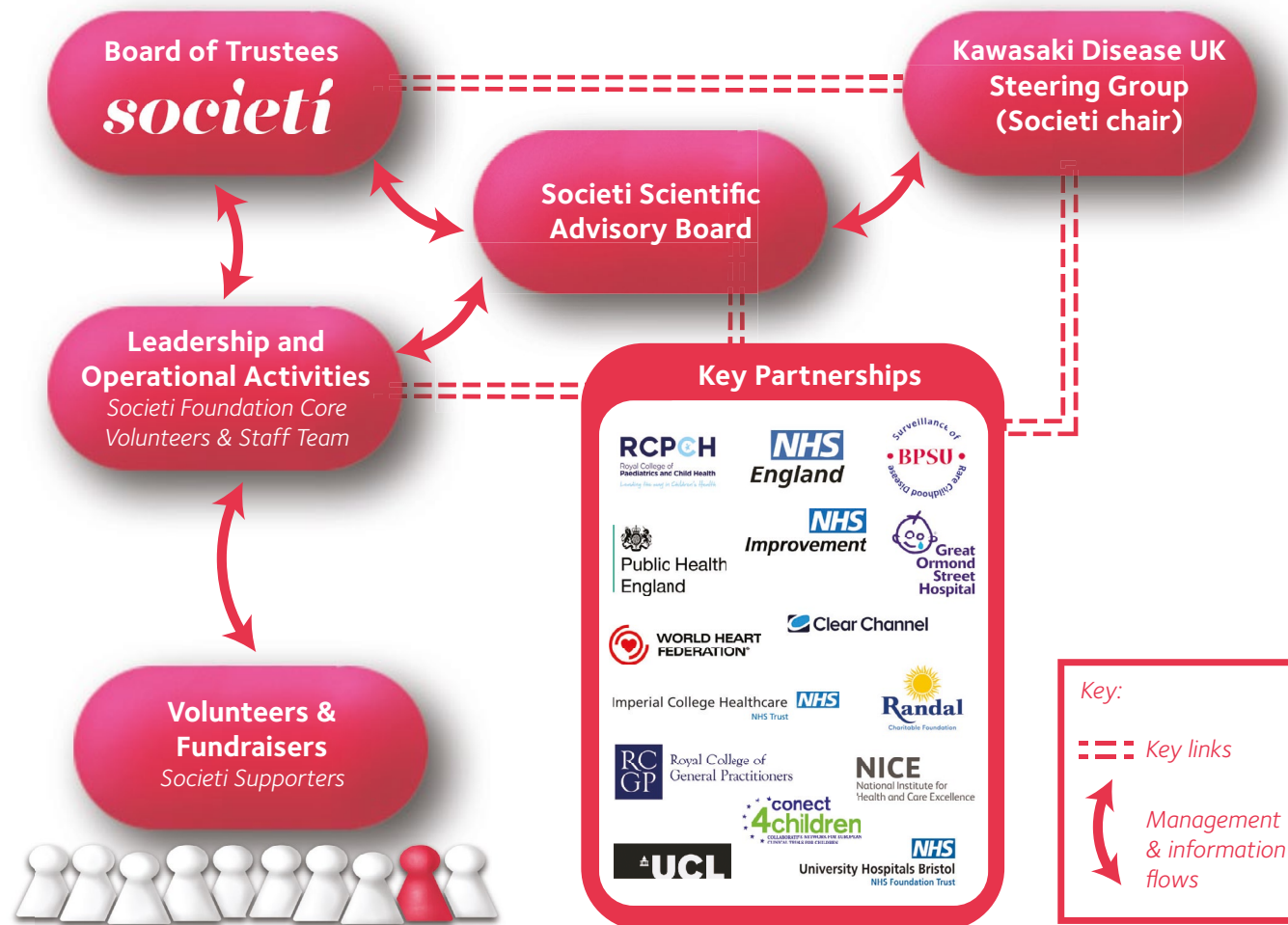


About Societi Foundation

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 - and through expanded knowledge, stem the rising number of children carrying a lifelong legacy of heart damage. They cannot act for themselves. So Societi must.

1 2 3 4 5 6

Our Organisational Structure





Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation

Our Activities -
Awareness Raising



Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



About Societi Foundation

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.



We place huge importance on partnership and relationships – the issues we face are huge and we know we simply can't tackle them alone. 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 very thankful to receive support from a number of organisations including Clear Channel, The Randal Charitable Foundation Lanarca, Microsoft, Adobe and Google whose donated services and/or financial support during the period have expedited the work of Societi in a way that otherwise would not be achievable by our young charity.



Societi Foundation

Annual Report and Accounts

January 2021 - December 2021



Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation

Our Activities -
Awareness Raising



Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



About Societi Foundation

Our future plans

In 2021, Societi Foundation reported on achievements from its first UK National Strategy for Kawasaki Disease, and comprehensively revised the strategy with ambitious targets for the five years ahead. Our aim remains the same - to tackle the leading cause of acquired heart disease in children in the UK and it defines the focus areas for our work, going forward.



In 2016, Societi Foundation led the development of the first ever UK Strategy for Kawasaki Disease. 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.

In 2021, to take our work and our organisation forward, building on the successes to date, Societi has both celebrated our achievements since publishing that strategy, and developed a fully refreshed strategy. This takes into account a review of Societi's core purpose, the current Kawasaki Disease environment, new evidence available from research and resources and capabilities available to our organisation.

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.

Societi's aims have been reviewed against all the evidence currently available and remain aligned to the aims of the 2016 strategy with an exception of an update to Family Support to enable a sustained focus in this area.

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





**Annual
Report**



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



**Our Activities -
Awareness Raising**

Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Awareness Raising

Activities around raising awareness of Kawasaki Disease

We raise awareness of Kawasaki Disease to improve prompt diagnosis – through multi media campaigns, reaching GPs, paediatric clinicians, health professionals and parents. Click on the buttons below to find out about our activities around raising awareness of Kawasaki Disease:



Clear Channel helping to Get Kawasaki Disease known!

Once again, the exceptional team at Clear Channel generously donated advertising space for a whole week, in January 2021, including on Awareness Day (26 January), to help us get Kawasaki Disease known, reaching tens of thousands of people!

All week, Societi's campaign was displayed on Clear Channel's spectacular Adshel Live and Storm Board digital screen network – in shopping centres, on busy streets and city centres, even on huge screens at the side of motorways – right across the UK!

The campaign raised awareness of Kawasaki Disease across the UK to levels which otherwise Societi would not be able to obtain.

We are so grateful to the incredible team at Clear Channel for this huge act of kindness, their continuing support, help and advice and for their phenomenal commitment to growing their #PlatformForGood Clear Channel Outdoor.





**Annual
Report**



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



**Our Activities -
Awareness Raising**

Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Awareness Raising

Activities around raising awareness of Kawasaki Disease

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Press coverage

Societi successfully published an article as part of our World Heart Day 2021 awareness campaign, in News Medical.

News Medical are one of the world's leading open-access medical and life science hubs with a global reach of 121 million annual visitors worldwide – their weight behind our work is just immense and means a great deal.

This is an important milestone for Societi Foundation – with support from such a trusted life sciences and medical publication, physicians across the globe will read our article and will now know to think Kawasaki Disease. And by doing this we are delivering on our aim – to put Kawasaki Disease at the forefront of doctor's minds.

The article is available to read [here](#).





Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



**Our Activities -
Awareness Raising**

Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Awareness Raising

Activities around raising awareness of Kawasaki Disease

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Work starts on new awareness animation

Towards the end of 2021, Societi started work on the production of a new awareness raising animation.

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.

Planning for the creation of the animation, and our initial investment in this important film started in October 2021, for a release on 26 January 2022 - International Kawasaki Disease Awareness Day.





**Annual
Report**



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



**Our Activities -
Awareness Raising**

Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Awareness Raising

Activities around raising awareness of Kawasaki Disease

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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.

Our Marketing, Media and Digital Lead continues to work to expand the reach we have through daily posts and campaigns on Facebook, Twitter Instagram and LinkedIn. 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:





Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



**Our Activities -
Awareness Raising**

Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Awareness Raising

Activities around raising awareness of Kawasaki Disease

We raise awareness of Kawasaki Disease to improve prompt diagnosis - through multi media campaigns, reaching GPs, paediatric clinicians, health professionals and parents. Click on the buttons below to find out about our activities around raising awareness of Kawasaki Disease:



Supporting our Supporters

We never cease to be astonished by the absolute dedication and simply astounding support from #TeamSocieti - families who have often been affected by Kawasaki Disease themselves or have been inspired by the work of our charity and get involved.

Throughout 2021, circumstances continued to be difficult for everyone because of Covid 19 and the restrictions that brought for everyone. But, that didn't stop our AMAZING supporters taking on fantastic challenges, raising much needed funds and raising awareness of Kawasaki Disease.

TeamSocieti showed new and ingenious ways of raising awareness and funds for Kawasaki Disease and they cycled miles, walked miles, ran miles, swam miles... everywhere from coast to coast and even up to the highest peaks!

We always strive to help our supporters in their awareness and fundraising efforts. Our gratitude to every single member of #TeamSocieti for their unrelenting effort and their show of support is endless.



[Read the
Facebook post](#)



[Read the
Facebook post](#)



[Read the
Facebook post](#)



[Read the
Facebook post](#)



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Facebook post](#)



[Read the
Facebook post](#)

Activities around raising awareness of Kawasaki Disease

We raise awareness of Kawasaki Disease to improve prompt diagnosis – through multi media campaigns, reaching GPs, paediatric clinicians, health professionals and parents. Click on the buttons below to find out about our activities around raising awareness of Kawasaki Disease:



The Societi newsletter

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 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.

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

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 2021 Christmas newsletter.



Annual Report



Independent Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities - Awareness Raising

Our Activities - Clinical Research



Our Activities - Clinical Supervision



Our Activities - Support for UK Families



Financial Review



Structure, Governance & Management



Activities around raising awareness of Kawasaki Disease

We raise awareness of Kawasaki Disease to improve prompt diagnosis – through multi media campaigns, reaching GPs, paediatric clinicians, health professionals and parents. Click on the buttons below to find out about our activities around raising awareness of Kawasaki Disease:



**Annual
Report**



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



**Our Activities -
Awareness Raising**

Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Societi Active

Led by simply fantastic volunteers, Hayley, Vikki, Gayle and Lucy, Societi Active continued to encourage our supporters to get active for Kawasaki Disease.

The team supported our marathon runners, led our virtual runs for World Heart Day and International Kawasaki Disease Awareness Day and inspired everyone with energy and enthusiasm.

Societi Active provide the information needed to start fundraising for Societi Foundation and suggest ways to promote challenges and raise awareness of Kawasaki Disease. They also provide training advice and tips from a qualified sports and running coach, offer bespoke training plans for runners, share 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!

Follow the Societi Active team on Facebook [here](#).





Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



**Our Activities -
Awareness Raising**

Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Awareness Raising

Activities around raising awareness of Kawasaki Disease

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Travelling as a team to Tokyo!

For Kawasaki Disease International Awareness Day 2021, Societi Active organised a BRILLIANT challenge to help protect tiny hearts - and amazing #TeamSocieti really stepped up to that challenge!

A massive team took part and collectively walked, ran and cycled the distance from Societi HQ all the way to Tokyo, Japan - that's 5885 miles!

Why Tokyo?!! It was the home of Dr Tomisaku Kawasaki who first identified Kawasaki Disease - a perfect challenge to mark such an important date.

With all those supporters out and about in their Societi running tops, t-shirts and hoodies and letting everyone know their progress on social media, the event was INCREDIBLE for awareness - and Societi Active raised a fabulous £530.50 too!

We are extremely grateful to everyone who took part.





**Annual
Report**



**Independent
Examiner's Report**

About Kawasaki Disease



About Societì Foundation



**Our Activities -
Awareness Raising**

Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Awareness Raising

Activities around raising awareness of Kawasaki Disease

We raise awareness of Kawasaki Disease to improve prompt diagnosis - through multi media campaigns, reaching GPs, paediatric clinicians, health professionals and parents. Click on the buttons below to find out about our activities around raising awareness of Kawasaki Disease:



The Virtual 10k for World Heart Day

Societì Active's Virtual 10k returned for its 3rd year in a row, thanks to our incredible volunteers Hayley, Vikki, Gayle and Lucy who dedicate hours of their time to organising, planning and running the event. Each year, our virtual 10k event is even more successful than the year before - and this year was no exception. This was our biggest Virtual run yet with over 80 supporters taking part and well over £1,500 raised to help raise awareness of Kawasaki Disease!

Aside from the important funds raised by the Virtual 10k, a huge amount of Kawasaki Disease awareness was also raised in communities throughout the UK (and even as far afield as Italy!) by our participants, all in their brand new Societì running shirts - simply stunning! Thank you to EVERYONE who took part!

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

societì
World Heart
Day 2021

societì.org.uk

societì **ACTIVE** **10K**
for World Heart Day!



Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



**Our Activities -
Awareness Raising**

Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Awareness Raising

Activities around raising awareness of Kawasaki Disease

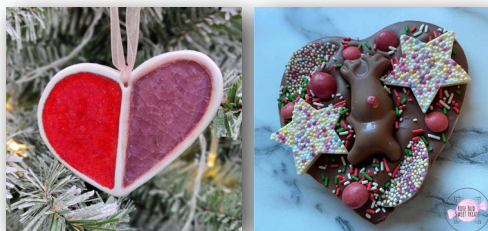
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Promoting Societi merchandise

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.

A popular addition to our online shop over the Christmas period were these beautiful, bespoke hand-crafted glass and ceramic Societi decorations. They were a reminder of what it means to be part of #TeamSocieti – a passionate and determined group of people that are dedicated to helping to protect children's hearts. And, as if that was enough, we also offered limited edition chocolate hearts made especially for Societi – yum yum!



ACTIVE

AT HOME

AWARENESS

Awareness Raising

Activities around raising awareness of Kawasaki Disease

We raise awareness of Kawasaki Disease to improve prompt diagnosis – through multi media campaigns, reaching GPs, paediatric clinicians, health professionals and parents. Click on the buttons below to find out about our activities around raising awareness of Kawasaki Disease:



Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



**Our Activities -
Awareness Raising**

Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



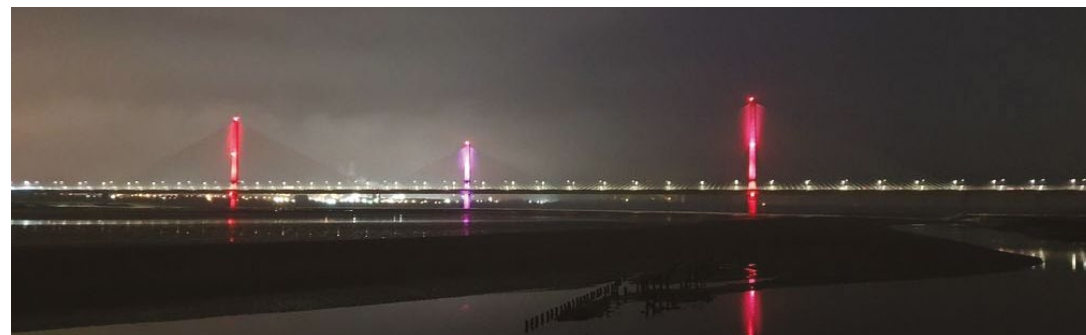
Lighting up for Kawasaki Disease awareness

FANTASTIC landmarks, including the Mersey Gateway Bridge and the Council House in Nottingham illuminated bright pink and red for Kawasaki Disease International Awareness Day 2021.

Beautiful beams lit up the sky, shining a light on Kawasaki Disease for International Kawasaki Disease Awareness Day. Landmarks lit up were accompanied by local media posts sharing information about Kawasaki Disease – stories were picked up in local papers and excellent coverage of the seriousness of this little known disease was achieved.

We are very grateful to the hard work of supporters who made this happen and for the support from the local authorities.

Due to this success we also worked throughout 2021 to encourage our supporters to approach their local authorities and local landmarks to light up for Kawasaki Disease Awareness Day 2022.





**Annual
Report**



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



**Our Activities -
Awareness Raising**

Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Awareness Raising

Activities around raising awareness of Kawasaki Disease

We raise awareness of Kawasaki Disease to improve prompt diagnosis – through multi media campaigns, reaching GPs, paediatric clinicians, health professionals and parents. Click on the buttons below to find out about our activities around raising awareness of Kawasaki Disease:



Building momentum with Members of Parliament

Societi works through partnerships to achieve our stated aims and those shared aims of our partners and stakeholders, some of which are a number of committed MP's working with us to get Kawasaki Disease known! We need political stakeholders to understand the seriousness and urgency of Kawasaki Disease if we are to create change which really benefits our children. Fabulous support from our generous partner, Lexington Communications allowed us to reach and secure positive engagement with a number of politicians.

In 2021, we were delighted to receive support from MP Henry Smith, MP Elliot Colbourn and MP James Davies. Their support is significant in building a powerful presence for Kawasaki Disease in the UK parliament.

Kawasaki Disease needs Government investment in research, awareness and education to prevent lifelong heart disease in our children. We continue to engage with our MPs across the UK.





**Annual
Report**



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



**Our Activities -
Awareness Raising**

Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Awareness Raising

Activities around raising awareness of Kawasaki Disease

We raise awareness of Kawasaki Disease to improve prompt diagnosis – through multi media campaigns, reaching GPs, paediatric clinicians, health professionals and parents. Click on the buttons below to find out about our activities around raising awareness of Kawasaki Disease:



KNOW Kawasaki Disease awareness film released

Working with parents of children who have been affected by Kawasaki Disease, Societi produced a powerful awareness raising film – featuring family voices and views.

Released on International Kawasaki Disease awareness day 2021, the film is powerful and hard hitting and gives an insight into the devastating affect Kawasaki Disease can have on families.

Massive thanks to ALL the wonderful parents who feature in our film. Their powerful voices are helping us get Kawasaki Disease known!

Thank you too, to the hundreds of fabulous people who helped us to get Kawasaki Disease known, protecting children's hearts by sharing our Kawasaki Disease awareness film.

Watch the film [here](#).





Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



**Our Activities -
Awareness Raising**

Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Awareness Raising

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Founder, Rachael talks about how Societi began

A video published to Societi's YouTube channel in November 2021 featured Founder, Rachael, as she explains about how and why Societi Foundation was established.

Rachael founded Societi after her family was affected by Kawasaki Disease. After months and many misdiagnoses, this little-known children's disease led to a lifetime of heart damage which, as Rachael became aware, is an all too familiar story for many hundreds of UK families.

Shared across our social media platforms, the video is a useful tool to explain the work that Societi does, some of the issues surrounding Kawasaki Disease and why awareness is so important.

Watch the video [here](#).





**Annual
Report**



Independent
Examiner's Report

About Kawasaki Disease



About Societì Foundation



**Our Activities -
Awareness Raising**

Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Awareness Raising

Activities around raising awareness of Kawasaki Disease

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Working with our sister organisations

Societì works with sister organisations across the globe to collaborate, share information and to get Kawasaki Disease known.

On Kawasaki Disease International Awareness Day, we joined sister organisations, Kawasaki Disease Canada and Malattia Di Kawasaki, Italy, in a webinar series 'The Heart of the matter' to talk about all things Kawasaki Disease.

Our shared commitment to getting Kawasaki Disease known is essential and we work together, debunking myths on Kawasaki Disease. Children in every part of the globe suffer from this disease and its devastating impacts! Working together we are stronger in our shared fight against Kawasaki Disease!



societì



Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



**Our Activities -
Awareness Raising**

Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Awareness Raising

Activities around raising awareness of Kawasaki Disease

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World Heart Day - Let's protect tiny hearts...

Our partnership with the World Heart Federation led to a concerted campaign once again for World Heart Day in 2021. #TeamSocieti worked incredibly hard to make 29 September - World Heart Day - a fantastic success. Our campaign focused on raising awareness of Kawasaki Disease with families, clinicians and just about EVERYONE who can make a difference and help to protect tiny hearts.

Together we shared awareness raising messages far across social media, told family stories, released informative podcasts, published media releases and held our Virtual 10k event, all to highlight the urgent need for more public awareness of Kawasaki Disease and investment to prevent heart damage in our children.

We are very grateful to every single one of our supporters and partners who made World Heart Day such a special day for our children.

Read our impact statement [here](#), with amazing highlights from #TeamSocieti on World Heart Day.

societi
World Heart
Day 2021

societi.org.uk

Fabulous Family Stories

Sharing family stories is an extremely powerful way to raise awareness of Kawasaki Disease. For World Heart Day, we asked Societi supporters to share their stories of Kawasaki Disease, to help others who may have been through similar experiences. It is our aim that these powerful stories, shared generously by our families, will be a valued source of support, help grow understanding of Kawasaki Disease and protect tiny hearts into the future.

We are incredibly grateful to everyone who has contributed their very special story, and have generously shared their unique Kawasaki Disease journey to help get Kawasaki Disease known. You can read our Family Stories [here](#).

Powerful Partners

We are deeply grateful to our incredible partners who tweeted and posted our awareness raising statements on World Heart Day - such powerful partnerships grow awareness and spread our important messages far and wide. These big voices help us create the change we need.

World Heart Day was an opportunity to engage with new partners too. We were thrilled two influential parent focused groups: Mumsnet and Netmums (with a combined following of over 280,000 people) offered to share our content and help spread the urgent message that all parents and carers need to know Kawasaki Disease.

With such strong partnerships and a growing number of partners, we WILL get this disease known, we can and will protect children's hearts from the devastating damage Kawasaki Disease can cause.

Social to shout about!

Support received from #TeamSocieti is essential for Societi to carry our work. YOUR support on all of our Social media platforms throughout September and on World Heart Day was just "phenomenal" and meant that our Kawasaki Disease awareness raising messages reached thousands more people! Support from YOU is simply vital if we are to get Kawasaki Disease known - THANK YOU!

Profile visits **↑175%**
Page views **↑74%**
Reach **↑23%**

Press coverage

We're really excited to have successfully published an article as part of our World Heart Day 2021 awareness campaign, in News Medical.

News Medical are one of the world's leading open-access medical and life science hubs with a global reach of 1.21 million annual visitors worldwide - their weight behind our work is just immense and means a great deal.

This is an important milestone for Societi Foundation - with support from such a trusted life sciences and medical publication, physicians across the globe will read our article and will now know to think Kawasaki Disease. And by doing this we are delivering on our aim - to put Kawasaki Disease at the forefront of doctor's minds. #ForOurChildren

Societi Active's Virtual 10k

Societi Active's Virtual 10k returned for its 3rd year in a row, thanks to our incredible volunteers Hayley, Vikki, Gayle and Lucy who dedicate hours of their time to organising, planning and running the event. Each year, our virtual 10k event is even more successful than the year before - and this year was no exception. This was our biggest Virtual run yet with over 80 supporters taking part and well over £1,500 raised to help raise awareness of Kawasaki Disease!

Aside from the important funds raised by the Virtual 10k a huge amount of Kawasaki Disease awareness was also raised in communities throughout the UK (and even as far afield as Italy!) by our participants, all in their brand new Societi running shirts - simply stunning!

Thank you to EVERYONE who took part!

If you'd like to take part in one of our future Societi Active events, make sure to follow our dedicated [Societi Active Facebook page](#) to find out what's coming up!

World Heart Day Podcast series

Societi Founder, Rachael, teamed up with some of the fantastic experts on our Scientific Advisory Board, to record and release a series of Kawasaki Disease podcasts, especially for World Heart Day.

Huge thanks go to the amazing doctors who gave their precious time to help create these informative podcasts, which have already been so useful to families and clinicians alike.

Our podcast series includes:

- Kawasaki Disease - "Presenting the facts and dispelling myths" with Professor Robert Tulloh**
Listen to the podcast [here](#)
Read the transcript [here](#)
- Kawasaki Disease - "What everyone needs to know" with Dr Damian Roland**
Listen to the podcast [here](#)
Read the transcript [here](#)
- Kawasaki Disease - "The latest research" with Professor Despina Eleftheriou**
Listen to the podcast [here](#)
Read the transcript [here](#)
- Kawasaki Disease - "Protecting tiny hearts into the future" with Dr Tom Johnson**
Listen to the podcast [here](#)
Read the transcript [here](#)



Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societì Foundation



Our Activities -
Awareness Raising

Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Awareness Raising

Activities around raising awareness of Kawasaki Disease

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International Kawasaki Disease Awareness Day

International Kawasaki Disease Awareness Day is THE most important day in Societì's calendar.

2021 was phenomenal – our most successful campaign yet! #TeamSocietì filled the entire month of January with Kawasaki Disease awareness raising and projects designed to get everyone to KNOW Kawasaki Disease.

Digital displays up and down the entire UK displayed Kawasaki Disease awareness raising messages – thanks to Clear Channel and their amazing Platform for Good support. Our new children's and Young People's portal, MySocietì was released, buildings throughout the country lit up red, Societì supporters walked, ran and cycled the distance from Societì HQ to Tokyo – the home of Dr Tomisaku Kawasaki! And there was so much more besides! A true team effort for everyone involved!

Read our Impact Statement [here](#), which highlights just some of #TeamSocietì's amazing successes, remarkable achievements and the hard work which led to our success!

International Kawasaki Disease Awareness Day 2021

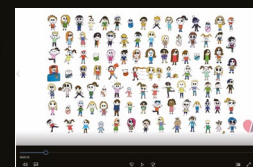


The launch of My Societì

One spectacular highlight was the launch of our much anticipated 'My Societì' young people's portal. The creation of My Societì really was an amazing collaboration from #TeamSocietì. From our design and tech gurus at O Street and Form Digital – to the young people who helped shape the portal – to all our doctors who generously shared their time and expertise! Thank you too, to the Foyle Foundation for their funding and to donations from Ladies Circle, making this project possible. We are very proud to have launched 'My Societì', full of trusted and clinician backed info, designed to answer questions young people affected by Kawasaki Disease may have.

KNOW Kawasaki Disease!

International Kawasaki Disease Awareness Day 2021 was phenomenal – our most successful campaign yet! #TeamSocietì filled the entire month of January with Kawasaki Disease awareness raising and projects designed to get everyone to KNOW Kawasaki Disease. This Impact Statement highlights just some of #TeamSocietì's amazing successes, remarkable achievements and the hard work which led to our success!



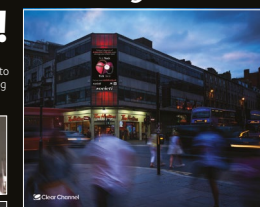
Sharing our powerful awareness raising video

Hundreds of fabulous people helped us get Kawasaki Disease known, protecting children's hearts by sharing our Kawasaki Disease awareness video – it's now been viewed hundreds of times! A massive thank you to ALL the wonderful parents who feature in our video – your powerful voices are being heard!



Utterly BREATHTAKING!!

Two FANTASTIC landmarks, the Mersey Gateway Bridge and the Council House in Nottingham illuminated bright pink and red this January. Beautiful beams lit up the sky for Kawasaki Disease awareness on International KAWASAKI DISEASE AWARENESS DAY. Why not get in touch with your council to ask if they can light up a local landmark on Kawasaki Disease awareness day next year!

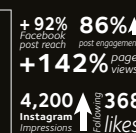


Clear Channel get Kawasaki Disease Known!

Once again, the exceptional team at Clear Channel generously donated advertising space for a whole week, including on awareness day, to help us get Kawasaki Disease known, reaching thousands of people! All week, Societì's campaign was displayed on Clear Channel's spectacular Adshel Live and Store Board digital screen network – in shopping centres, on busy streets and city centres, even on huge screens at the side of motorways – right across the UK! We are so grateful to Clear Channel for this huge act of kindness and for their phenomenal commitment to growing their #PlatformForGood Clear Channel Outdoor.

Working across the globe...

to get Kawasaki Disease known. On awareness day we joined sister organisations, Kawasaki Disease Canada and Italy, in a webinar series 'The Heart of the matter' to talk about all things Kawasaki Disease. Our shared commitment to getting Kawasaki Disease known is essential and we work together, debunking myths on Kawasaki Disease. Children in every part of the globe suffer this disease and its devastating impacts! Working together we are stronger in our shared fight against Kawasaki Disease!



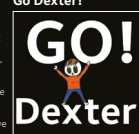
Building momentum
We have a number of committed MPs working with us to get Kawasaki Disease known! We were delighted to receive awareness day support from MP Henry Smith, MP Eliot Colbourn and MP James Davies. Their support is significant in building a powerful presence for Kawasaki Disease in the UK parliament. Kawasaki Disease needs Government investment in research, awareness and education to prevent lifelong heart disease in children. We continue to engage with our MPs across the UK – together we WILL make progress!

You made it to Tokyo!



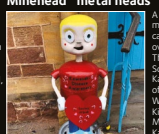
Thank you to EVERYONE who took part in Societì Active's BRILLIANT challenge to help protect tiny hearts. A massive team took part and collectively walked, ran and cycled the distance from Societì HQ all the way to Tokyo, Japan – that's 5885 miles!!! Wow! Why Tokyo? It was the home of Dr Tomisaku Kawasaki who first identified Kawasaki Disease – a perfect challenge to mark such an important date. This event has been INCREDIBLE for awareness – and Societì Active raised a fabulous £530.50 too! Wow!

Go Dexter!



One of our youngest ever fundraisers went the extra mile for International Kawasaki Disease awareness day setting himself a 2x2x12 challenge: 8 year old Dexter took on 2 challenges or 2k every 2 hours for 12 hours on awareness day. Dexter absolutely smashed his challenge and ran, walked, biked, bounced, balance hoovered and wiggled his way to help protect tiny hearts! Not only that, but Dexter and his army of supporters raised a staggering £700 too! Dexter you are AMAZING!

Minehead "metal heads"



A life size Societì Kid was made entirely out of metal by talented Steven Heard, a retired carpenter from Minehead. Steven has created over 50 'metal heads' that form an activity trail. The mastermind behind this is our wonderful Societì supporter Lisa – who does so much for Kawasaki Disease awareness – always thinking of innovative ideas! What a wonderful model of wonderful Societì Kid Reuben. Lisa! Now standing proud in Minehead for everyone to see, creating lots of Kawasaki conversations!

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

...Together we will!

societì



**Annual
Report**



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



**Our Activities -
Clinical Research**

Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Clinical Research

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:



Updating our Diagnosis Day research poll

Towards the end of 2021, Societi started work to collect information as part of an important update to our Diagnosis Day poll - a research project conducted in 2018, on supporters experience of their child's Kawasaki Disease diagnosis. It's clear the diagnosis experience varies from family to family and through this research, we are trying to understand more about just what is happening when our children are first being diagnosed.

Responses to the poll were collected from November 2021 with the poll remaining open into 2022.

The results and the subsequent analysis of the poll, will help direct and focus Societi's work to benefit families affected by Kawasaki Disease in the future - and help them have quicker, more accurate diagnoses.





**Annual
Report**



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



**Our Activities -
Clinical Research**

Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Clinical Research

Activities around clinical research

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Leading Public and Patient Involvement (PPI) for Europe-wide clinical trial

Societi continues to play an ongoing role in the delivery of KDCAAP (Kawasaki Disease Coronary Artery Aneurysm Prevention), the largest Kawasaki Disease clinical trial of its type to ever take place. Societi leads the patient and public (PPI) elements and is part of the Trial Management Group and Trial Steering Group too – with an important part to play making sure the views of families and patients are represented. Our work includes ensuring the profile of the trial is raised and the information families need, as they consider taking part in the trial, is available in user friendly formats.

Societi 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.





Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



**Our Activities -
Clinical Research**

Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Clinical Research

Activities around clinical research

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Raising awareness of KD-CAAP

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

A KD-CAAP Twitter account dedicated to promoting awareness of the KD-CAAP trial continued to post during 2021 on a weekly basis and followers continue to grow in numbers.

Societi cross-posts to the Societi Twitter account which has a regular, active following of over 1,200.

Societi's Facebook page, which has an international following of over 1,800, 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.





Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



**Our Activities -
Clinical Research**

Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Clinical Research

Activities around clinical research

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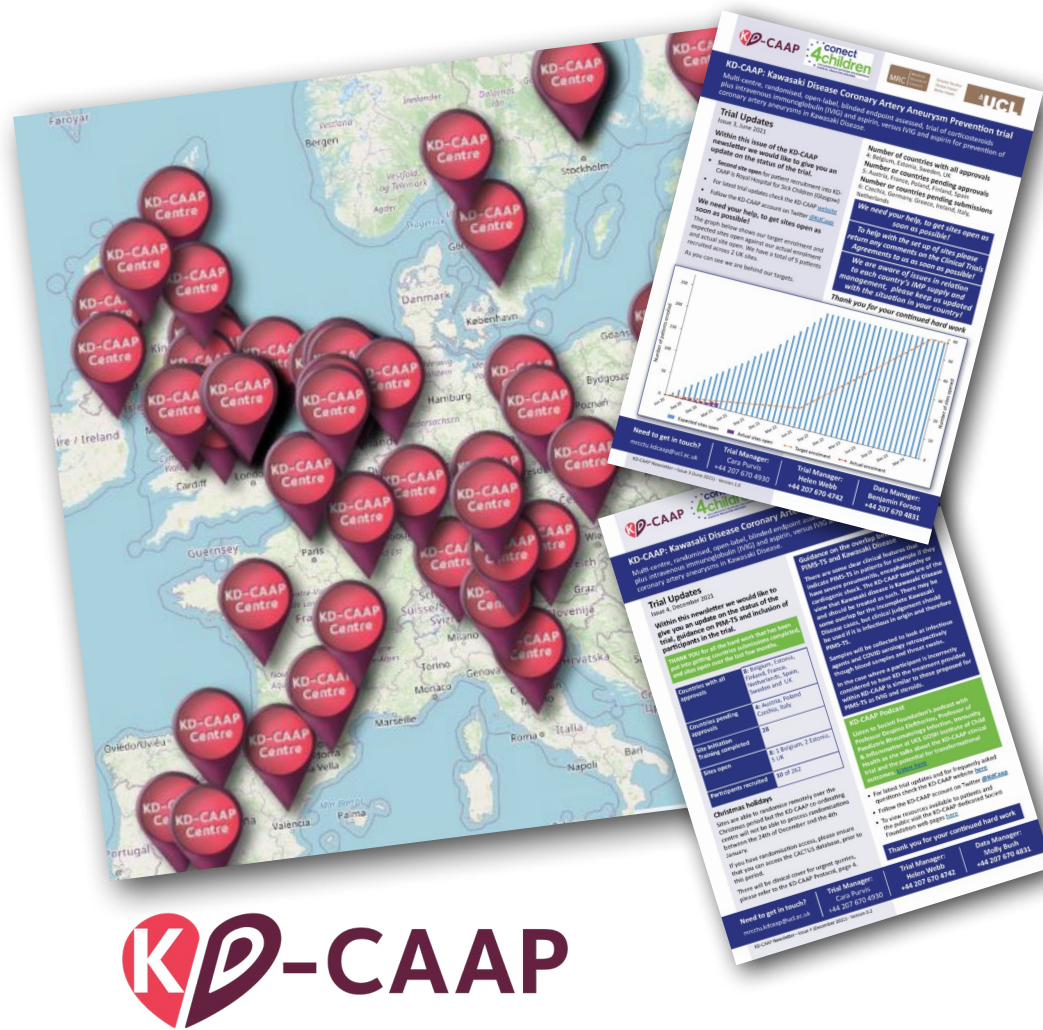
Reviewing and updating KDCAAP trial web pages and resources

Societi continues to review and update a series of dedicated KD-CAAP web pages with new trial information as it becomes available.

Content includes lots of useful information about the trial, a range of downloadable resources for families and an interactive map of KD-CAAP centres across Europe.

The web pages developed for the trial can be viewed [here](#) or by clicking on the image opposite.

Societi also reviews and helps to develop trial resources including a trial newsletter providing design input and reviewing content.



KD-CAAP





Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



**Our Activities -
Clinical Research**

Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Clinical Research

Activities around clinical research

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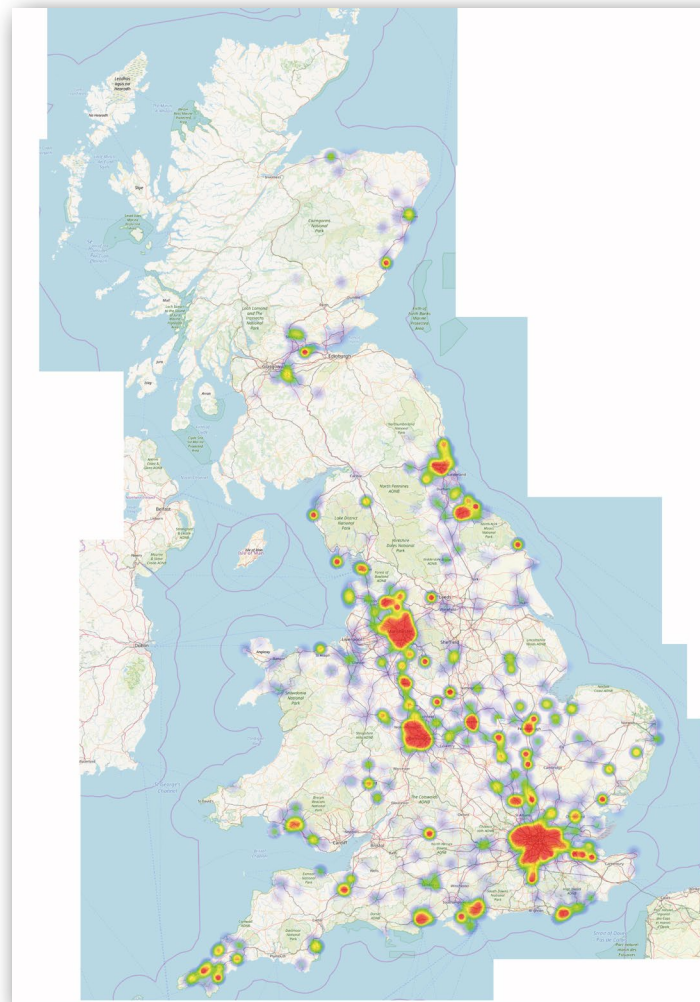


Supporting research into incidence of Kawasaki Disease

Societi supported research undertaken by paediatric researcher, Dr Fiona Pearce (UH Nottingham) into the incidence of Kawasaki Disease in England from 2006 to 2021.

Societi Trustees and members of our Scientific Advisory Board were invited to review and comment on the paper which confirms an increase in Kawasaki Disease incidence across England and draws valuable insights including, for example, the effect of child deprivation status on Kawasaki Disease.

Societi also offered support to the project to produce graphic visual representations of the paper's findings. Societi Foundation (R McCormack) will be included as a co-author on the paper, on publication, reflecting the considerable contribution made into the study development.





**Annual
Report**



**Independent
Examiner's Report**

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



Our Activities -
Clinical Research



**Our Activities -
Clinical Supervision**

Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Clinical Supervision

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:



Working with Societi's 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.



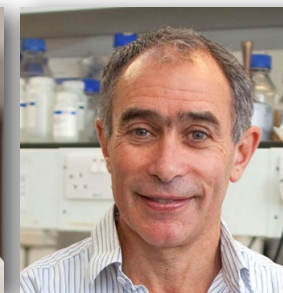
**Prof Despina
Eleftheriou**

*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*



**Annual
Report**



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



Our Activities -
Clinical Research



**Our Activities -
Clinical Supervision**

Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Clinical Supervision

Activities around clinical supervision

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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 2021, the group focused on areas including the impact of Covid-19 on Kawasaki Disease and emerging and ongoing issues, the endorsement of our updated National Strategy for Kawasaki Disease, research updates, parliamentary and Government matters, development of a Kawasaki Disease registry and progress on the adoption of lifetime guidance for Kawasaki Disease.





**Annual
Report**



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



Our Activities -
Clinical Research



**Our Activities -
Clinical Supervision**

Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Clinical Supervision

Activities around clinical supervision

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Embarking on our Strategic Children's Hospital Partnership Programme

Societi started work on a 3-year children's hospital partnership programme, thanks to generous investment and support from the Randal Charitable Foundation who awarded a grant for the work.

This programme will include vital work to dramatically improve Kawasaki Disease knowledge and early disease identification by doctors, to save lives, shorten diagnosis times and enable rapid treatment of Kawasaki Disease – the leading cause of acquired heart disease in UK children.

Such powerful support means we can really drive forward with knowledge building among children's doctors, who will then be equipped to ensure timely diagnosis and improved care for affected children. Our goals include a reduction in both loss of life from Kawasaki Disease and in the rate of heart damage in children over the course of this fabulous partnership programme.

You can read more about this partnership on the Societi website [here](#).





Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



Our Activities -
Clinical Research



**Our Activities -
Clinical Supervision**

Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Clinical Supervision

Activities around clinical supervision

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Engaging with healthcare providers

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

During 2021 we enjoyed a continued increase in reach and communications with thousands of healthcare providers on Twitter, Facebook, Instagram and LinkedIn – promoting key awareness messages and other important information.

Occasions marked on social media in the period include International Nurses Day, Mental Health Awareness Week, International Clinical Trials Day and World Health Day.





**Annual
Report**



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



Our Activities -
Clinical Research



**Our Activities -
Clinical Supervision**

Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Clinical Supervision

Activities around clinical supervision

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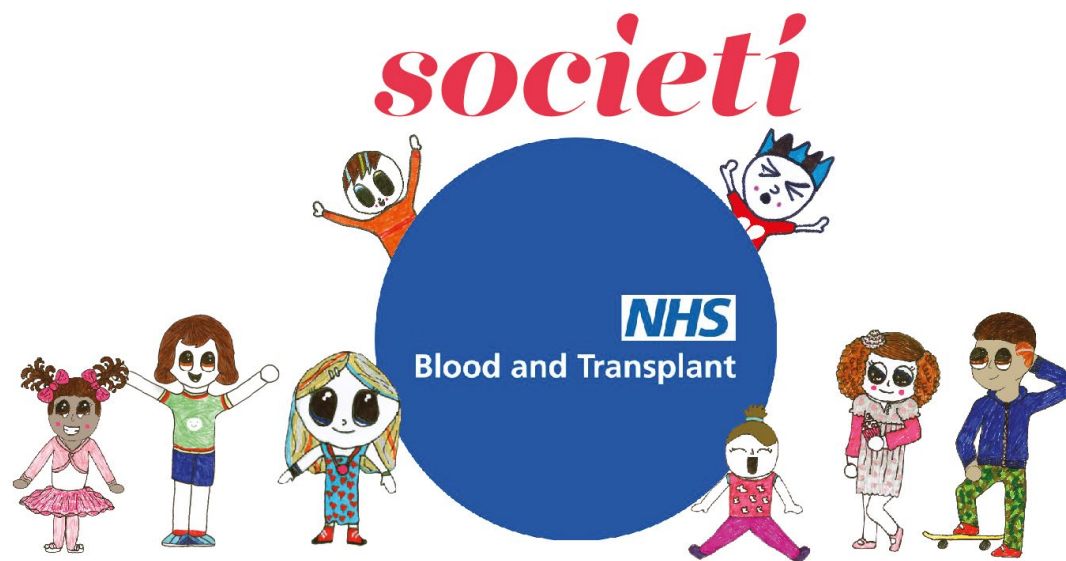
Working with NHSBT

Societi were excited to work in partnership with NHS Blood and Transplant (NHSBT) to raise the profile of blood plasma donations for lifesaving immunoglobulin medicines for people who depend on these treatments – such as children affected by Kawasaki Disease.

Immunoglobulin is extremely important in the treatment of Kawasaki Disease – it is a very special lifesaving medicine made from the antibodies in plasma donations. Antibodies are made by the immune system to fight bacteria, viruses and toxins.

There is a global supply shortage of immunoglobins due to rising demand. By re-starting plasma donation in England, it will strengthen the supply chain – something Societi Foundation is extremely passionate about supporting.

Working alongside NHSBT also gave us the chance to raise awareness and improve knowledge around Kawasaki Disease with NHSBT colleagues.





**Annual
Report**



**Independent
Examiner's Report**

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



Our Activities -
Clinical Research



**Our Activities -
Clinical Supervision**

Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Clinical Supervision

Activities around clinical supervision

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Updating and reviewing our clinicians information

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.

Learning information and resources for clinicians

A UK Strategy for Kawasaki Disease

In 2016 Societi Foundation led the development of the first ever UK Strategy for Kawasaki Disease. 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 in the UK. [...]

Kawasaki Disease - Presenting the facts and dispelling myths An interview with Professor Robert Tulloh

Kawasaki Disease - What everyone needs to know! An interview with Dr Damian Roland

Clinician's Information Poster Clinician's Information Poster

[More resources and downloads for clinicians »](#)

Kawasaki Disease Research

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

August 2018
Kawasaki Disease is an increasingly common vasculitis with risk of coronary artery aneurysms. The last UK survey was in 1990. Current epidemiology, treatment patterns and complication rates are unknown. The aim of this study, undertaken across the UK and Ireland, was to address this knowledge gap.

Kawasaki disease: New info to enhance our index of suspicion

May 2018
Every clinician needs a high index of suspicion. This paper contains new information to enhance it.

How to spot zebras - Kawasaki Disease

May 2018
'When you hear hoofbeats, think of horses not zebras' - the old adage is well-known to GPs but what should you do when faced with a zebra, not a horse?

[More research articles and links for clinicians »](#)

Kawasaki Disease Management

Lifetime cardiovascular management of patients with previous Kawasaki Disease

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

Understanding some of the possible longer term issues

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

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

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

[More resources about Kawasaki Disease Management »](#)



**Annual
Report**



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



Our Activities -
Clinical Research



**Our Activities -
Clinical Supervision**

Our Activities - Support
for UK Families



Financial Review



Structure, Governance
& Management



Clinical Supervision

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:

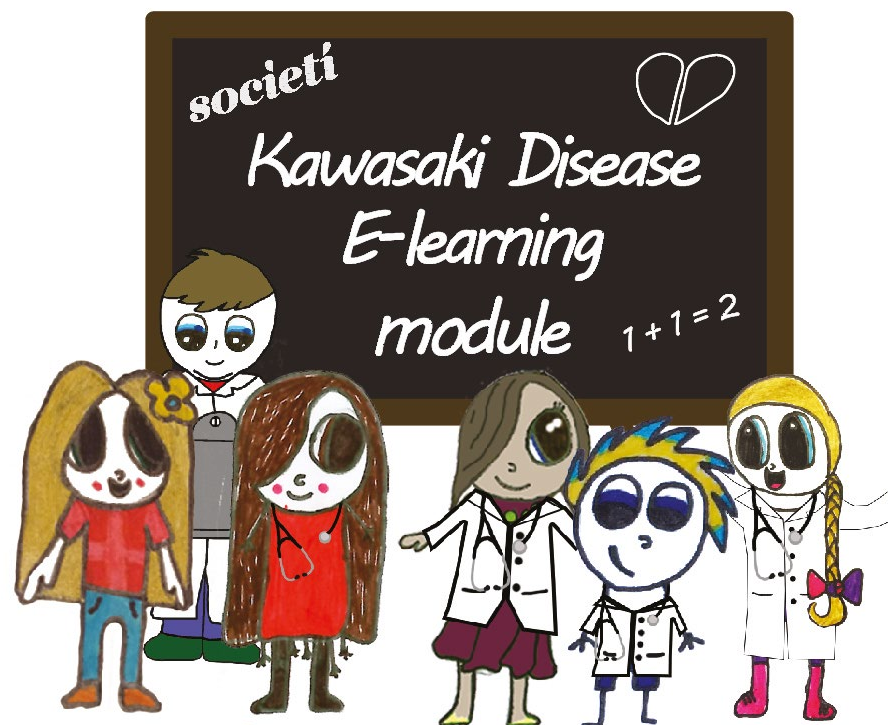


Renewing our e-learning module with RCGP

In 2020 Societi partnered with the Royal College of General Practitioners (RCGP) - the professional body for UK GPs to develop and release a Kawasaki Disease e-learning module.

Development and initial hosting of the course, which was made available to 100,000 GPs within the UK, was funded with generous donations from Veswas Ltd and Alsford Timber.

In 2021, after reviewing an encouraging statistics report on access and use of the module from RCGP, Societi made the decision to renew the course hosting to keep it available on the RCGP learning platform. Societi funded renewal of the hosting with another very generous donation from Virtual Runner after we were nominated by a supporter to receive a proportion of race entry fees for a race held in January 2021.





Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



**Our Activities - Support
for UK Families**

Financial Review



Structure, Governance
& Management



Support for UK families

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:



Launching My Societi

On Kawasaki Disease Awareness Day in January 2021, Societi launched [My Societi](#), a children and young people's information portal which was designed by young people for young people affected by Kawasaki Disease.

Much collaboration and partnership contributed to the creation of the portal and our grateful thanks go out to all of our partners, especially the young people and Societi supporters whose contribution to the portal was so valuable.

The project, funded by a grant from The Foyle Foundation, has been a huge success and we are very proud of the resulting resource that will provide essential and trustworthy information to young people, tailored to their specific needs.

The portal will continue to be reviewed and updated with new and relevant information and resources for young people.





**Annual
Report**



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



**Our Activities - Support
for UK Families**

Financial Review



Structure, Governance
& Management



Support for UK families

Activities around support for UK families

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Sharing family stories and support for families

Sharing family stories is an extremely powerful way to help others going through similar experiences of a Kawasaki Disease diagnosis and to raise awareness of Kawasaki Disease.

Work began during 2020 to engage with supporters who wanted to share their family stories to help others. The family stories were released and shared across our social media throughout September 2021 in the run up to World Heart Day. They are now available to all families using our website.

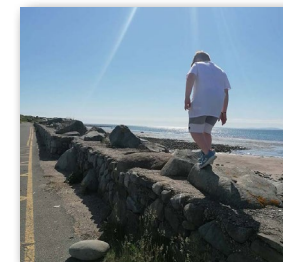
It is our hoped that these stories will help affected families, grow understanding, awareness and knowledge about Kawasaki Disease and protect the tiny hearts of the future.



Aileen's Story



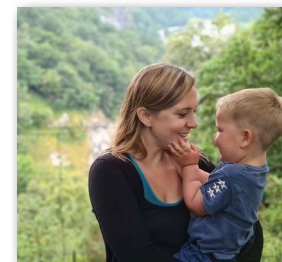
Ali's Story



Laura's Story



Loren's Story



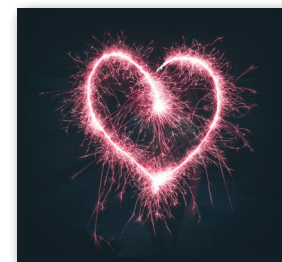
Michaela's Story



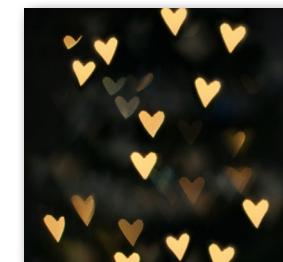
Michelle's Story



Sarah's Story



Lorna's Story



Heather's Story



Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



**Our Activities - Support
for UK Families**

Financial Review



Structure, Governance
& Management



Support for UK families

Activities around support for UK families

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Release of Societi podcasts

Societi worked with the fantastic experts on our Scientific Advisory Board, to record and release a series of Kawasaki Disease podcasts.

Huge thanks go to the amazing doctors who gave their precious time to help create these informative podcasts, which are extremely useful to families and clinicians alike.

The podcast series includes:

Kawasaki Disease - “Presenting the facts and dispelling myths” with Professor Robert Tulloh

Kawasaki Disease - “What everyone needs to know” with Professor Damian Roland

Kawasaki Disease - “The latest research” with Professor Despina Eleftheriou

Kawasaki Disease - “Protecting tiny hearts into the future” with Dr Tom Johnson

Transcript of the podcasts are also available on our website [here](#).





Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



**Our Activities - Support
for UK Families**

Financial Review



Structure, Governance
& Management



Support for UK families

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:



Updating and promoting our online and downloadable 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 and 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.

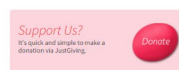
Feedback received from supporters suggests that our resources are invaluable tools for those affected by Kawasaki Disease and their families.

Visit our website [here](https://societi.org.uk).



Kawasaki Disease Symptoms

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





Annual
Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



**Our Activities - Support
for UK Families**

Financial Review



Structure, Governance
& Management



Support for UK families

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:



Kawasaki Disease and Covid-19

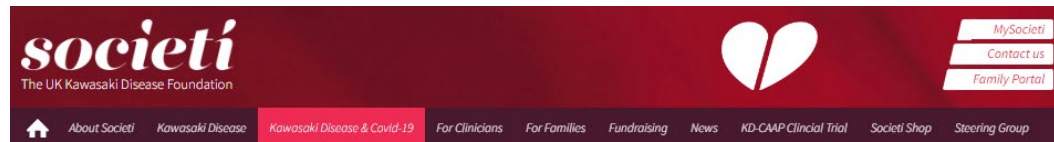
Covid-19 continued to have an impact on our day to day lives during 2021. Understandably, parents of children affected by Kawasaki Disease continued to have worries and a lot of questions about the issues brought about by the pandemic.

Societi continued to work hard to provide up to date information and give answers wherever possible to the questions asked by our supporters.

Consulting with our Scientific Advisory Board (SAB), a series of detailed statements about Kawasaki Disease and Covid-19 were constantly reviewed, updated and promoted throughout the year.

During 2021, Societi received an overwhelming amount of requests for advice and information about Covid-19 vaccines for children affected by Kawasaki Disease. In response, Societi, along with incredible support from our SAB, published a new statement on children, young people and vaccines for Covid-19.

You can visit our Kawasaki Disease and Covid-19 web pages [here](#).



Societi Foundation statement on children, young people and vaccines for Covid-19

Published on 5 October 2021 – updated 21 February 2022

The advice for Covid-19 vaccination of children and young people is constantly being updated as the Joint Committee on Vaccines and Immunisation (JCVI) assesses the health benefits and risks for our children with careful scrutiny.

When the vaccine roll out first started almost a year ago, this was for adults only because the vaccines had not yet been tested for use by children and young people. Since then, research on the vaccine into its effectiveness and safety for use in children has been done, showing high levels of safety. Around the world, children and young people are being vaccinated in their millions. Careful monitoring of vaccines in all age groups continues to show high levels of effectiveness and safety compared to the risk of Covid-19, including in children.

Different ways Covid-19 is affecting children and young people

The risk of serious illness from Covid-19 in children is very low, although there will be a very small number of children who become seriously ill. One of the reasons the vaccine is being offered is to protect children from this very low risk, but also to protect them from getting unwell and having to miss even more of their school education and social activities than they already have.

Vaccination does more than prevent serious infection

The decision has been made by assessing the balance of medical benefits – reducing even further the risk of children being seriously ill. But it's also taken into account the education benefits, social, emotional and overall wellbeing benefits too. Preventing Covid-19 infection and illness means we can try to make sure children and young people aren't affected further by missed school and college, missed social opportunities with their friends and missed activities. Immunising children helps stop the wider spread of COVID in the community, protecting older people such as grandparents and other vulnerable people. The decision to recommend vaccination has been made having compared the impact of these things with the rare potential side effects of Covid-19 vaccination.

We've provided some links below to help you easily access the most up to date information about vaccination of children and young people.

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Annual Report



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



**Our Activities - Support
for UK Families**

Financial Review



Structure, Governance
& Management



Support for UK families

Activities around support for UK families

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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.

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.



KSSG homepage

About us

Events and Useful Links

Contact us

What is Kawasaki Disease?

Kawasaki Disease is an acute illness usually seen in children, most commonly under 8 years of age. It is an inflammatory process that affects almost every system in the body.

Dr Tomisaku Kawasaki of Tokyo, Japan, first described the signs (what we can see) and the symptoms (what the child feels) associated with Kawasaki Disease in 1967. Since then it has been seen in virtually every country in the world.

Many parents find it difficult that there is no diagnostic test for Kawasaki Disease. The diagnosis is based on the following criteria:

Temperature of 5 days or more plus 2 (or more) of the following:

- Red eyes (not sticky)
- Sore mouth, cracked red lips, red tongue (often strawberry like)
- Skin rash
- Swollen glands in the neck (or sometimes stomach)
- Changes to the fingers and toes often with redness

Though not a symptom for the purposes of a timely diagnosis during the acute stage of Kawasaki Disease, peeling of the skin may occur between 14 to 21 days after the start of the fever. This only affects about half of the children who have Kawasaki Disease and parents may notice this in their children later. It may also be noticed in children where a diagnosis has only been able to be made later.

Most of these symptoms occur in the first few days of the illness, although they may not all be present initially. There are also other typical features we see, which are those of irritability, loss of appetite, moodiness, diarrhoea, tummy ache, vomiting and jaundice.



societì
Societi website »

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Back to the main Societi Foundation
website, the UK Foundation for Kawasaki
Disease



Get in touch

National Help Line: 02476 612178

Helpline Email:
helpline@kssg.org.uk

General Enquiries Email:
enquiries@kssg.org.uk

KSSG Fact Sheet

Download the KSSG fact sheet here

Kawasaki Disease Fact sheet

Societi Foundation
Annual Report and Accounts
January 2021 - December 2021



**Annual
Report**



Independent
Examiner's Report

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review

Structure, Governance
& Management



Financial Review

1

2

Financial position

At the period end, the charity had total reserves of £123,247 (2020: £44,785) composed of unrestricted funds of £103,247 (2020: £36,477) and restricted funds of £20,000 (2020: £8,308).

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 undertaken by Societi for our beneficiaries.

Following the impact of the COVID-19 pandemic on the charitable sector and the potential cost of living impact on donors, the charity has factored this into determining the desired level of reserves alongside its growth aspirations.

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 £103,247 which included functional fixed assets of £6,340. The 'free reserves' available to the charity was £96,907 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.

As a newly established organisation, at the time of the development of this policy we have no paid staff so continuity planning for such costs, in challenging circumstances are not allowed for in the reserves. However it is foreseen that with growth, this position will change and our reserves policy will need to change to reflect this. Similarly, only minimal costs are incurred by Societi currently in respect of its organisational overheads and as we grow, Trustees recognise that these will increase and again, our reserves position will need to be amended to reflect the need to ensure operational continuity.

Trustees have considered operational costs and the considerable challenges of circumstances such as Covid-19, when setting the reserves policy, organisational sustainability, current and planned commitments and 'seed-corn' funding requirements which may be needed.



**Annual
Report**



Independent
Examiner's Report

About Kawasaki Disease



About Societì Foundation



Our Activities -
Awareness Raising



Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review

Structure, Governance
& Management



Financial Review

1 2

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

1. the low turnover of the organisation – from which a modest sum must be identified as reserves to protect the sustainable operation of the organisation, and this translates as a higher relative percentage as presently, income is low.
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. experience of establishing and growing Societì as a new organisation – Trustees have a proven track record of delivering the work of the charity within a very small budget having started the charity without grants or access to donations/fundraising.

Management of Reserves

Any reserves held in excess of the target percentage will be reviewed by Societì 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 Societì'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 Societì'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 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.



Structure, governance and management

1

2

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.

Societi Foundation Annual Report and Accounts January 2021 - December 2021



**Annual
Report**



*Independent
Examiner's Report*

About Kawasaki Disease



About Societi Foundation



Our Activities -
Awareness Raising



Our Activities -
Clinical Research



Our Activities -
Clinical Supervision



Our Activities - Support
for UK Families



Financial Review



**Structure, Governance
& Management**

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

Reference and administrative details

Registered Charity number

1173755

Principal address

Victoria Court
Holme Lane
Winthorpe
Newark
Nottinghamshire
NG24 2NU

Trustees

Professor R Tulloh
R E A Greenwood
R D Greenwood
G Higgins
Professor P Brogan

Independent Examiner

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

Approved by order of the board of trustees
on 14 September 2022 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



Annual
Report



**Independent
Examiner's Report**

**Independent
examiner's statement**

Statement of financial
activities



Balance sheet



Notes to the financial
statements



Detailed statement of
financial activities



Independent Examiner's Report

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 2021.

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: 10 October 2022



Annual
Report



**Independent
Examiner's Report**

Independent examiner's
statement



**Statement of financial
activities**

Balance sheet



Notes to the financial
statements



Detailed statement of
financial activities



Independent Examiner's Report

Statement of financial activities for the Year Ended 31 December 2021

	Notes	Unrestricted funds £	Restricted funds £	Year ended 31.12.21 Total funds £	Period 1.7.20 to 31.12.20 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies		85,777	97,188	182,965	30,611
Other trading activities	2	2,242	-	2,242	653
Other income		334	9,900	10,234	3,604
Total		<u>88,353</u>	<u>107,088</u>	<u>195,441</u>	<u>34,868</u>
EXPENDITURE ON					
Raising funds		33,614	-	33,614	12,250
Charitable activities					
Kawasaki Disease awareness		73,465	9,900	83,365	31,334
Total		<u>107,079</u>	<u>9,900</u>	<u>116,979</u>	<u>43,584</u>
NET INCOME / (EXPENDITURE)		(18,726)	97,188	78,462	(8,716)
Transfers between funds	12	<u>85,496</u>	<u>(85,496)</u>	<u>-</u>	<u>-</u>
Net movement in funds		66,770	11,692	78,462	(8,716)
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>36,477</u>	<u>8,308</u>	<u>44,785</u>	<u>53,501</u>
TOTAL FUNDS CARRIED FORWARD		<u>103,247</u>	<u>20,000</u>	<u>123,247</u>	<u>44,785</u>

Societì Foundation
Annual Report and Accounts
January 2021 - December 2021



Annual
Report



**Independent
Examiner's Report**

Independent examiner's
statement



Statement of financial
activities



Balance sheet

Notes to the financial
statements



Detailed statement of
financial activities

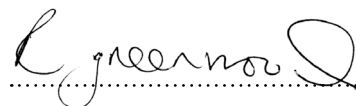


Balance sheet 31 Dec 2021

	Notes	Unrestricted funds £	Restricted funds £	2021 Total funds £	2020 Total Funds £
FIXED ASSETS					
Intangible assets	7	5,980	-	5,980	4,046
Tangible assets	8	360	-	360	595
		<u>6,340</u>	<u>-</u>	<u>6,340</u>	<u>4,641</u>
CURRENT ASSETS					
Stocks	9	1,388	-	1,388	3,296
Debtors	10	78,262	57,813	136,075	168
Cash at bank		23,049	20,000	43,049	48,630
		<u>102,699</u>	<u>77,813</u>	<u>180,512</u>	<u>52,094</u>
CREDITORS					
Amounts falling due within one year	11	(5,792)	(57,813)	(63,605)	(11,950)
NET CURRENT ASSETS		<u>96,907</u>	<u>20,000</u>	<u>116,907</u>	<u>40,144</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>103,247</u>	<u>20,000</u>	<u>123,247</u>	<u>44,785</u>
NET ASSETS		<u>103,247</u>	<u>20,000</u>	<u>123,247</u>	<u>44,785</u>
FUNDS	12				
Unrestricted funds				103,247	36,477
Restricted funds				20,000	8,308
TOTAL FUNDS				<u>123,247</u>	<u>44,785</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 14 September 2022 and were signed on its behalf by:

R E A Greenwood – Trustee


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Annual
Report



**Independent
Examiner's Report**

Independent examiner's
statement



Statement of financial
activities



Balance sheet



**Notes to the financial
statements**

Detailed statement of
financial activities



Independent Examiner's Report



Notes to the Financial Statement for the Year Ended 31 Dec 2021

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 statement.



Independent Examiner's Report



Notes to the Financial Statement - continued for the Year Ended 31 Dec 2021

2. Other trading activities

	Year Ended 31.12.21 £	Period 1.7.20 to 31.12.20 £
Merchandise income	2,242	653
	Governance costs £	Totals £

Kawasaki Disease Awareness	16,342	1,200	17,542
Support costs, included in the above, are as follows:			

3. Support costs

	Year Ended 31.12.21 £ Kawasaki Disease awareness	Period 1.7.20 to 31.12.20 Total activities £
Postage and stationary	526	1,074
Insurance	186	93
Accountancy	562	444
Office costs	5,074	2,012
Legal and professional services	-	900
Administrative staff costs	6,595	5,886
Amortisation of intangible fixed assets	3,164	1,026
Depreciation of tangible fixed assets	235	118
Independent examination	1,200	900
	<u>17,542</u>	<u>12,453</u>
	£	£
Independent examination fee	900	300

4. Independent examination

5. Trustees' remuneration and benefits

There were no trustees' remuneration or other benefits for the year ended 31 December 2021 nor for the period ended 31 December 2020. **Trustees' expenses** - There were no trustees' expenses paid for the period ended 31 December 2021 nor for the period ended 31 December 2020.

6. Staff costs

	Year ended 31.12.21 £	Period 1.7.20 to 31.12.20 £
Wages and salaries	54,600	23,166
Social security costs	16	-
Other pension costs	1,264	210
	<u>55,880</u>	<u>23,376</u>

No employees received employee benefits over £60,000
The average monthly number of employees during the year was as follows:

	Year ended 31.12.21	Period 1.7.20 to 31.12.20
Administration	2	2
No employees received emoluments in excess of £60,000.		



Annual
Report



**Independent
Examiner's Report**

Independent examiner's
statement



Statement of financial
activities



Balance sheet



**Notes to the financial
statements**

Detailed statement of
financial activities



Independent Examiner's Report



Notes to the Financial Statement - continued for the Year Ended 31 Dec 2021

7. Intangible fixed assets

Cost

At 1 January 2021
Additions
At 31 December 2021

Amortisation

At 1 January 2021
Charge for year
At 31 December 2021

Net book value

At 31 December 2021
At 31 December 2020

8. Tangible fixed assets

Cost

At 1 January 2021 and 31 December 2021

Depreciation

At 1 January 2021
Charge for the year
At 31 December 2021

Net book value

At 31 December 2021
At 31 December 2020

9. Stocks

Stocks

10. Debtors: amounts falling due within one year

Payments and accrued income

11. Creditors: amounts falling due within one year

Taxation and social security
Other creditors

Website £

6,843
5,098
11,932

2,788
3,164
5,952

5,980
4,046

Computer equipment £

713

118
235
353

360
595

2021 £
1,388

2021 £
136,075

2021 £
847
62,758
63,605

2020 £
3,296

2020 £
168

2020 £
1,700
10,250
11,950



Annual
Report



**Independent
Examiner's Report**

Independent examiner's
statement



Statement of financial
activities



Balance sheet



**Notes to the financial
statements**

Detailed statement of
financial activities



Independent Examiner's Report



Notes to the Financial Statement - continued for the Year Ended 31 Dec 2021

12. Movement in funds

Unrestricted funds

	At 1.1.21 £	Net movement in funds £	Transfers between funds £	At 31.12.21 £
General fund	36,477	(18,726)	85,496	103,247

Restricted funds

Young Person's Portal	8,308	-	8,308	-
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Randal Charitable Foundation	-	20,000	-	20,000
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KD-CAAP Trial	-	77,188	(77,188)	-
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	8,308	97,188	(85,496)	20,000
--	-------	--------	----------	--------

TOTAL FUNDS	44,785	78,462	-	123,247
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Net movement in funds, included in the above are as follows:

Unrestricted funds

General fund		88,353	(107,079)	(18,726)
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Restricted funds

Lanarca fund		9,900	(9,900)	-
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Randal Charitable Foundation		20,000	-	20,000
------------------------------	--	--------	---	--------

KD-CAAP Trial		77,188	-	77,188
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		107,188	(9,900)	97,188
--	--	---------	---------	--------

TOTAL FUNDS		195,441	(116,979)	78,462
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Incoming resources £

Resources expended

Movement in funds



Independent Examiner's Report



Notes to the Financial Statement - continued for the Year Ended 31 Dec 2021

Comparatives for movement in funds

Unrestricted funds

General fund

53,501

(17,024)

36,477

Restricted funds

Young Person's Portal

-

8,308

8,308

TOTAL FUNDS

53,501

(8,716)

44,785

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

Unrestricted funds

Incoming resources £

Resources expended £

Movement in funds £

General fund

22,468

(39,492)

(17,024)

Restricted funds

Lanarca fund

3,300

(3,300)

-

Young Person's Portal

9,100

(792)

8,308

TOTAL FUNDS

34,868

(43,584)

(8,716)

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 - The fund arose from a grant made to Societi to focus on building a strategic partnership with children's hospitals in the UK promoting awareness campaigns and engagement initiatives for Kawasaki Disease.

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

Transfer between funds

KD-CAAP Trial - The project requires claims to be made following the expenditure on the project with claims being made in arrears. During the period claims were made for prior year expenditure which was funded out of general funds. A transfer of £ 77,188 was therefore required to recognise the reimbursement to the general fund

Young Person's Portal Fund - The project was completed in the period and there were no ongoing restrictions over the fixed asset so it was transferred to the general fund.

13. Related party disclosures

During the period, the Charity received gifts in kind of £35,256 (2020: £3,756 from Lanarca Limited, a company in which trustees R E A Greenwood and R D Greenwood are directors. Additionally salaries for the period of £Nil (2020: £1,868) have been recharged from Lanarca Limited at cost and with no uplift for the secondment of a Design and Research staff member



Annual
Report



**Independent
Examiner's Report**

Independent examiner's
statement



Statement of financial
activities



Balance sheet



Notes to the financial
statements



**Detailed statement of
financial activities**

Independent Examiner's Report

Detailed Statement of financial activities for the Year Ended 31 Dec 2021

	Year Ended 31.12.21 £	Period 1.7.20 to 31.12.20 £		Year Ended 31.12.21 £	Period 1.7.20 to 31.12.20 £
INCOME AND ENDOWMENTS			Support costs		
Donations and legacies			Other		
Donations	48,232	17,755	Postage and stationery	526	1,074
Gift aid	2,289	-	Insurance	186	93
Grants	97,188	9,100	Accountancy	562	444
Gifts in kind	35,256	3,756	Office costs	5,074	2,012
	182,965	30,611	Legal and professional fees	-	900
Other Trading Activities			Administrative staff costs	6,595	5,886
Merchandise income	2,242	653	Computer software	3,164	1,026
Other income			Computer equipment	235	118
Other income	10,234	3,604		16,342	11,553
Total incoming resources	195,441	34,868	Governance costs		
EXPENDITURE			Independent Examination	1,200	900
Raising donations and legacies					
Wages	27,300	11,583	Total resources expended	116,979	43,584
Pensions	632	105			
Fundraising costs	84	-	Net (expenditure)/income		
	28,016	11,688		78,462	(8,716)
Other trading activities					
Opening stock	3,296	2,445			
Purchases	3,690	1,416			
Closing stock	(1,388)	(3,296)			
	5,598	562			
Charitable activities					
Wages	27,300	11,583			
Social security	16	-			
Pensions	632	105			
Subscriptions	295	185			
Advertising	168	162			
Resource films	5,900	900			
Donated services	7,512	3,756			
Recharged staff costs	24,000	1,868			
Raising awareness costs	-	322			
	65,823	18,881			