



# *Societi Foundation Priorities for Partnership*

*July 2021*

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



Persistent fever



Cracked lips/  
'strawberry' tongue



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands

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Kawasaki Disease is the #1 cause of acquired heart disease in UK children

Foreword

A word from our Board of Trustees

Over a career spanning more than 30 years in paediatric cardiology, I have specialised in treating children with Kawasaki Disease. This has also been my clinical research focus, finding answers for clinicians and parents about this hitherto little known, but important disease. I've seen the devastation it can cause for children and their families – all too often because of delayed diagnosis and treatment. Devastation which is exacerbated because we still know far too little about Kawasaki Disease and too few doctors can recognise it.

In 2015, I was contacted by Rachael McCormack, parent of a child who had been affected by Kawasaki Disease. Rachael described her aim: to establish a charity to get Kawasaki Disease known. Working together with fellow clinicians also expert in this field, Rachael led the establishment of a Scientific Advisory Board which I joined, to guide the focus of our charity. We published our first UK strategy for Kawasaki Disease and soon after, I joined the newly established Board of Trustees.

It was clear to me that she was determined to make a difference – yet I was unprepared for the pace and scale of change she has achieved. She has done this by investing – in Societi Foundation's assets, investing in relationships with our partners and investing in the connections with families who have turned to our charity for support.

In just five years we've made remarkable progress and frankly, transformed the landscape around Kawasaki Disease. We know there's much, much more to do – and we'll need the support of many powerful partners to achieve all our goals – especially people who want to make a difference. But I feel confident that the next five years, under Rachael's leadership will create even more impact – protect thousands more children from the severe consequences of Kawasaki Disease and ultimately, save lives being taken by this sinister disease.

Robert M L Tullloh

Professor Robert Tullloh, Societi Trustee

A word from our Founder

We've had a remarkable journey since December 2015, when I began Societi and it's my privilege to share with you some highlights from the achievements of our young organisation – Societi, the UK Foundation for Kawasaki Disease. You'll find in the pages which follow a host of key milestones already achieved – in communication, co-ordination, clinical developments and in the growth of a UK-wide conversation on this previously little spoken of disease.

As Founder, I established Societi to bring a voice to Kawasaki Disease and the thousands of children it has silently affected in the UK. It was clear that my expectation for change and action, as a parent with experience of Kawasaki Disease, would not be met without a catalyst for change. And so Societi began!

Now in our fifth year, Societi has made great inroads into changing the landscape of Kawasaki Disease – however, there is much more that needs to be done. We are actively seeking urgently needed investment so we can grow and accelerate our impact. For too long, the treatment and care of children in the UK has been hampered by gaps in knowledge and understanding, limited investment, poor levels of awareness of Kawasaki Disease and limited clinical expertise, except in just a few locations.

We aim to address this. 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.

Rachael McCormack

Rachael McCormack, Founder

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Kawasaki Disease – key facts

Where we are today

28%

of affected children with heart damage

39%

of infants develop coronary artery aneurysms

8

8 day average treatment time  
Too slow!

Inconsistent care for children

Partial UK coordination knowledge pockets, poor general awareness

Where we need to be

4%

(or less) of affected children with heart damage

dramatic reduction in infants developing coronary artery aneurysms

5

5 day average treatment time

Consistent care for children

UK-wide coordination high levels of awareness, strong partnerships

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

Across the globe, incidence of **Kawasaki Disease** has doubled in the last decade. In the UK, hospital admissions have increased **FOURFOLD** in the same period

Awareness of **Kawasaki Disease** is low

39% of treated infants develop coronary artery aneurysms

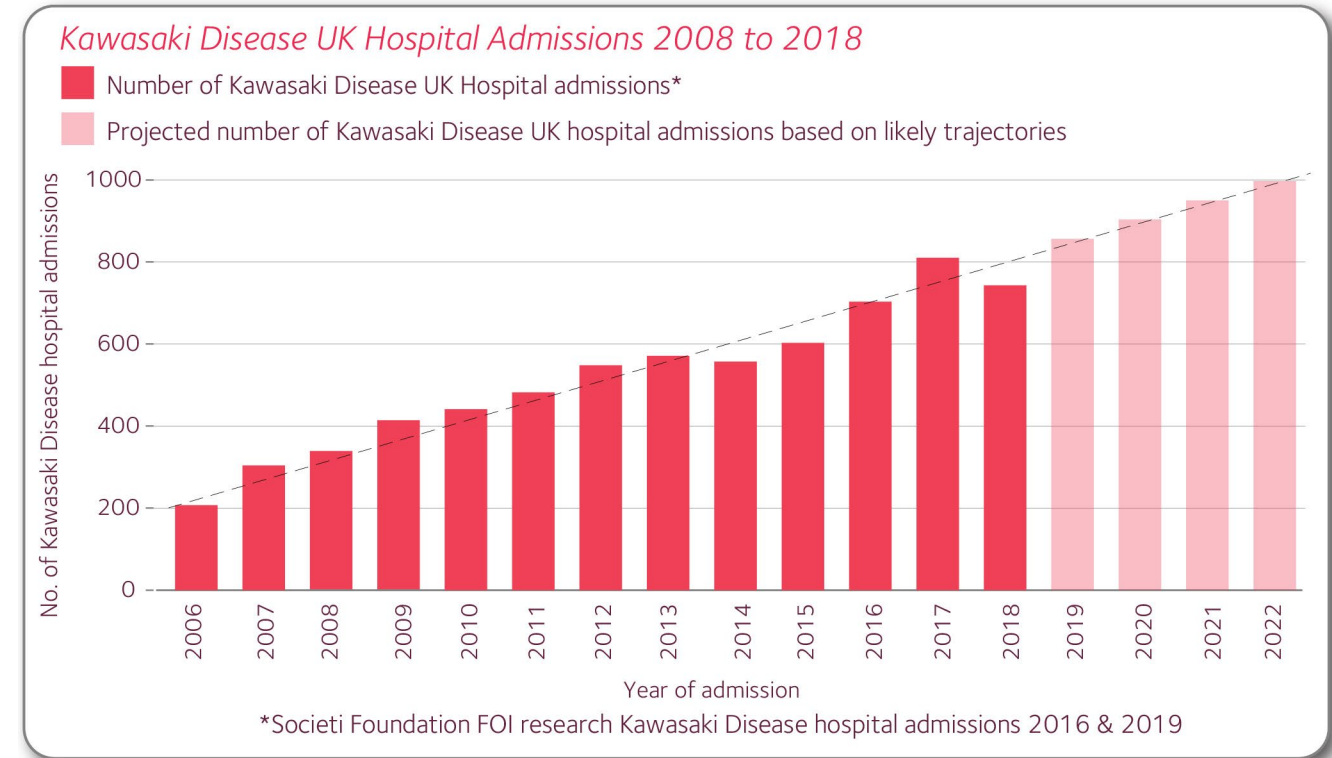
28% of all treated children will suffer some heart damage

19% of treated children overall develop coronary artery aneurysms

More UK children today are diagnosed with **Kawasaki Disease** than some forms of bacterial meningitis

Delayed treatment = increased heart damage

An estimated **20,000** children and young people in the UK are affected by **Kawasaki Disease** today





What difference can Societi make?

Our aims

We are an influencing and policy shaping organisation, always working through partnerships to achieve our aims.

Societi has four aims:



1. Awareness raising - a voice for Kawasaki Disease



2. Clinical research - sharing knowledge, influencing funders and enabling co-ordination



3. Clinical supervision - shaping new care protocols and health policy



4. Support for UK families - enabling sustained focus on family support

Responding to need

Further on in this document, you will find information on Societi's priorities and key activities for which we will need to find new funding sources, if we are to succeed. These priorities are a direct response to need - informed by evidence through research and which we believe will positively affect outcomes by reducing life long heart damage in children affected by Kawasaki Disease.

Research on which we draw includes a milestone study from the British Paediatric Surveillance Unit (BPSU), *Kawasaki disease: a prospective population survey in the UK and Ireland from 2013 to 2015* and two Freedom of Information (FOI) studies in 2016 and 2018 obtaining data on Kawasaki Disease hospital admissions from every NHS trust and health board in the UK.

Key findings from these studies which we believe we must address to bring about change include:



Early treatment is critical



Kawasaki Disease is rapidly on the rise in the UK



19% of children will develop coronary artery aneurysms



28% of children will suffer heart damage



39% of infants will develop coronary artery aneurysms



47% of children will not show all symptoms



There is significant over representation of Kawasaki Disease in those of ethnic backgrounds



Kawasaki Disease is seen slightly more often in boys than girls



Higher incidence in children from rural areas



Cases of Kawasaki Disease are broadly constant all year round



1 in 5 affected by Kawasaki Disease are over 5 yrs old



One third of patients are younger than 1 year old

Action will change outcomes

Kawasaki Disease is a serious illness. In 1,000 children admitted to hospital with Kawasaki Disease every year, around 280 will suffer some heart damage. Around 190 children every year will suffer lasting coronary artery aneurysms (CAA), putting them at heightened risk of a major cardiac event and sudden death in later life. Up to 3% of children, every year, may die from acute Kawasaki Disease.

Kawasaki Disease hospital admissions in the UK are increasing year on year. With a 3 - 4 fold increase over the last decade, this will only serve to push these numbers higher.

Early diagnosis and treatment greatly reduces the risk of heart damage in children.

Using data taken directly from the BPSU study, the graph opposite shows the extent to which treatment times can affect outcomes for children. It illustrates the relationship between the number of days to treatment from illness onset and the rate of CAA. The treatment referred to in the graph is aspirin and intravenous immunoglobulin (IVIG).

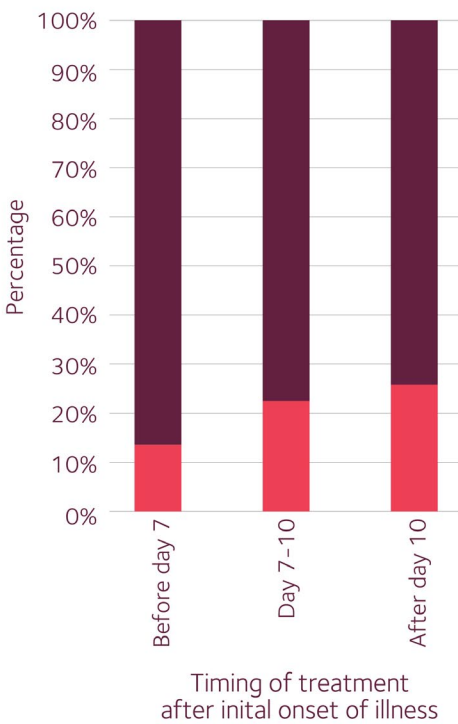
25.8% of children treated with IVIG after day 10 developed life threatening coronary artery aneurysms. The graph also shows that when children were treated before day 7 the rate of CAA fell to 13.6%. Currently the rate for all children suffering CAA is 19% overall - equating to 190 children every year. If all children received a timely diagnosis and treatment this number could be reduced to around 136 - perhaps less, **saving c. 60 children every year from a lifetime of heart damage.**

The figures in the chart above only account for children suffering clinically defined coronary artery aneurysms. 28% of all children (up to 280 children every year) affected by Kawasaki Disease will suffer some form of heart damage.

In 2017, a retrospective study of the impact of unrecognised Kawasaki Disease, coronary aneurysm and ectasia in adults under 50 years old found almost 4% of patients likely to have had a previous history of unrecognised Kawasaki Disease. In light of the findings from the study, the group now advocate an increased awareness of Kawasaki Disease and coronary aneurysm/ectasia amongst adult cardiologists.

Association of treatment timing with coronary artery aneurysms (CAA)

Percentage of Kawasaki Disease cases resulting in CAA  
Percentage of Kawasaki Disease cases resulting in no CAA



**There are an estimated 20,000 children, young people and adults living in the UK with the effects of Kawasaki Disease.**

With no registry currently available, there is no accessible, definitive data on these patients and no way to inform them of updates or advances in patient care protocol.

**Therefore there is potential to improve the outcomes and improve lives for many more people with Kawasaki Disease in the UK.**

It is essential that we continue to raise awareness of Kawasaki Disease with the general public as well as with primary care, emergency medicine and paediatric clinicians.

# societì Leadership – driving change

## Our people

### Our core team



**Rachael**, our founder and Trustee, is an energetic and dynamic leadership professional with wide ranging executive experience across public and private sector organisations. She is recognised for a focus on enabling high impact, delivery through partnership, achievement of outcomes and a leadership approach which is collaborative and decisive.



**Lucy** is Societì's Marketing, Media and Digital Lead. A public relations and communications expert, with over 10 years experience in developing effective and innovative communications strategies within the charity sector. She has organised major events and campaigns that have led to significant changes in attitudes, public perception, and awareness.



**Rob**, MA DM FRCPCH Honorary Professor of Congenital Cardiology and pulmonary hypertension, 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 supported Societì before its formal establishment and sits on our Trustee Board, providing clinical oversight for our organisation.



**Claire** has over 20 years experience working to provide comprehensive, technical, graphic and research support across a broad range of disciplines. A valued member of the team, she continues to apply those skills for Societì with her combination of experience and creative flair enabling her to provide high impact and flexible support.

### Our Trustee Board

Our five Trustee Board Members, Rachael McCormack, Prof Rob 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.

**TeamSocietì** TeamSocietì is a simply amazing network of over 2,000 Societì supporters. Every single member of TeamSocietì is dedicated to improving awareness and care for those affected by Kawasaki Disease across the UK and shares the core values of Societì Foundation. Volunteer fundraisers and awareness raisers across the UK help guide, shape and inform our work. TeamSocietì fundraising accounts for 95% of all of Societì Foundation's income. It is vital that we continue to support TeamSocietì and build on their strength, passion, determination and extensive reach to achieve our common goals.

## societì Scientific Advisory Board

Kawasaki Disease has many effects on a child and a multi-disciplinary approach to research/care is needed. Societì is supported by the phenomenal clinical expertise of:

**Prof Despina Eleftheriou**; Great Ormond Street Hospital and Institute of Child Health

**Prof Paul Brogan**; Great Ormond Street Hospital and Institute of Child Health

**Prof Michael Levin**; Imperial College London

**Dr Tom Johnson**; Bristol Heart Institute

**Dr Damian Roland**; University Hospitals, Leicester

**Dr Owen Miller**; Evelina London Children's Hospital

**Dr Filip Kucera**; Great Ormond Street Hospital.

## societì Kawasaki Disease Steering Group

The UK Kawasaki Disease Steering Group comprises national leaders and influencers from key organisations who together act as a catalyst for positive change:

**Societì Foundation** – Chair

**Societì Scientific Advisory Board** – including clinicians from Great Ormond Street, Bristol Heart Institute, University Hospital Leicester, Imperial College London & Evelina London Children's Hospital

**NHS England** – National Clinical Directors – Children, Young People and Transition & Heart Disease

**British Congenital Heart Association** – Representative

**British Heart Foundation** – Chief Executive

**Public Health England** – Medical Director's representative

# societì Delivery through partnerships

## Our partners

### Key partnerships in place

We are not standing still in the face of our challenges. Each week we forge new relationships and partnerships, expand our networks, promote key messages through social media and raise the profile of Kawasaki Disease in all we do. Today, we are;

- PPI lead and partner in a multi-site, pan-European clinical research trial across 15 countries for acute Kawasaki Disease treatment funded by **Conect4Children**. Societì leads work with families and creates patient information and clinical awareness resources
- PPI lead for a national surveillance study for PIMS-TS, led by the **British Paediatric Surveillance Unit** and our work includes promoting this to clinicians and affected families
- working actively with **NHS England and Public Health England** through our UK Steering Group for Kawasaki Disease
- promoting our E-learning module created in partnership with **RCGP** for Kawasaki Disease which is CPD accredited by the **RCPC**

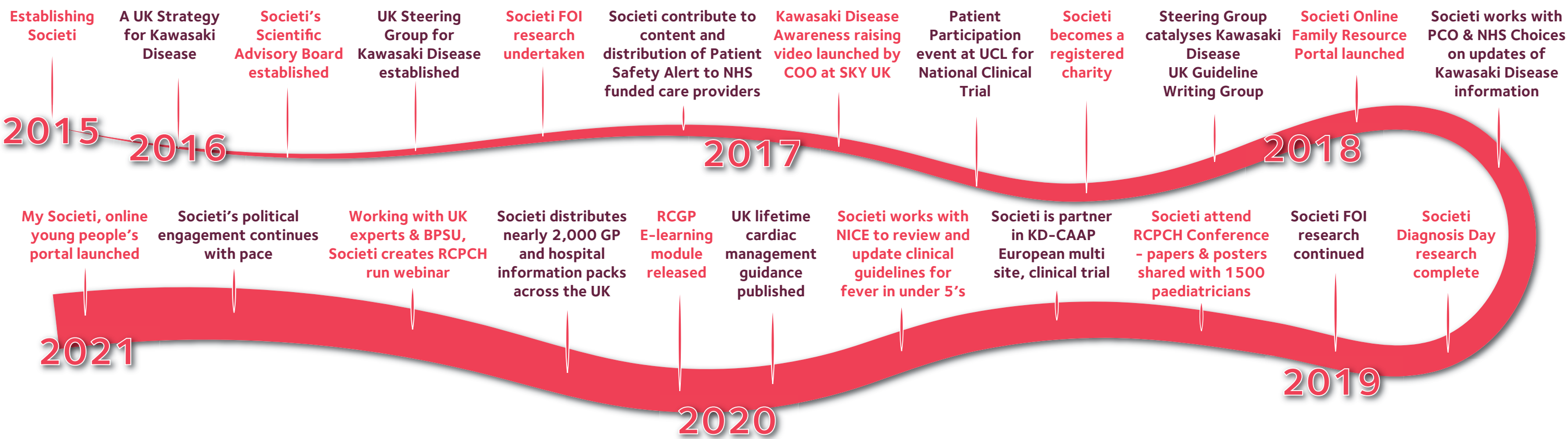
- in dialogue with the **BPSU, PCO and RCPCH** – working together on a range of projects to raise awareness with the medical community
- collaborating with **sister organisations** in Australia, Canada, Italy and Spain. Our organisations have a shared commitment in the fight against Kawasaki Disease across the globe
- working with the **World Heart Federation** through social media to bring global awareness to Kawasaki Disease
- partnering through our Scientific Advisory Board with **Bristol Heart Institute, Great Ormond Street Hospital, Evelina London Children's Hospital** and **St Mary's Hospital London**.
- directly in touch with the offices of dozens of MPs holding meetings and discussions and attending **Westminster** to speak about the need for a patient registry and public investment in awareness raising, to address the increasing incidence of Kawasaki Disease.

## Societì - Creating Impact Through Partnership





Our achievements



Key points along our journey

*Key partnership milestones*

Having worked to establish early partnerships with leading medics and key agencies, we quickly created a UK Strategy for Kawasaki Disease. This has framed our work and focused our energy. Our Achievements Timeline above summarises the many areas in which we have made real progress. Some of these projects are described further here.

*UK Kawasaki Disease Steering Group* – Understanding the key role of a shared conversation across policy makers and funders, Societi brought together this group engaging senior officers from Public Health England, the NHS, the British Heart Foundation and leading clinicians. Together we pursue an agenda to change the UK Kawasaki Disease policy and care.

*New UK medical guidelines* – Societi catalysed and contributed to an Expert Writing Group, which created new whole of life UK Kawasaki Disease clinical guidance. The guidance was published in Dec 2019.

*European clinical trial* – With no major UK based research underway or planned, we brought together leading doctors to identify priority research requirements which would bring greatest benefit to patients. A clinical trial working group, across 3 research centres, led by Great Ormond Street Hospital led to the successful mobilisation of a pan-european clinical trial on acute treatment of Kawasaki Disease. Societi is a partner and PPI lead for the trial, now underway, leading work with families, patient information and clinical awareness resources.

*Creation of Family Resource Portal & 'My Societi' dedicated teen resource*– Societi developed a BMA award winning online Family Resource Portal designed to help and inform parents of children affected by Kawasaki Disease. As well as accurate, up-to-date, clinically backed information, the Portal includes material from partners such as Medicines for Children. 'My Societi', a Young People's portal was published in January 2021 – created by young people for young people. Both portals are easy to use, informative resources readily available to patients and families – when they need it most.

*Political engagement* – Currently there is no public investment at all made to grow awareness of Kawasaki Disease – the single biggest opportunity we have to reduce acquired heart disease in children.

Similarly there is no national database kept of those affected by Kawasaki Disease. We have been working to seek the support of Government on both these issues – so that the ever-growing number of children facing lifelong heart disease can be stemmed, and a registry of all patients can be built and maintained, to aid patient communication, research and grow knowledge.

*Partnerships* – Throughout our journey we have forged critical partnerships, investing in these to advance Kawasaki Disease care including with the RCPCH, RCGP, BPSU, NHS England, Public Health England and the World Heart Federation. Partnerships with donor companies and pro bono supporters have been equally as important.

## Our priorities

*Where we want to be*

In the UK, progress has been hampered by a lack of investment. Many gaps in our understanding of this enigmatic and most serious disease still exist. Whilst there has been a global research effort over many years now, **in the last 35 years there has been no improvement in outcomes for children affected by Kawasaki Disease in the UK** and very little improvement in clinical care.

To achieve change at scale we now need support from an equally ambitious and bold partner who can directly enable a step change with support and investment. Our current partners recognise the serious threat posed by Kawasaki Disease; just as meningitis was recognised (and outcomes transformed) 25+ years ago.

Some forms of bacterial meningitis are less common today than Kawasaki Disease is – and the impact of Kawasaki Disease is just as serious. Yet Kawasaki Disease awareness is at a negligible level presently – we urgently need to change this.

Societì is an ambitious organisation, determined to meet these challenges.

There is much to do.

*Priorities for partnership investment*

We have set out below eight areas – all of which would be accelerated substantially with support and investment. These are:

1. Every doctor to know Kawasaki Disease
2. Strategic partnerships – children's hospitals
3. An engaged adult cardiology community
4. A Registry for Kawasaki Disease
5. UK led research
6. Raising awareness
7. Support for UK families
8. Organisational capacity

Taking each in turn, we have given a brief summary of each area in the pages which follow. Purposely these are not costed at this stage. We'd welcome the opportunity to discuss any of these further, if one or more are of interest.

*1. Every doctor to know Kawasaki Disease*

**Investment to enable over three years = £119,614.**

We have focused our efforts to date on GPs, recognising that most children present to their GP within 2 days of illness. If GPs can recognise and treat patients with Kawasaki Disease as the emergency it is, early treatment will reduce the risk of lifelong heart damage.

We have a Primary Care Resource pack, including our RCPCH endorsed TEMPERS (mnemonic) information leaflet. We have distributed nearly 2,000 packs already and we need all 7,500 GP practices in the UK to receive at least one.

Hospital doctors still routinely fail to recognise Kawasaki Disease and the medical emergency that it presents.

In partnership with RCGP we have developed an E-Learning course for clinicians (diagnosis and acute management) which, is now available to over 100,000 clinicians UK wide.

Additional capacity and investment to engage clinicians (e.g. Primary Care pack for distribution) will enable us to significantly expedite our work in all of the above areas and new areas too.

*2. Strategic partnerships – children's hospitals*

**Investment to enable over three years = £77,880.**

We aim to build strategic partnerships with all major children's hospitals in the UK, and in doing so, grow knowledge which ensures improved care for affected children.

Currently, treatment for acute Kawasaki Disease varies considerably depending on location; our own research with all English NHS Trusts revealed over 40 differing sets of "guidance" in place in England alone. This variation means sub optimal care and care which is often not expert-led.

We need to change this and through

strategic partnerships we can enable consistency of care, knowledge transfer and grow expertise.

We need dedicated internal capacity to achieve development of these partnerships. This is a high priority if we are to expedite change in outcomes.

*3. An engaged adult cardiology community around Kawasaki Disease*

**Investment to enable over three years = £55,380.**

To date, Kawasaki Disease has been invariably viewed by the medical profession as an illness of young children. We need to change that – empowering adult cardiologists to recognise and take ownership of their role to manage the lifetime care of affected patients. This means a transformation in understanding across an entire clinical group.

Increasing numbers of patients with acquired heart disease from Kawasaki Disease are transitioning to the care of adult services where there is significantly less awareness and experience of the condition than in paediatric services.

With an expert writing group, led by the then NHS England Clinical Director for Heart Disease (Prof Huon Gray), we developed innovative new lifecourse cardiac management guidance, published December 2019.

Our aim is that clinical surveillance of patients is transformed, and their emergency management (when facing a major cardiac event) can be prepared for and be expertly delivered. Growing awareness and adoption of guidance, working with cardiologists, now needs core capacity.

We need dedicated capacity which we can commit to working with the UK cardiology community. This clinical leadership is crucial if we are to safeguard those with CAA's who need long term care – as they face much higher, lifelong risks of major cardiac problems.

## 4. A registry for Kawasaki Disease



**Investment to enable over three years = £187,210.**

There is no accessible, definitive data on UK patients affected by Kawasaki Disease.

A Registry presents a significant opportunity for change by demonstrably strengthening both the core academic and patient contexts for Kawasaki Disease – bringing far reaching benefits.

With an estimated 20,000 children, young people and adults living in the UK, a registry has the potential to further research and to protect the health and improve the lives of many.

We have been highlighting this need to stakeholders and within UK Parliament since 2016. Whilst there is complete agreement on its value with stakeholders, no agency has been able to identify resource to enable this.

A Registry is urgently needed to underpin future research, grow awareness, assist communication with patients and critically, build knowledge here in the UK.



## 5. Research

**Investment to enable over three years TBC.**

Poor awareness, low clinical knowledge levels and a lack of recognition for Kawasaki Disease as a serious threat to the heart health of our children mean there has been very little investment in research.

There is a rapidly rising population of those affected by Kawasaki Disease – a population which faces significant risks, and with a lack of UK research, these risks are not quantified or managed.

Yet the challenges of living with Kawasaki Disease are huge – it can lead to an atypical presentation of a major cardiac event in a young person, often with little or no warning. This is because of

the slow progression of the disease, many years after the acute stage and the development of collateral arteries over time in the heart which provide minimally adequate function – until a crisis is reached. Sudden death can then occur. This is not a rare event, **30% of patients with giant aneurysms will die suddenly, have a heart attack or need a transplant.**

This area, and many other aspects of Kawasaki Disease, needs investment in UK led research so that care can improve, and lives can be saved.



## 6. Raising awareness

**Investment to enable over three years = £253,500.**

Building knowledge of Kawasaki Disease with clinicians is critical. We aim to grow awareness with the public too – as only when Kawasaki Disease is commonly known, will children have the very best chances of early diagnosis, early treatment and a strong recovery.

Time is critical. Days really count when a child is ill with Kawasaki Disease. We aim to raise general awareness, empowering parents/carers to act with knowledge and confidence if they suspect Kawasaki Disease.

As well as our work within the UK, we are building on our international relationships – working with the 15 countries involved with the KD-CAAP clinical trial and our sister organisations across Europe, Canada and Australia. This will further strengthen our awareness raising capabilities, especially around World Heart Day and International Kawasaki Disease Awareness Day.

Our ability to reach more people rests on expanded organisational capacity to develop new programmes and capital to invest in the delivery of these.



## 7. Support for UK families

**Investment to enable over three years = £97,890.**

Having a child affected by a serious, life threatening disease that can leave a life-long legacy of heart damage is a traumatic experience that up to one thousand families a year affected by Kawasaki Disease face.

Societi has sought to support these families by providing clear, concise and up to date information, accessible at a time when it is most needed. Our award winning Family Resource Portal and our newly released 'My Societi' young people's portal are just some of the resources produced to help families at a time of crisis.

Investment will mean Societi can provide specialist, professional support on an individual basis – including a dedicated helpline with access to a trained counsellor with knowledge of Kawasaki Disease.

## 8. Organisational capacity

**Investment to enable over three years = £1,123,200.**

All of our focus areas for investment and support need a growth in capacity (employed staff) within our organisation, to advance.

If we are to prevent heart damage in thousands more children, we need dedicated funds to support and increase our core staff team to actively drive progress sustainably and consistently.



Thank you

Thank you for reading our paper. I am personally deeply grateful to you for inviting me to highlight our areas of need.

I hope the information we have included on our work, our trajectory and our ambition is helpful as you consider potential support for Societi. We are working to transform outcomes and knowledge around Kawasaki Disease in the UK. I know that with your support we could accelerate this spectacularly.

Please let me know if there is anything additionally that I can help with, I'd be delighted to discuss any aspect of this document further.

With very best wishes,

Rachael McCormack

Rachael McCormack, Founder  
for Societi



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



# societí

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Photo by Paweł Czerwinski on Unsplash

