

societì
The UK Foundation for Kawasaki Disease

A UK Strategy for
Kawasaki Disease

*2021 - 2025 Refresh
& 2016-2020 Review*



societi.org.uk

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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Executive Summary

Refreshing our strategy

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.

To take our work and our organisation forward, building on the successes to date, Societi has developed a refreshed strategy which takes into account a review of Societi's core purpose, the current Kawasaki Disease environment, new evidence available from research and the resources and capabilities available to our organisation.

The Kawasaki Disease environment

The work carried out by Societi since establishment, has brought about a change around Kawasaki Disease awareness and profile throughout the UK. Although much more still needs to be done, awareness is growing, especially within clinical areas where we have focussed our efforts.

Through Societi's work, the amount of reliable Kawasaki Disease information available to the public and clinicians has grown exponentially. The cornerstones set in place by Societi and our partners provide an ideal platform from which to build further awareness and competency around Kawasaki Disease. The recent changes to the Kawasaki Disease environment have been reflected in the refreshed strategy.

Responding to research

Research completed during the previous five years has provided Societi with further insights into areas which must be addressed in order to make a change for children affected by Kawasaki Disease. Societi has considered the following recent findings and uses these as a focus for the refreshed strategy:

-  Early treatment is critical
-  Kawasaki Disease is rapidly on the rise in the UK
-  19% of all children will have coronary artery aneurysms
-  28% of children will suffer heart damage
- <1 CAA 39% icon" data-bbox="311 520 348 562"/> <1% of infants will have coronary artery aneurysms
-  47% of children will not show all symptoms
-  There is an over representation of ethnic backgrounds affected by Kawasaki Disease
-  Kawasaki Disease is seen slightly more often in boys than girls
-  Higher incidence in children from rural areas
-  Kawasaki Disease is broadly consistent all year round
-  >5% of 1 in 5 affected by Kawasaki Disease are over 5 yrs old
-  <1/3 One third of patients are younger than 1 year old

A Strategy to achieve our aims

Societi's aims have been reviewed against the all the evidence currently available and remain aligned to the aims of the 2016 strategy with an the exception of an update to Family Support.

Our refreshed strategy sets objectives against Societi's four aims to ensure that we respond directly to the needs of those affected by Kawasaki Disease in the UK.

Awareness raising

The key aims of Societi regarding awareness raising are to:

- Raise public awareness of Kawasaki Disease, including incidence, symptoms, key data from research and consequences of delayed diagnosis
- Provide correct, clinician backed, accessible information to the public and families, children & young people affected by Kawasaki Disease
- Provide continued support to #TeamSocieti in their fundraising efforts for Societi
- Extending understanding of Kawasaki Disease among funders and policy makers

Research

The key aims of Societi regarding research are:

- European KDCAAP clinical trial - PPI lead
- Continuation of in house, self-funded research
- Development of a UK patient registry for Kawasaki Disease
- Continue to support research and information gathering on Kawasaki Disease, Covid-19 and PIMS-TS. Take further opportunities to be involved in research where they arise
- Develop a comprehensive research portfolio and actively seek funding, working with partner organisations

Clinical Supervision



The key aims of Societi regarding clinical supervision are to:

- Raise awareness with key paediatric centres, neonatal units and midwifery departments across the UK of key data from recent research
- Significantly extend detailed knowledge base within the paediatric medical community
- Act directly to promote widespread adoption of standardised national protocols re initial acute phase and long term care for Kawasaki Disease
- Raise GP and primary care staff awareness of Kawasaki Disease including symptoms, key data from research and the importance of early diagnosis
- Continue to lead and promote the work of the UK Kawasaki Disease Steering Group



Support for UK families

The key aims of Societi regarding support for UK families are to:

- Ensure active engagement with the Support Group and maintain an accurate, ongoing, visible online presence for KSSG and review online resources to ensure these remain up to date with current data and evidence
- Development and maintenance of Kawasaki Disease information including information relating to the ongoing Covid-19 pandemic and PIMS-TS
- Creation of a Family Advisory Board (FAB) - an online Q&A service delivered by trained, clinician backed Societi Volunteers
- Enable access to a qualified counsellor with knowledge of Kawasaki Disease for families in need of one to one, emotional support after a diagnosis of Kawasaki Disease

Societi's core purpose

Our vision

Our vision is for "just" 66 million people to know Kawasaki Disease. That's everyone in the UK. We want them to know Kawasaki Disease just like they already know meningitis. Just like they already know measles.

Kawasaki Disease is a serious illness that causes acquired heart disease in up to a quarter of all children affected. That's a life changing impact. A life threatening effect.

Kawasaki Disease is on the rise and our only defence against it right now is rapid diagnosis and early treatment. To achieve this, everyone needs to know Kawasaki Disease – doctors, parents, carers, everyone who works with children — in fact, everyone who has children in their world.

To achieve our vision we have made it our mission to educate clinicians, raise awareness with the public and use all possible means at our disposal to get Kawasaki Disease known.

Our mission

Our mission is to get Kawasaki Disease known.

We will work to ensure that **every clinician:**

- knows to THINK Kawasaki Disease in a child with persistent fever
- understands the urgency, complexity and seriousness of the disease
- has access to accurate clinical information, current care protocols and up to date guidance

We will work to ensure **every parent and carer:**

- knows to THINK Kawasaki Disease in a child with persistent fever
- has access to accurate information, support and best practice clinical care for their child, if affected by Kawasaki Disease

We will work to ensure **every person affected by Kawasaki Disease:**

- has access to accurate information, the support they need and consistent, best practice clinical care throughout their life

We will ensure **every policy shaper and influencer in children's health:**

- understands the urgency and seriousness of this disease – and provides investment and support to tackle the growing threat of Kawasaki Disease

Our values – priority, pace, partnership

We are an influencing and policy shaping organisation, always working through influential, supportive partnerships to enable Kawasaki Disease to be identified as a **priority** by funders and policy makers.

We will work with others to enable them to recognise Kawasaki Disease as a priority for action and investment. We will act **with pace** and with a momentum that comes from our motivation to succeed.

We know we cannot deliver our strategy alone. We will forge strong and lasting, powerful **partnerships** with organisations and agencies who share our determination to transform the environment around Kawasaki Disease in the UK, and beyond.

Our Strategic Aims

Our aims

After review, it is proposed that the strategic aims of Societi Foundation remain aligned with our aims from our first strategy, with an update to the Family Support aim to reflect increasing asks from parents and patients to do more in this area directly.

To build upon the success already achieved, each of these four areas must continue to be progressed as part of an integrated, proactive response to the identified needs.



Awareness raising
a voice for Kawasaki Disease



Research
sharing knowledge, influencing funders and enabling co-ordination



Clinical supervision
shaping new care protocols and health policy



Support for UK families
enabling sustained focus on family support

societì What Societi means to our supporters



“
ROBERTA

Such important work in these worrying times.

”

“
GILLIAN

I want Kawasaki Disease known - we were fortunate, the paediatric A&E team at Addenbrookes recognised the symptoms and were able to give my child the life saving treatment that was so desperately needed. I want this to be the case in all cases. Thank you Societi, I know you made the difference for us.

”

“
SHARRON

Your dedication Rachael and any help to get this message out to so many families will help get this terrible disease recognised, and hopefully in time, so families remain families as a result.

”

“
THE DALY FAMILY

Keep up the fantastic work!

”

“
HELEN

Thank you for the fantastic work you do.

”

“
MARIE

I found the information on your website regarding Covid very useful and reassuring so thank you!

”

“
NATALIE

Thank you to you ALL at Societi for all your amazing commitment and support that you have given to us and all the families xx”

”

“
GAYLE

You and your brilliant charity are amazing!

”

“
JEFF

Love your website and your learning materials- great work!

”

“
HOLLY

I would love to help you in all the ways you have helped us. Thank you very much.

”

“
CHANTELLE

Mum of a Kawasaki Disease warrior. You're doing an amazing job supporting us families, thanks so much.

”

societì What Societi means to our supporters



“
FRAN

Thank you to Rachael and Societi you are all amazing.

”

“
LYN

Sending well wishes and a heartfelt thank you for posting and continuing to update information re; Kawasaki Disease & COVID-19. I greatly appreciate checking your site regularly.

”

“
JASMINE

Thank you for all that you do! x

”

“
JOANNE

Thank you for your FACT based info regarding Covid-19.

”

“
MIKE & BARBARA

Keep up the good work!

”

“
KAT

A year ago we were in hospital with our 15week baby. It took a while for the diagnosis to be made but her tiny heart is still beating. THANK YOU for all you do.

”

“
KATHRYN

Thank you for all of your support and the work you do to ensure Kawasaki Disease is known. From the family and friends of Alexander - the loveliest, happiest son we could have asked for - who will be remembered forever.

”

“
REBECCA

A great cause doing amazing work.

”

“
KEISHA

“We are Team Societi. Eternally grateful for everything you do for all our children. x

”

“
EMMA

Many thanks for all you do. My son was diagnosed with Kawasaki Disease last year and it's so important we raise awareness.

”

“
SHIRLEY

There are so many families who are so grateful for all you have done in the fight to get Kawasaki Disease known.

”

“
HAYLEY

It really is amazing what you have achieved in such a small amount of time. Here's to the next five years.

”

Societi's resources and capabilities

The Board of Trustees

Our Trustee Board members bring together a strong combination of skills and expertise. Knowledge and experience of Kawasaki Disease, paediatric cardiology, paediatric rheumatology and vasculitis, strategic business management, national policy development, stakeholder engagement and third sector delivery are all brought to Societi via our Board. Societi is committed to continuing to recruit for new Trustee Board members to further increase our knowledge base and skill areas.

Societi Scientific Advisory Board

Societi is supported by the phenomenal clinical expertise of a Scientific Advisory Board – a multi-disciplinary team of expert professors and doctors with unrivalled UK experience in the field of Kawasaki Disease. The Board underpins Societi's work to ensure that all decisions, resources and activities are based around solid scientific judgement. This board has been established and expanded since our first strategy and today plays a central role in the work of our charity. Since our first Strategy, the Scientific Advisory Board has adopted Terms of Reference for its work and membership.

The UK Kawasaki Disease Steering Group

The UK Kawasaki Disease Steering Group, chaired by Societi, comprises key national leaders and influencers who act together as a catalyst for positive change around Kawasaki Disease. As a group we act as the UK advocates for Kawasaki Disease, with a specific focus on awareness, knowledge sharing and to encourage best practice in clinical care across the UK. The wealth of knowledge and experience within the group provides direction to Societi and shapes key activity areas.

Staff team

Leadership of Societi is brought through the voluntary contribution our Founder, Rachael continues to make. Societi currently operates with just three part time staff members carrying out most of Societi's day to day core activities, providing support to #TeamSocieti and driving forward our project work. The team is supported by volunteers on key projects and specialists commissioned to deliver particular elements such as accountancy advice. Pro bono support is currently donated by firms in specialist areas including public affairs, data control and political engagement.

#TeamSocieti

#TeamSocieti is a network of over 2,000 volunteer fundraisers and awareness raisers across the UK, all regularly working towards fulfilling our mission to **get Kawasaki Disease known!**

Growing in numbers all the time, #TeamSocieti is continually educating local communities and online networks all over the country about Kawasaki Disease. These networks are key to Societi's national awareness campaigning. It is vital that we continue to support #TeamSocieti in their work and capitalise on their strength, passion, determination and extensive reach to achieve our common goals.

Partnerships

Societi places huge importance on the partnerships we have built and relationships we have developed. Our partners, stakeholders and the organisations we are in dialogue with are many and varied. We are so grateful to those partners who support us by bringing influence, helping us make impact – and those who support us financially. Societi will continue to seek new partners and work with existing partners to transform the levels of understanding and knowledge about Kawasaki Disease. Through strong partnerships, we can lever investment, enable research, raise awareness and develop then implement new care standards. The shift in clinical practice which results will improve the prospects of children affected by Kawasaki Disease.

Funding

In total, we have only modest sums available to us currently but work hard to ensure both high effectiveness and high impact in every spending decision. 95% of all the funds Societi receives are from fundraising by parent and family fundraisers and donors.

#TeamSocieti is therefore a critical part of our organisation and we depend on this community for our organisation's success. As previously stated, we will continue to support #TeamSocieti in every way possible.

Working with #TeamSocieti, Societi has run successful fundraising campaigns, especially around World Heart Day and International Kawasaki Disease Awareness Day. These campaigns will continue in future becoming increasingly high impact as experience and knowledge grows within our organisation and across #TeamSocieti.

Little support has been available to Societi from public funding areas despite numerous attempts to secure this. Societi has worked to engage political stakeholders in recent years, highlighting the urgent need for investment by Government and other public bodies to address the growing threat posed by Kawasaki Disease. This work will continue to be pursued with pace.

To date Societi has not had a great deal of success in making grant applications. However, we are committed to continuing to seek potential funders for key work programmes and projects – and we will make applications where our charitable purposes and funding criteria are closely matched.

Research informing our work

Since our first strategy in 2016, our evidence base has grown with research completed by Trustees and research our charity has undertaken. Research findings provide us with evidence led areas of focus and this focus strengthens our ability to make greater impact.

The figures and charts below show data taken from the British Paediatric Surveillance Unit (BPSU) study, *Kawasaki disease: a prospective population survey in the UK and Ireland from 2013 to 2015* and highlight

important findings from the study.

The figures opposite show findings taken from the Societi Foundation Freedom of Information (FOI) research studies 2016 and 2019 relating to the number of hospital admissions for Kawasaki Disease during the years 2006 to 2018. Research findings have underpinned the priorities in this strategy and will actively shape our work plan as we deliver the goals of this strategy.

Kawasaki Disease in the UK - Kawasaki disease: a prospective population survey in the UK and Ireland from 2013 to 2015, Professor R Tulloh et al

CAA rate - all patients

The overall rate for coronary artery aneurysms in all children with Kawasaki Disease is 19%.

Heart damage - all patients

28% of all children with Kawasaki Disease will suffer some form of cardiac complications.

CAA rate - under 1s

Infants under 1 year display the fewest symptoms, but have the highest coronary artery aneurysms rate at 39%.

19% CAA
19% of all children will have coronary artery aneurysms

28%
28% of children will suffer heart damage

<1 CAA 39%
39% of infants will have coronary artery aneurysms

Inverse relationship to urbanicity

Very strong relationship with rurality - higher incidence in children from rural areas

Clinical presentation

47% of all Kawasaki Disease cases are incomplete. Not all children will display all symptoms.

Delay in diagnosis

On average, children were diagnosed at an average 7.8 days, increasing risk of cardiac damage. Risk increases proportionately with increasing delay.

Rurality
Higher incidence in children from rural areas

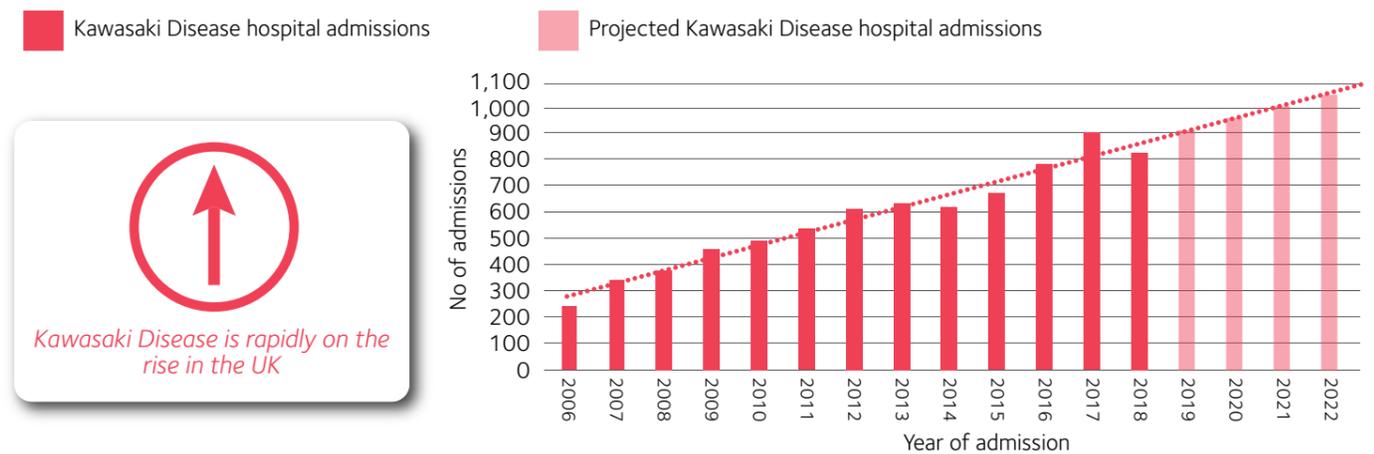
47%
47% of children will not show all symptoms

Early treatment is critical

Kawasaki Disease in the UK - Societi FOI research studies 2016 and 2019

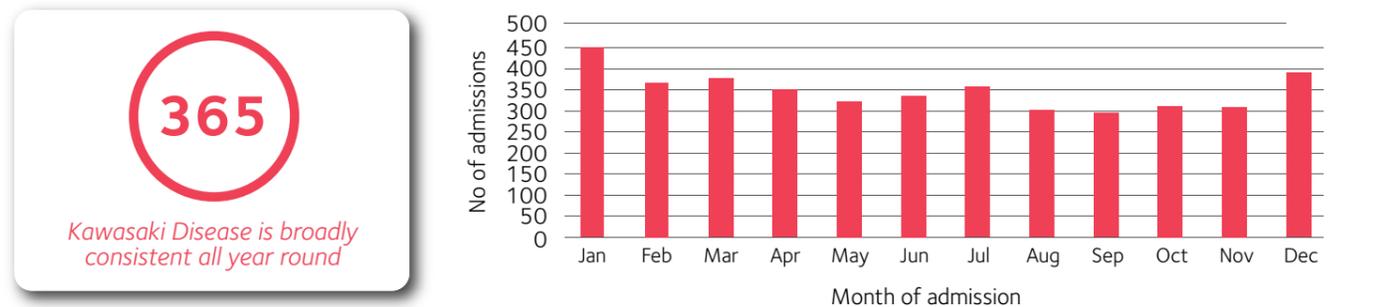
Number of Kawasaki Disease hospital admissions by year

The following illustration shows the number of Kawasaki Disease admissions per year in the UK. The data shows a dramatic rise in the number of hospital admissions for Kawasaki Disease over the period 2006 - 2018, strongly suggesting a sharply increasing incidence. The projection in the graph below shows well over 1000 hospital admissions for Kawasaki Disease per year by 2022.



Number of Kawasaki Disease hospital per month

The following illustration shows the number of Kawasaki Disease admissions per month in the UK. Peak admission months are noted as December and January, consistent with other UK study findings, but admissions in fact showed these were broadly consistent all year round.



Age in Kawasaki Disease - over 5s

>5 20%
1 in 5 affected by Kawasaki Disease are over 5 yrs old

Findings from the FOI study on age groups affected were consistent with global findings - and in the UK admissions data shows 1 in 5 are over 5 years as shown in the figure to the right.

Age in Kawasaki Disease - under 1s

<1 1/3
One third of patients are younger than 1 year old

Findings from the FOI study show that one third of patients are aged one year or younger. The BPSU study finds this group show the least symptoms with 39% suffering CAA.

Ethnicity in Kawasaki Disease

There is an over representation of ethnic backgrounds affected by Kawasaki Disease

Data gathered on ethnicity revealed there is a relative over representation in children of ethnic backgrounds affected by Kawasaki Disease when compared to the combined 2011 censuses for England and Wales, Scotland, and Northern Ireland.

Gender in Kawasaki Disease

Kawasaki Disease is seen slightly more often in boys than girls

Societi FOI study found data relating to patient gender are contrary to the often quoted 2:1 male preponderance in Kawasaki Disease. This is in fact much lower in the UK, at 1.5:1 M:F.

A refreshed UK Strategy for Kawasaki Disease 2021 - 2025

National awareness raising & fundraising

Our refreshed UK Strategy for Kawasaki Disease 2021-2025

Our refreshed UK Strategy is set out below and on the following pages. Our objectives and a rationale is described; as we move forwards towards achieving our strategic aims.

An action plan (appendix 1) has also been developed which outlines the actions Societi will take in order to fulfil our aims.

Strategic Aim 1: National awareness raising & fundraising	
Objective	Rationale
1.1 Raise public awareness of Kawasaki Disease in the UK, including incidence, symptoms, key data from research and consequences of delayed diagnosis.	Awareness of Kawasaki Disease in the general public, and clinicians is currently low contributing to delayed diagnosis and treatment Raised awareness, including targeting populations at higher risk of Kawasaki Disease, will enable parents, carers and clinicians to recognise Kawasaki Disease and understand the importance of prompt treatment
1.2 Provide correct, clinician backed, accessible information to the public and families, children & young people affected by Kawasaki Disease	Access to up-to-date, reliable Kawasaki Disease information will allow those affected by Kawasaki Disease to make informed choices relating to their acute illness, treatment and recovery, long term care and future health
1.3 Provide continued support to #TeamSocieti in their fundraising efforts for Societi	95% of the funding that Societi receives is generated by #TeamSocieti fundraisers and donors. Encouraging, supporting and enabling fundraising is vital to the ongoing operations of the organisation
1.4 Extending understanding of Kawasaki Disease among funders and policy makers	Raising awareness of Kawasaki Disease among funders and policy makers could lead to greater investment. It will accelerate the recognition of Kawasaki Disease as a major children's illness of national concern
1.5 Work with organisations internationally where opportunities arise, especially around World Heart Day and Kawasaki Disease International Awareness Day	Working with organisations internationally will allow for greater knowledge sharing and a collaborative approach where relevant to awareness raising

A refreshed UK Strategy for Kawasaki Disease 2021 - 2025

Research

2. Research

Strategic aim 2: Research	
Objective	Rationale
2.1 European KDCAAP clinical trial - PPI lead	Key opportunity to work with clinical centres throughout the UK and Europe, raising awareness of Kawasaki Disease. Supporting informed enrolment into the clinical trial will enhance engagement rates and increase trial impact
2.2 Continuation of in house, self-funded research	With a lack of public investment still limited the scale of research undertaken into Kawasaki Disease, it is important that Societi makes advancements in knowledge through 'own-hand' research. This will build knowledge and underpin future improvements - for instance in diagnosis times and consistency of clinical care. Societi's research has already played a pivotal role in accelerating positive change. This work area will continue to inform our areas of focus and action - ensuring work is completed in the areas where it is most needed.
2.3 Development of a UK patient registry for Kawasaki Disease	No central database exists in the UK of patients affected by Kawasaki Disease - limited information sharing, patient communication and research. A Kawasaki Disease registry will lead to greater understanding of the scale of population affected, facilitate patient information, support self care and informed care, improve communication and build further the case for investment and U.K. research
2.4 Continue to support research and information gathering on Kawasaki Disease, Covid-19 and PIMS-TS. Take further opportunities to be involved in research where they arise	It is important to recognise Covid-19 and PIMS-TS as ongoing issues for families affected by Kawasaki Disease. Societi will continue to be PPI lead for BPSU PIMS-TS Covid-19 study. We support the work of the BPSU in gathering data and insights into PIMS-TS to aid understanding, clinical care regime development and support for affected families.
2.5 Develop a comprehensive research portfolio and actively seek funding, working with partner organisations	Lack of UK-led research over time reflect low/no priority placed on Kawasaki Disease as an illness of concern within the UK. Raising awareness and profile of the disease needs to be undertaken in concert with investment in research, growing UK-based clinical expertise and interest. Societi will develop a prioritised research portfolio and work with partner institutions to secure investment in targeted research to benefit the UK population.



*A refreshed UK Strategy for
Kawasaki Disease 2021- 2025
Clinical supervision*

*3. Clinical
supervision*

Strategic aim 3: Clinical supervision	
Objective	Rationale
3.1 Raise awareness with key paediatric centres, neonatal units and midwifery departments across the UK of key data from recent research	Assumptions made by clinicians when considering a possible Kawasaki Disease diagnosis will be rebalanced based on the most recent information available. This should include data about incidence, age, ethnicity, gender and seasonality relating to outcomes for those affected by Kawasaki Disease ensuring the best care for patients
3.2 Significantly extend detailed knowledge base within the paediatric medical community	Improved awareness will lead to quicker diagnosis and treatment, reducing the risk of heart damage in children
3.3 Act directly to promote widespread adoption of standardised national protocols re initial acute phase and long term care for Kawasaki Disease	Widespread adoption of published guidance will give a consistent approach to care and ensure best practice for Kawasaki Disease patients throughout the UK
3.4 Raise GP and primary care staff awareness of Kawasaki Disease including symptoms, key data from research and the importance of early diagnosis	GPs and front-line medical staff are critical in the early care pathway for children affected by Kawasaki Disease. Prompt diagnosis and treatment will reduce risk of severe heart damage in affected children
3.5 Continue to lead and promote the work of the UK Kawasaki Disease Steering Group	The work of this well-established national partnership continues to offer opportunities for UK wide collaboration towards the improvement of Kawasaki Disease care throughout the UK, as well as influencing national / public bodies around the priority to be placed on Kawasaki Disease



*A refreshed UK Strategy for
Kawasaki Disease 2021 - 2025
Support for UK families*

*4. Support for
UK families*

Strategic aim 4: Support for UK families	
Objective	Rationale
4.1 Ensure active engagement with the Support Group and maintain an accurate, ongoing, visible online presence for KSSG and review online resources to ensure these remain up to date with current data and evidence	Participation through KSSG of KSSG members in Societì programmes will support continued representative engagement of the UK community affected by Kawasaki Disease and benefit from the expertise of KSSG leadership Societì must ensure access to KSSG web pages so that affected families can easily find and contact KSSG. Ongoing literature and content review will ensure families have access to accurate information in a timely manner - to the extent this is under the control of Societì
4.2 Development and maintenance of Kawasaki Disease information including information relating to the ongoing Covid-19 pandemic and PIMS-TS	Families need to be able to reference reliable, clinician backed information relating to their child's illness and are informed of their child's care needs now and in the future supporting informed decision making. Information is available online and offline including Societì's website, information portals, social media presence and printed materials
4.3 Creation of a Family Advisory Board (FAB) - an online Q&A service delivered by trained, clinician backed Societì Volunteers	Families currently only have access to non specialist advisory support, including that provided by non trained personnel, though some have direct personal experience of Kawasaki Disease. Family feedback demonstrates this is sometimes of huge value but equally, specialist advice is needed in some cases. The FAB will provide support with access to an online service offering help, advice and providing answers from trained volunteers. Volunteers will have a direct link to the Societì Scientific Advisory Board and training in dealing with family/emotional matter. FAB members will also receive training from clinical experts in Kawasaki Disease.
4.4 Enable access to a qualified counsellor with knowledge of Kawasaki Disease for families in need of one to one, emotional support after a diagnosis of Kawasaki Disease	Having a child affected by a serious, life threatening disease is a traumatic experience that up to one thousand families a year affected by Kawasaki Disease will have to face. Access to a qualified counsellor with sound knowledge of Kawasaki Disease issues will help to alleviate the pressures families find themselves under during a stressful and uncertain period

2016 - 2020 UK Strategy review

In 2016, Societi Foundation published the first ever UK Strategy to address Kawasaki Disease, the leading cause of acquired heart disease in children in the UK.

After undertaking a review of the environment around Kawasaki Disease, the UK strategy was developed recognising four parallel areas to be progressed as an integrated, proactive response to identified needs.

The 2016 strategy, set out in summary overleaf, focussed on these four areas which were adopted as the strategic aims for Societi Foundation:

- National awareness raising
- Research
- Clinical supervision
- Support for the support group

Against each aim, a series of steps were defined. A review of achievements towards each aim is set out on the pages which follow.

The strategy was developed to ensure deliberate focus in Societi's work, as a starting point from which to engage with partners and discuss mutual opportunities to address the challenges we collectively face.

Review Summary

In the five years to the end of 2020, Societi Foundation has made huge inroads to changing the landscape surrounding Kawasaki Disease.

Our charity has progressed from an initial start-up organisation to registered charity status, and growing reach across the UK. We have made measurable impact, successful in steps towards the achievements of our aims, despite only modest amounts of funding. The review which follows summarises our progress in achieving our strategic aims - and outlines areas where opportunities exist to progress and add further value.

1. National awareness Raising Review

Raising awareness of Kawasaki Disease with the public and clinicians directly and positively impacts outcomes for affected children. Getting Kawasaki Disease known so it can be rapidly diagnosed and treated will reduce the number of children who acquire heart disease from Kawasaki Disease. For this reason, awareness raising has been, and will remain, Societi's main strategic aim.

Because of Societi's work, at least 3,000,000 members of the public in the UK have now heard of Kawasaki Disease. Societi has also engaged with thousands of clinicians who are now better placed to recognise a child affected by Kawasaki Disease and make an earlier diagnosis.

As successful as Societi has been at raising awareness of Kawasaki Disease, there is still much more that needs to be done. To ensure an early diagnosis for affected children, we need to tell 'just' 66 million - the UK population about Kawasaki Disease. The profile of Kawasaki Disease in the UK remains too low, within the public and clinical environment and Societi needs to accelerate work to address this.

Activity	2016-2020 review
Strategic aim 1: National awareness raising	
1.1 Awareness campaign – raising public awareness of the symptoms of Kawasaki Disease	<p>Societi Foundation leads an ongoing, multi-channel public awareness campaign which to date has engaged upwards of 3,000,000 people. We have built a substantial following on social media platforms where we create and share engaging content, explaining not only the symptoms of Kawasaki Disease but also the issues surrounding it and why it is so important for parents and carers to know Kawasaki Disease. Societi has also taken the UK lead in International Kawasaki Disease Awareness Day (26 January). The day has now become an 'Awareness Month' and is proving more and more successful each year, with increasingly huge amounts of social media traffic across the globe. 'Awareness month' has also seen increasing numbers of awareness raising events in local communities across the UK and even into Europe.</p> <p>Societi Foundation has developed and maintains a comprehensive website which includes a vast resource of reliable Kawasaki Disease information for both the general public and clinicians alike. A BMA award winning Family Resource Portal which sits within Societi's website has also been developed to provide families with up to date, accurate information and supportive resources. The portal includes Societi commissioned family story films, advice videos featuring UK leading Kawasaki Disease expert Professor Robert Tulloh, a parent guide, a 'typical' Kawasaki Disease journey and much more.</p> <p>Offline, Societi's supporter base has grown exponentially with a network of over 2000 volunteer fundraisers and awareness raisers across the UK regularly working to raise awareness of Kawasaki Disease in their local communities. Societi Foundation works to support these volunteers by providing information and accurate awareness raising resources.</p>
Raising GP/front line medical awareness of the symptoms of Kawasaki Disease and knowledge sharing	<p>Societi Foundation has developed GP information packs and hospital information packs containing RCPCH endorsed information, guidance and resources aimed specifically at clinicians. The aim is to distribute packs to every GP and hospital throughout the UK. So far over 1,000 GP packs costing over £5 each have been distributed. Over 100 hospital packs have also been sent.</p> <p>Societi partnered with RCGP to fund and develop a Kawasaki Disease e-learning module, designed to raise awareness and build knowledge of Kawasaki Disease amongst GPs. Societi produced and developed a variety of content and resources to be used within the module which was authored by Societi Trustee and GP, Dr Louise Tulloh. The module is now available to over 100,000 UK healthcare professionals as part of their continued professional development and is being actively marketed by Societi and RCGP.</p>
Significantly extending detailed knowledge base within paediatric doctor community	<p>Societi has ensured huge visibility for Kawasaki Disease with clinicians attending the RCPCH annual conference on a number of occasions, engaging thousands of interested clinicians and sharing Kawasaki Disease information. Societi has also displayed technical posters and run a training workshop at the conference in partnership with BPSU.</p>



Activity	2016-2020 review
Strategic aim 1: National awareness raising	
Extending the understanding of Kawasaki Disease amongst funders and policy makers	<p>Societí worked with Paediatric Care Online (PCO) staff from the RCPCH to include Kawasaki Disease in a host of the “Key Practice Points” (doctor information pages) on their app – an online resource available to over 18,000 members of RCPCH. Societí also later worked with the PCO team to publish updated pages including one on “Pyrexia of unknown origin” – or fever of unknown cause, now highlighting information on Kawasaki Disease. Societí information and resources are also available to clinicians through the PCO website.</p> <p>Together with leading UK experts and with input from the BPSU, Societí created a clinicians webinar, run by RCPCH to highlight how out-dated information about Kawasaki Disease is hampering best practice for affected children. The webinar also presented recent research findings on incidence (UK and Ireland) – including revealing data on lifetime heart damage caused – the webinar is currently RCPCH’s most popular webinar. Societí has also created an information and resource booklet for use by clinicians as an addition to Kawasaki Disease workshops and webinars. The booklet was designed to help clinicians understand diagnosis considerations, increase knowledge of differential diagnosis issues, increase awareness of urgency of treatment and disease severity and abandon prevailing ‘myths’ around Kawasaki Disease. As well as use with webinars and workshops the booklet is an excellent aid for all clinicians wishing to increase their knowledge around Kawasaki Disease.</p>
	<p>As well as a dedicated section on our website, Societí has developed a range of key documents designed to inform funders and policy makers of the issues surrounding Kawasaki Disease. Documents include the UK Strategy, infographics, partnership proposals, newsletters and impact statements.</p>
	<p>Societí has received pro bono Public Affairs support from Lexington Health to develop plans to reach UK policymakers, politicians and wider stakeholders. Societí has been directly in touch with the offices of dozens of MPs, held meetings, discussion and more. Societí attended Westminster where we spoke about the need for a patient registry, the increasing incidence of Kawasaki Disease and the serious damage it causes and the legacy it leaves for far too many children. We’ve talked about the need for awareness – and the need for investment to support UK led research and UK knowledge building across our medical community.</p> <p>Societí have sought support from the British Heart Foundation who, as well as sitting on the board of the UK Kawasaki Disease Steering Group, actively supported Societí in raising awareness of Kawasaki Disease through their extensive media channels. Societí also developed an application to the British Heart Foundation for targeted funding for Kawasaki Disease, retailoring to address feedback given. The application was unsuccessful due to changes in the organisations priorities.</p>



Activity	2016-2020 review
Strategic aim 1: National awareness raising	
<p>1.2 UK Care protocol – Development and adoption of standardised national protocols re initial acute phase and long term care for Kawasaki Disease. Incorporate digital technology (apps) for ease of use and updates</p>	<p>Societí coordinated an expert writing group to produce much needed new UK lifetime cardiac management guidance for those who have been affected by Kawasaki Disease. The group consulted widely and included experts in Kawasaki Disease, paediatric cardiology and adult cardiology from across the UK and USA. The guidance – Lifetime cardiovascular management of patients with previous Kawasaki Disease paper sets out in detail the lifetime clinical care needs of those who suffer lasting heart damage and has been published by Heart BMJ. Societí Trustee, Professor Robert Tulloh gave an interview for a downloadable podcast with the BMJ Heart Journal to give an overview of the paper.</p> <p>Societí contributed directly to the content of, and distribution of, a patient safety alert (PSA) issued to all NHS Trusts in England. The PSA required action by all providers of NHS funded care to assess and act on risks re failure to recognise acute coronary syndrome in Kawasaki Disease patients.</p> <p>Societí founder, Rachael McCormack, was appointed to the “Fever under 5’s” Committee of the National Institute for Health and Care Excellence (NICE). The work of the national committee was to review and consider updates to clinical guidelines for fever in the under 5’s. NICE describe the purpose of the guideline as “designed to assist healthcare professionals in the initial assessment and immediate treatment of young children with fever presenting to primary or secondary care.”</p> <p>Societí Foundation worked closely with NHS England and NHS Choices, guided by Societí Trustee and Kawasaki Disease expert, Professor Tulloh, to comprehensively update the information on the NHS Choices website about Kawasaki Disease. A ‘go-to’ resource for health information, Societí had the full support of the team at NHS Choices as we worked together to jointly create fully updated online content for Kawasaki Disease.</p>
<p>1.3 National Kawasaki Disease partnership – Establish a group of interested stakeholders and agencies, co-ordinated by Societí</p>	<p>Societí established and chairs the UK Kawasaki Disease Steering Group – a UK wide partnership group comprising key national leaders and influencers who can act together as a catalyst for positive change around Kawasaki Disease – for awareness, for knowledge sharing and to encourage best practice in clinical care across the UK. Advocacy in all these areas is the remit of this group. The group meets twice yearly and works to advance focus areas such as research, knowledge sharing, awareness raising and encouraging and enabling best practice in clinical care.</p> <p>Societí recruited and is supported by a Scientific Advisory Board – a group of seven Kawasaki Disease experts from across the UK. The Scientific Advisory Board ensures Societí has access to the clinical expertise needed in our work. Clear terms of reference guide the work of this Board which has been instrumental in the issuing of timely, evidence based, consensus information on key matters of concern to the Kawasaki Disease community, including the Board’s work with the Medicines and Healthcare products Regulatory Agency on Kawasaki Disease and vaccines.</p>



2. Research review

Societì has catalysed and advanced the development of vital Kawasaki Disease research, as well as undertaking in-house research as resources have allowed.

In house research has included the first ever national review of the number of hospital admissions of Kawasaki Disease. With no registry of central database of cases, there has hitherto been no way of assessing the number of people affected by Kawasaki Disease in the UK - though clinician assessments have been made. Our research unveiled that many more cases were being admitted than previously thought and the rate of increase in admissions was significant.

Analysis from the research undertaken has already proved invaluable to further understanding about Kawasaki Disease, and findings have been used to inform Societì's work in all areas.

There has never been a UK 'call' - via the NIHR or other research funder linked to Kawasaki Disease and whilst

globally, much research has been ongoing over time, an obvious gap in UK-led research has been shown - and more work is needed to address this.

With limited research, there has been limited clinical profile, and very few clinicians with expert understanding of this complex disease. This in turn means variable care standards for those affected by Kawasaki Disease have been able to emerge. Societì recognised that tackling the research gap will deliver many linked benefits.

Limited funding for research into Kawasaki Disease has hampered work towards fulfilling Societì's ambitious research plan. Societì must showcase and build on existing work to engage with stakeholders and potential research funders to enable aims to be achieved.

Activity	2016 - 2020 review
Strategic aim 2: Research	
2.1 Immediate national trial - Engaging all hospitals in efficacy of initial phase treatment trial IgG v IgG + CS	Societì catalysed and advanced the development of a clinical trial to research better acute treatments for Kawasaki Disease. The trial titled KDCAAP (Kawasaki Disease Coronary Artery Aneurysm Prevention) will investigate the potential for better acute treatments for Kawasaki Disease which may reduce the heart damage children can experience when affected by Kawasaki Disease. This pan-European trial received funding in April 2019 from Conect4Children. Societì is a partner in the trial team and we'll be involved throughout, leading the work with families and creating patient information and clinical awareness resources.



Activity	2016 - 2020 review
Strategic aim 2: Research	
2.2 Research portfolio - Development of comprehensive research portfolio which sets out programme of UK research needs over time	A lack of UK investment has hampered much needed research into Kawasaki Disease. Societì has therefore undertaken several research projects to inform the current UK Kawasaki Disease landscape, highlight needs within clinical care and evidence the need for further research. Societì undertook a Freedom of Information request relating to Kawasaki Disease in 2016 and in 2019. In 2016, essential data was captured regarding Kawasaki Disease incidence in England spanning 10 years, between 2006 and 2015. Building on this research, Societì repeated the Freedom of Information request in 2019 contacting Trusts and Health Boards throughout the whole of the UK, requesting information spanning from 2006 until 2018. The resulting database of Kawasaki Disease information is at an unprecedented scale and is a powerful tool to help shape and inform our work around Kawasaki Disease. Analysis of the research findings into the incidence of Kawasaki Disease is currently ongoing. With an apparent increase in reports from families of issues arising around diagnosis, and no current UK data on what was occurring in the diagnosis environment, Societì Foundation undertook to evaluate the picture with a neutral poll of parents. The study aimed to highlight some of the issues around Kawasaki Disease diagnosis and delayed treatment times. Information from the study was analysed in April 2018 and found growing delays across the UK in Kawasaki Disease diagnosis, no increase in Kawasaki Disease awareness, continued confusion around Kawasaki Disease symptoms and significantly increasing risk to children in terms of acquired heart disease from Kawasaki Disease in the UK. Many of the longer term effects of Kawasaki Disease are not yet fully understood or well enough known. Many families have questions which, if we could find or share answers could improve long term care for those affected. Societì launched a fundraising campaign for UK based research into Kawasaki Disease, designed to find answers to key questions. Research questions are to be selected by working closely with families, together with clinicians, focusing on areas which will help improve long term outcomes for those affected by Kawasaki Disease. The project is currently in the planning stage.
2.3 Investment strategy - Development of timed and prioritised investment plan showing needs and funding/investment sources to enable achievement of aims including (but not exclusively) research aims	Societì developed an investment plan highlighting the research theme areas most in need of research. This document has been discussed and developed with the Societì Scientific Advisory Board, however members have had little capacity to take this forward. Funding for further research highlighted as needed in this paper has yet to be secured but will continue to be pursued.



3. Clinical supervision review

The establishment of the UK Kawasaki Disease Steering Group and the Scientific Advisory Board have been major achievements for Societì and have contributed to many of the successes within the area of clinical supervision.

The links created between the specialist centres in the coming together of the group has generated a powerful alliance with a depth of knowledge and expertise that is previously unrivalled in the UK. Societì confidently draws upon the expertise of these groups to evidence the need for change within the clinical Kawasaki Disease environment – and in it’s role as an advocate for policy change around Kawasaki Disease.

Guidance offered by the Steering Group, challenging and supporting the work

of our charity has been invaluable. The clinical expertise of the Scientific Advisory Board has allowed the acceleration of new national guidance for clinical practice – such as the Lifetime Cardiovascular Management Guidelines (published in Heart December 2019) -- and the availability of expertise through the Scientific Advisory Board has revolutionised access to accurate information for parents and patients.

It is imperative that the Steering Group and Scientific Advisory Board continue to guide, support and contribute to the direction of Societì, which in turn will enable further improvements in clinical care for Kawasaki Disease patients throughout the UK.

Activity	2016 – 2020 review
Strategic aim 3: Clinical supervision	
<p>3.1 UK Centre for Kawasaki Disease - four national clinics – Establish and fully resource the development of four linked centres, connected to extant paediatric and adult cardiology services, for the specialist treatment and long term clinical management of Kawasaki Disease patients</p> <p>?London ?South West ?North West ?Glasgow</p> <p>Together, these centres comprise a virtual UK Centre for Kawasaki Disease</p>	<p>Establishment of the UK Kawasaki Disease Steering Group has brought leading UK Kawasaki Disease experts together, linking centres UH Bristol, Great Ormond Street and St Mary’s London as well as the involvement of others including the National Clinical Director for Heart Disease and the National Clinical Director for Children, Young People and Transition and The British Heart Foundation Chief Executive Officer.</p> <p>Much information sharing and progress in the specialist treatment and long term clinical management of Kawasaki Disease has been made possible between these centres including the creation of new long term guidance ‘Lifetime cardiovascular management of patients with previous Kawasaki Disease’ which was authored by experts, including members of the UK Kawasaki Disease Steering Group and Scientific Advisory Board.</p>



Activity	2016 – 2020 review
Strategic aim 3: Clinical supervision	
<p>3.2 Virtual sharing platform - Create a confidential, online mechanism for case conferencing and data sharing on both urgent and non-urgent Kawasaki Disease cases across the UK</p>	<p>This programme of work has not been completed as initially proposed. It has been envisaged that improved access to Kawasaki Disease expertise (which was highlighted as centre-specific and localised) could be achieved by enabling greater collaboration of clinicians through a virtual clinic.</p> <p>Whilst the virtual clinic environment itself has not been pursued, the development and expansion of Societì’s Scientific Advisory Board since 2016 has directly led to collective discussion and dialogue across centres on strategic themes and key topics such as Kawasaki Disease and vaccines, international collaboration , training course content development and provision of responses to emerging issues.</p> <p>The Scientific Advisory Board has also played a key ambassadorial role in our work raising awareness across the clinical community, indirectly accelerating clinician awareness.</p>



4. Support for KSSG review

The Support Group has an invaluable role in supporting families affected by Kawasaki Disease – a hugely important task that Societì supports where possible.

To help the Support Group to carry on with their work, Societì Foundation’s aims were designed in dialogue with KSSG to ensure no duplication of efforts. Societì focuses in complementary areas

to KSSG awareness raising, to ensure precious time within the group can stay focussed on supporting families.

Other areas of support include updating of the group’s information and development and maintenance of their website pages, hosted by Societì.

Societì will continue to support the Support Group going forward.

Appendix 1
Societì’s UK
Strategy Action
Plan

UK Strategy Action Plan

The following pages illustrate the actions and activities Societì will undertake to achieve the objectives set under each strategic aim in the 2021 – 2025 UK Strategy.

This Action Plan is a guide to drive Societì’s work and is by no means intended to be exhaustive.

Activity	2016 – 2020 Review
Strategic aim 4: Supporting the UK Support Group	
<p>4.1 Online information & resources – Development of a search engine optimised ‘single reference point’ of information and data on Kawasaki Disease – with spaces for patients/families and clinicians – www.societì.org.uk</p>	<p>The KSSG website gives vital contact information for families who are affected by Kawasaki Disease and who need to connect with the Support Group. KSSG’s website was incorporated into the newly developed Societì website where it is still hosted with it’s own URL. Societì maintains and updates the KSSG website as and when required.</p> <p>KSSG developed a Parent Guide booklet for families affected by Kawasaki Disease. Societì fully rewrote this booklet in 2017 for KSSG to ensure outdated information was replaced and it has subsequently also been incorporated it into the Societì Family Resource Portal.</p> <p>By integrating our online presence we have also strengthened the “Google Search” for Kawasaki Disease and search terms including Kawasaki Disease in the UK now immediately locate the Societì website</p>
<p>4.2 Resources for KSSG – Enabling support to the UK support group to allow their greater reach, to access and work with more families; and provide extended support to its growing community of over 1,500 families</p>	<p>Societì’s focus is complementary to that of KSSG and we have ensured continued capacity for supporting families within KSSG by undertaking a plan of UK public and clinical awareness raising. Where KSSG would previously have spent some of their time and resources raising awareness, they can now support more families – KSSG are the only group in the UK to offer dedicated telephone and email support to families with a confirmed or suspected Kawasaki Disease diagnosis.</p> <p>KSSG direct newly affected families to the Societì website for access to reliable information and have distributed Societì awareness leaflets in joint awareness initiatives with parents. Societì similarly direct those looking for emotional support to KSSG.</p> <p>Societì have attended the KSSG Family Day to provide information and resources to families attending.</p> <p>The Societì Board of Trustees considered and approved a proposal for an annual funding grant for KSSG to support their essential works including meeting elements of their core costs. This is an open offer which the Support Group may take up at any time.</p>



Strategic Aim 1: National Awareness Raising and Fundraising

Objectives

1.1 Raise public awareness of Kawasaki Disease, including incidence, symptoms, key data and consequences of delayed diagnosis

Actions/ Activities

- a) Continue to develop engaging awareness raising digital content shared across social media and website within a robust digital media plan
- b) Deliver social media campaigns including targeting areas of higher ethnic diversity and delivering key messages and relevant knowledge acquired from research
- b) Working increasingly with international sister organisations around key events (International Kawasaki Disease Awareness Day, World Heart Day)
- c) Advance our work to encourage and inspire supporters via social media, newsletters, press releases and website to hold awareness raising events within their local communities
- d) Build on work done to date and continue to support and enable #TeamSociety to raise awareness in their local communities across the UK by designing, developing and providing effective resources
- e) Investigate and take advantage of cost effective ways to raise awareness offline, e.g. lighting up landmarks for Awareness Day, take advantage of media interest through quality press releases and continue to work with Clear channel where possible to utilise multimedia advertising e.g. billboards

1.3 Provide continued support to #TeamSociety in their fundraising efforts for Societi

a) Continue to strengthen our portfolio of resources and fundraiser support information available to #TeamSociety

1.5 Work with organisations internationally where opportunities arise, especially around World Heart Day and Kawasaki Disease International Awareness Day

- a) Continue communications with international sister organisations to share knowledge and collaborate to increase awareness, especially for international awareness days
- b) Build on relationships with European centres established through the KD-CAAP clinical trial for knowledge sharing and increased awareness opportunities

1.2 Provide correct, clinician backed, accessible information to the public and families, children & young people affected by Kawasaki Disease

- a) Regularly maintain and update societi.org.uk and the Family Resource Portal adding new and improved resources where relevant
- b) Maintain and further develop My Societi, children and young people's Portal to ensure that children growing up with a legacy of Kawasaki Disease have access to reliable and age relevant information
- c) Continue to promote resources such as the website, Family Resource Portal and long term issues leaflet to ensure these are being used effectively
- d) Provide relevant and useful information to GPs, hospitals, schools and day nurseries to be displayed and distributed to the general public

1.4 Extending the understanding of Kawasaki Disease amongst funders and policy makers

- a) Update and develop a Partnership Proposal document to secure increased public body and corporate support, develop understanding about the scale of challenges and highlight opportunities and urgent need to tackle Kawasaki Disease as a national priority
- b) Identify potential partner organisations including Government and the Department of Health to target with proposed opportunities
- c) Review and redevelop the policy & funder area on the Societi website to ensure this is high impact and relevant

UK Strategy for Kawasaki Disease – Action Plan



Strategic Aim 2: Research

Objectives

2.1 KDCAAP European trial – PPI lead

Actions/ Activities

- a) Leading work with families, producing patient information and providing resources that participating families need as they consider, and progress through the trial
- b) Develop web based resources for clinicians and families participating in the trial
- b) Grow a social media presence for the KD-CAAP trial as a means of informing and updating families involved and other interested parties

2.1 Develop a comprehensive research portfolio and actively seek funding, working with partner organisations

- a) Pursue opportunities available to enable, support and undertake UK-led research into Kawasaki Disease, growing UK-based clinical expertise and interest.
- b) Continue collaboration with existing and new partners to seek funding into UK-led research.

2.2 Continuation of in house, self-funded research

- a) Continue Freedom of Information research and analysis with all UK Trusts and Health Boards
- b) Investment in external analysis of FOI findings. Promotion of translation of findings and incorporation into Societi awareness raising material
- c) Identify other own-hand research opportunities such as the Diagnosis Day paper bringing added insights to the experience of families affected by Kawasaki Disease

2.3 Development of a UK patient registry for Kawasaki Disease

- a) Investment in the development, maintenance and widespread promotion/uptake of a patient led, Societi co-ordinated patient registry
- b) Gather investment for and share insights and learning from registry establishment

2.4 Continue to support research & information gathering on Kawasaki Disease, Covid-19 and PIMS-TS. Take further opportunities to be involved in research where they arise

- a) Leading work with families for the BPSU study, producing patient information and providing resources that participating families need as they consider, and progress through the trial
- b) Develop web based resources for participating clinicians and families
- c) Promote Societi's work contributing to research relating to Kawasaki Disease, Covid-19 and PIMS-TS, taking further opportunities to support research as they become available



Strategic Aim 3: Clinical Supervision

Objectives

3.1 Raise awareness with key paediatric departments, neonatal units and midwifery departments across the UK of key information and data, including that from recent research

- a) Work to establish communication channels with paediatric departments, neonatal units and midwifery networks across the UK
- b) Maintain and update awareness raising material tailored to educate paediatric clinicians in the most recent research findings
- c) Maintain communication across networks recording feedback to assess impact and identify opportunities for further engagement

Actions/ Activities

3.5 Continue to lead and promote the work of the UK Kawasaki Disease Steering Group

- a) Lead, chair and enable proactive engagement around twice annual Steering Group Meetings
- b) Encourage partner-led actions arising from the priorities identified by the Steering Group
- c) Act to implement identified work areas assigned to Society Foundation
- d) Expand representation of the group to include devolved administration representatives

3.2 Significantly extend detailed knowledge base within paediatric medical community

- a) Undertake a co-ordinated program of direct engagement opportunities (e.g. conferencing, workshops and webinars)
- b) Capitalise on existing gatherings to promote Kawasaki Disease knowledge sharing and develop events where gaps exist, together with clinician partners
- c) Grow the work and visibility of the Scientific Advisory Board to engage more clinicians in the Kawasaki Disease agenda

3.3 Act directly to promote widespread adoption of standardised national protocols re initial acute phase and long term care for Kawasaki Disease

- a) Work with UK Trusts and Health Boards to promote the adoption of acute and long term guidance throughout the UK
- b) Develop material tailored to audiences which support the adoption of guidance and consistency of care standards
- c) Undertake research to assess uptake and effectiveness of promotional work

3.4 Raise GP and primary care staff awareness of Kawasaki Disease including symptoms, key data and the importance of early diagnosis

- a) Issue GP and hospital Kawasaki Disease information via packs and online to every GP surgery and hospital throughout the UK
- b) Widespread promotion and marketing of the Kawasaki Disease e-learning module produced in partnership with the RCGP
- c) Identify new opportunities to address knowledge gaps e.g. podcasts, webinars, CPD packs and seek opportunities to speak at key events



Strategic Aim 4: Support for UK Families

Objectives

4.1 Ensure active engagement with the Support Group and maintain an accurate, ongoing, visible online presence for KSSG and review online resources to ensure these remain up to date with current data and evidence

- a) Engagement through social media, newsletters and campaigns to ensure Society programmes are highlighted to KSSG members
- b) Maintain and update the KSSG website, hosted within society.org.uk
- c) Keep KSSG online materials, leaflets and information under review, updating when needed to ensure consistency and accuracy of information to families

Actions/ Activities

4.2 Development and maintenance of Kawasaki Disease information including information relating to the ongoing Covid-19 pandemic and PIMS-TS

- a) Constant monitoring, updating and development of Society website and online portals ensuring that information available is the most current & up to date
- b) Review and update all Society printed materials
- c) Act quickly to publish clinically backed information in response to questions and expressed concerns relating to Kawasaki Disease, Covid-19 and PIMS-TS
- d) Develop and maintain relationships with key staff at all UK major children's hospitals to ensure Society literature is available to all families with a new Kawasaki Disease diagnosis

4.3 Creation of a Family Advisory Board (FAB) – an online Q&A service delivered by trained, clinician backed Society Volunteers

- a) Provide training to volunteer FAB members to provide family/emotional online support to families.
- b) Provide the FAB with a direct link to the Scientific Advisory Board to ensure clinical support where needed.
- c) Promotion of the FAB online services to UK families

4.4 Enable access to a qualified counsellor with knowledge of Kawasaki Disease for families in need of one to one, emotional support after a diagnosis of Kawasaki Disease

- a) Liaise with mental health organisations to share knowledge on best practice in the provision of crisis counselling for affected families
- b) Seek investment to allow for a role within Society of a qualified counsellor and associated provisions such as a dedicated helpline

*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

societí

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