

Societi Foundation National Strategy Review

Impact Statement 2016 - 2020



In 2016, Societi Foundation published the first ever National Strategy to address Kawasaki Disease, the leading cause of acquired heart disease in children in the UK. This impact statement summarises the work of Societi Foundation in delivering the national strategy and highlights the achievements realised. The strategy focussed on the 4 areas below - the strategic aims for Societi Foundation:



National awareness raising



Research



Clinical supervision



Support for the support group

The strategy was developed as a starting point from which to engage with partners to discuss mutual opportunities to address the challenges we collectively face and to drive the work of Societi Foundation. In the four years to the end of 2019, Societi Foundation working together with our volunteers and partners has made huge inroads around changing the landscape of Kawasaki Disease awareness and investment.

Our charity has progressed from an initial start-up organisation to registered charity status, successfully contributing towards the achievements of its aims with modest amounts of funding. This impact statement summarises the progress made towards achieving the set strategic aims.





Our Achievements: Strategic Aim 1

National Awareness Raising

Raising awareness of Kawasaki Disease has the potential to directly improve outcomes for affected children. Because of Societi's direct work, up to 3,000,000 members of the public in the UK have now heard of Kawasaki Disease. Many more know it as a result of our volunteers and partners. 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. We need to tell 'just' 66 million - the UK population - about Kawasaki Disease. The profile of Kawasaki Disease in the UK remains too low, both within the public and clinical environment and Societi needs to carry on working to address this.

1.1 Awareness Campaign

Raising public awareness of the symptoms of Kawasaki Disease

- Ongoing, public awareness campaigns engaging upwards of 3,000,000 people
- UK lead in International Kawasaki Disease Awareness Day (26 January) which has now become an 'Awareness Month'
- Developed and maintained a comprehensive website which includes a vast resource of reliable Kawasaki Disease information
- Developed a BMA award winning Family Resource Portal providing families with accurate information and supportive resources.
- Grown an exceptional network of over 300 volunteer fundraisers and awareness raisers across the UK providing

Raising GP/front line medical awareness of the symptoms of Kawasaki Disease and knowledge sharing

- Developed and distributed over 1,600 GP and hospital information packs containing RCPCH endorsed information, guidance and resources.
- Funded and partnered with RCGP to develop a Kawasaki Disease e-learning course available to over 100,000 UK healthcare professionals.

Significantly extending detailed knowledge base within paediatric doctor community

- Attended the RCPCH annual conference on a number of occasions, engaging thousands of interested clinicians
- Worked with Paediatric Care Online to include Kawasaki Disease in "Key Practice Points" (doctor information pages) on their app available to over 18,000 members of RCPCH
- Developed a clinician webinar with leading UK experts and the BPSU, run by RCPCH

Extending the understanding of Kawasaki Disease amongst funders and policy makers

- Developed a range of key documents designed to inform funders and policy makers of the issues surrounding Kawasaki Disease
- Developed plans to reach UK policymakers, politicians and wider stakeholders. Societi has been directly in touch with the offices of dozens of MPs
- Attended Westminster to speak about Kawasaki Disease and the need for awareness and investment
- Sought support from the British Heart Foundation who, as well as sitting on the board of the UK Kawasaki Disease Steering Group, actively supported Societi in raising awareness of Kawasaki Disease through their extensive media channels

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

- Coordinated an expert writing group to produce much needed new U.K. lifetime cardiac management guidance which has been published by Heart BMJ, endorsed by professional bodies
- Contributed directly to a patient safety alert issued to all NHS Trusts in England
- Sat on the "Fever under 5's" Committee of the National Institute for Health and Care Excellence (NICE) to review and update clinical guidelines
- Worked closely with NHS England and NHS Choices, to comprehensively update the information on the NHS Choices website about Kawasaki Disease

1.3 National Kawasaki Disease Partnership

Establish a group of interested stakeholders and agencies, co-ordinated by Societi

- 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
- Recruited and is supported by a Scientific Advisory Board - a group of seven Kawasaki Disease experts from across the UK.





Our Achievements: Strategic Aim 2

Research

Societi has catalysed and advanced the development of vital Kawasaki Disease research, as well as undertaking in-house research. Analysis from the research undertaken has already proved invaluable to further understanding about Kawasaki Disease and findings have been used to inform Societi's work in all areas. Limited funding for research into Kawasaki Disease has hampered work towards fulfilling Societi's ambitious research plan. Societi must showcase and build on existing work to engage with stakeholders and potential research funders to enable aims to be achieved.

2.1 National Trial - KDCAAP

Engaging all hospitals in efficacy of initial phase treatment trial IgG v IgG + CS

- Catalysed and advanced the development of a clinical trial of Kawasaki Disease acute treatments, which may reduce heart damage in children affected by Kawasaki Disease

2.2 Research Portfolio

Development of comprehensive research portfolio which sets out programme of UK research needs over time

- Undertaken several research projects that serve to inform the current UK Kawasaki Disease landscape, highlighting needs within clinical care and evidence the need for further research
- Undertook a Freedom of Information request relating to Kawasaki Disease in 2016 and in 2019. 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
- Undertook a neutral mini poll of parents aiming to highlight some of the issues around Kawasaki Disease diagnosis and treatment times
- Launched a fundraising campaign for UK based research into Kawasaki Disease, designed to find answers to key questions

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

- Discussed and developed an investment plan highlighting the research theme areas most in need of research with the Societi Scientific Advisory Board



Our Achievements: Strategic Aim 3

Clinical Supervision

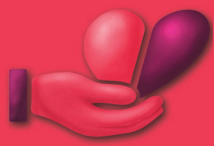
The establishment of the UK Kawasaki Disease Steering Group has been a major achievement for Societi and has contributed to many of the successes within the area of clinical supervision. The links created between the specialist centres in the coming together of the group has generated a powerful alliance with a depth knowledge and expertise that is unrivaled in the UK. Societi can confidently draw upon the expertise of the group to evidence the need for change within the clinical Kawasaki Disease environment. It is imperative that the Steering Group continue to advise, support and contribute to the direction of Societi, enabling further improvements in clinical care for Kawasaki Disease throughout the UK.

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

- Establishment of the UK Kawasaki Disease Steering Group bringing 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 CEO





Our Achievements: Strategic Aim 4

Support for KSSG



The UK Support Group, KSSG have an invaluable role in supporting families affected by Kawasaki Disease – a hugely important task that Societi supports where possible. To help the Support Group to carry on with their work, Societi has taken on the role of awareness raising to free up capacity within the group as they focus on emotional support for families.

Other areas of support include updating the group's information, development, maintenance and hosting of their website within the Societi website. Societi continues to support the Support Group going forward and will look into ways where support can be given in other ways.

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.societi.org.uk

- Incorporated KSSG's website into the newly developed Societi's website where it is still hosted with its own URL
- Societi maintains and updates the KSSG website as and when required
- Fully rewrote KSSG Parent Guide for KSSG to ensure outdated information was replaced and was subsequently incorporated it into the Societi Family Resource Portal

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

- Societi has freed up precious time and resources for 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 Kawasaki Disease diagnosis
- KSSG directs newly affected families to the Societi website for access to reliable information and have distributed Societi awareness leaflets in joint awareness initiatives with parents. Equally, Societi directs those needing emotional support or listening to KSSG
- Societi have attended the KSSG Family Day to provide information and resources to families attending

