

societá

*A National
Strategy
for Kawasaki
Disease*





Persistent fever



Cracked lips/tongue



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands

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UK Strategy

There is an imperative to act - now - to address Kawasaki Disease, the leading cause of acquired coronary artery disease in children in the UK.

Having undertaken a review of the current environment around Kawasaki Disease, a U.K. Strategy has been developed by Societi; recognising the four parallel areas which must be progressed as part of an integrated, proactive response to the immediate needs identified.

The Strategy, set out in summary overleaf, highlights the four strategic aims for Societi:

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

Against each aim, a series of steps have been defined and a rationale which describes the significance of these steps and their impact is also given.

In delivering the Strategy, recognising the cumulative inaction over time to address needs, the increasing incidence being evidenced and the significant long term threats posed by Kawasaki Disease, we would highlight the need to implement this Strategy as a priority, with pace and through strong partnerships.

Delivering the Strategy - Priority, Pace, Partnership

Driving forward implementation of the strategy across all four of the strategic aims for Societi means we must work to enable Kawasaki Disease to be identified as a priority by funders and policy makers. Individual components of the strategy are critical, but dynamic implementation of our comprehensive, integrated approach is now urgently needed.

Every year, hundreds of children are treated for Kawasaki Disease. Of these, approaching 100 children develop heart complications and other serious complications. Not enough is known about the long term effects of Kawasaki Disease but what is known is that today it is the leading cause of acquired coronary artery disease in children in the UK. What is also not known is the level of misdiagnosis and the number of children who go untreated and who are silently affected by Kawasaki Disease. We have the knowledge to dramatically reduce acquired coronary artery disease in children. We must now resource putting that knowledge in place and proactively prevent catastrophic, avoidable heart damage for an ever growing population of children and young people.

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

Strategic Aim 1

- National Awareness Raising

Activity	Rationale
STRATEGIC AIM 1: NATIONAL AWARENESS RAISING	
<p>1.1 Awareness campaign – raising public awareness of the symptoms of Kawasaki disease</p> <p>Raising GP/front line medical awareness of the symptoms of Kawasaki disease and knowledge sharing</p> <p>Significantly extending detailed knowledge base within paediatric doctor community</p> <p>Extending the understanding of Kawasaki Disease amongst funders and policy makers</p>	<p>Parents are unaware of the disease. Without correct and early diagnosis, effective treatment cannot be given, lifelong consequences can accrue</p> <p>GPs and front line medical staff have low awareness of the disease but are critical in the early care pathway to prompt diagnosis (See also 2.1)</p> <p>Poor awareness leads to misdiagnosis and under diagnosis, which in turn leads to under reporting and under resourcing. (See also 2.1) Direct engagement opportunities (e.g. conferencing, national Kawasaki Disease study day(s)) could expedite levels of learning and enable integrated CPD</p> <p>Poor awareness has led to long term under-investment and lack of prioritisation of Kawasaki Disease by both funders and policy makers.</p>
<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>No common standards for Kawasaki Disease care or follow up exist within the UK. NHS London protocol for cardiovascular management launched (Sept/15) but not yet widely shared/adopted and are not resourced. European guidance is pending (2016)</p> <p>Formal mechanism is needed to enable rapid embedding of agreed treatment and care protocols including associated investment to enable delivery of protocols</p>
<p>1.3 National Kawasaki Disease Partnership – Establish a group of interested stakeholders and agencies, co-ordinated by Societì</p>	<p>Perceived wrongly as 'rare', Kawasaki Disease has been hampered by underinvestment. Only by securing partner engagement and developing understanding about the scale of the challenge as well as the opportunities presented can this balance be redressed.</p> <p>From within a national partnership, opportunities for collaborations, mutually beneficial investment, funding and joint campaigning will be identified.</p>

Activity	Rationale
STRATEGIC AIM 2: RESEARCH	
<p>2.1 Immediate National Trial - Engaging all hospitals in efficacy of initial phase treatment trial IgG v IgG + CS</p>	<p>Rate of heart complications is globally unprecedented in UK presentation of the disease at c. 28% treated children versus c. 4% globally; treatment options must respond and an evidence platform is needed urgently to enable evolution of current initial treatment (IgG only); (connected to 1.1 and 2.2)</p>
<p>2.2 Research portfolio – Development of comprehensive research portfolio which sets out programme of UK research needs over time</p>	<p>Overview of comprehensive research needs for Kawasaki disease essential in order to co-ordinate effective research planning, enable strong international collaborations and investment requirements from funders. (connected to 2.3)</p>
<p>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</p>	<p>Identification of investment and funding gaps at a strategic level is urgently needed to allow Societi to secure stakeholder engagement across a range of potential partners in enabling elements appropriate to funders own needs/ priorities and timelines (connected to 2.2, 1.2 and 1.1)</p>

*Strategic Aim 3
– Clinical Supervision*

Activity	Rationale
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>Specialist clinics are critical to the successful management of Kawasaki Disease. It is a complex disease of increasing incidence, and many unknowns – and demands a broad range of specialisms in the proper care of the disease. These factors dictate the need for knowledge bases to be built and rapidly advanced in the UK.</p> <p>Through the development of linked, specialist clinics which together comprise a virtual UK Centre for Kawasaki Disease, general paediatric services will be able to rapidly access current guidance, expertise and individual case advice, ensuring significantly improved outcomes.</p> <p>Through the UK Centre for Kawasaki Disease, long term care can be maintained for both paediatric and adult populations (see also 1.2)</p>
<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>Specialists involved in diagnosing and treating Kawasaki Disease span a range of specialists including cardiology, rheumatology and infectious diseases.</p> <p>In order to get the most prompt determination of next steps in a case being treated at one centre but presenting with complications demanding input from another, case conferencing supported by specific resources will enable multi-disciplinary perspectives to be brought and aid substantially improved outcomes, together with ongoing knowledge transfer.</p>

*Strategic Aim 4
- Supporting Our Support Group*

Activity	Rationale
STRATEGIC AIM 4: SUPPORTING OUR 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.societi.org.uk</p>	<p>Kawasaki Disease is a complex and worrying disease from a patient’s perspective; and with much online data out-of-date, incomplete or not relevant to the UK picture, there is an urgent need for a high profile, accessible and universally recognised as reliable source of information and signposting.</p> <p>As more clinicians are aware of and diagnose Kawasaki Disease, building an online community of knowledge and a clinical/research data room for rapid access to the most up-to-date guidance documents and protocols would improve outcomes.</p>
<p>4.2 Resources for KSSGUK – 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>Established for over 20 years, KSSG is the UK support group run entirely by volunteers, offering a helpline (phone) and email support. They contribute strongly to national research projects and hold a family day each year but their reach is limited by volunteer capacity and available funds. They are however a critical lifeline for families experiencing Kawasaki Disease, and in the years following disease diagnosis. KSSG have played a pivotal part in building the dataset on Kawasaki Disease experiences in the UK.</p>

Kawasaki Disease Symptoms

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Rash



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Swollen glands

societí

Victoria Court,
Holme Lane,
Winthorpe, Newark,
Notts NG24 2NU

rachael@societi.co.uk

