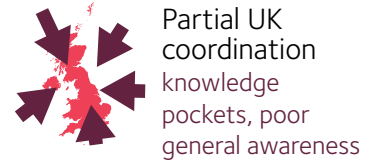
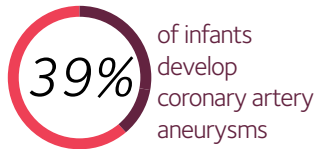
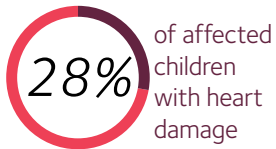


societì *The UK Foundation for Kawasaki Disease*

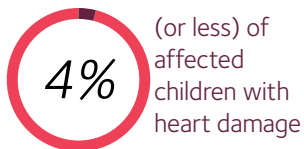
Kawasaki Disease is the leading cause of acquired heart disease in children in the UK. It's time we changed that...

...Together we will

Where we are today



Where we need to be



General Awareness & Diagnosis

What is needed?

- Establish "common knowledge" with the general public of Kawasaki Disease, including awareness by doctors, particularly in primary care and paediatrics
- Funding for underpinning training for all clinicians who see children to enable rapid diagnosis of Kawasaki Disease
- Ensure access to UK specific information on Kawasaki Disease, its symptoms and diagnosis, for a range of audiences
- Care protocols developed and nationally adopted for diagnosis and immediate treatment requirements
- Funded capacity for Societi Foundation through which to continue and grow its work with pace

What is in place?

- Negligible public awareness and low Primary care / A&E awareness with no standardised care protocols
- Awareness in paediatric training grades assumed but unconfirmed, majority of GPs currently do not know Kawasaki Disease
- Medical knowledge is in specialist knowledge "pockets" only and children receive inconsistent care
- UK specific information on Kawasaki Disease is available at www.societi.org.uk
- Incomplete evidence base for UK presentation / diagnosis, which needs investment in research

Treatment & Long Term Care

What is needed?

- Knowledge embedded in secondary care (A&E, paediatrics and paediatric cardiology)
- Multi-disciplinary team participation and knowledge (cardiology, infectious disease, rheumatology)
- Protocols developing and nationally adopted for acute and lifetime care and for monitoring of impacts following Kawasaki Disease – with a rapid pathway back to secondary care if GP/parental concerns.
- Continuity at transition for patients, from paediatric cardiology to adult cardiology services
- A comprehensive UK evidence base from which to derive (practice based) UK specific policy and action – a funded portfolio of research is critically needed to address the inadequate data in the UK
- A registry funded for the estimated 20,000 UK patients previously affected, urgently required to enable access to correct clinical supervision and support essential research

What is in place?

- No nationally consistent treatment or acute care protocols, reliant instead on knowledge only in specialist localised groups
- Significant gaps in patient data – inconsistent approaches to data by different Trusts
- Inconsistent acute treatment approaches and a gap in clinical data to support improved treatments
- No nationally recognised protocols, inconsistency of long term supervision; 2013 Guidelines not widely adopted; NHS London cardiovascular management guidelines 09/15 not adopted and NHS patient safety alert – Kawasaki Disease 05/16 not actioned by the majority of Trusts
- Expert Writing Group underway developing lifetime cardiac management guidance