

A Manifesto for **Kawasaki Disease**

Societi Foundation is the UK Foundation for Kawasaki Disease - #1 cause of acquired heart disease in UK children.

Ahead of the General Election in 2024, we want to draw attention to the fact that today, the UK is one of the worst countries in Europe for child mortality and has some of the worst outcomes in Kawasaki Disease in Europe.

We have set out a number of key needs in this Manifesto, on behalf of our growing community - an estimated 20,000 people in the UK who have been affected by Kawasaki Disease. We ask the incoming government, and MPs elected on 4 July 2024, to do all they can to respond to these needs, to stop the devastation caused too often by Kawasaki Disease, and make the overdue, urgent investment in protecting children's hearts from Kawasaki Disease.

For all our children, we recognise the need for immediate collaborative action, by government - together with medical royal colleges, funding bodies, clinicians and children's health organisations if the UK is to meaningfully improve child health.

Currently the mortality rate for children under the age of five years in the UK is 30 per cent higher than the average for western Europe, with 5 excess deaths a day, compared to the best performing countries ⁽¹⁾

1. Societi Foundation pledge to work in partnership to highlight the need to collaborate and ensure accelerated investment in children's health.

Annual UK health research funding had been increasing during the 18 years to 2022, reaching £5 billion - but concerningly, it is now starting to plateau. Funding for children's health makes up a tiny proportion of research funding, despite children and young people representing almost a quarter of the UK population ⁽²⁾. The total UK research spend in the five years to 2018 was around £10 billion; the amount spent on child health research was around £300 million - just 3%. ⁽³⁾

2. We pledge to do all we can to champion the need for children's health research and work to secure funds for urgent research priorities for those affected by Kawasaki Disease.

Long-term heart damage from Kawasaki Disease can be reduced with rapid diagnosis and early treatment. 28% of children with Kawasaki Disease in the UK suffer lifelong heart complications, this rises to 39% in babies under 1 year of age. This is unacceptable and could be reduced by better awareness of the disease both by families and by doctors who need to be ready to see and treat Kawasaki Disease. We have made impact in improving awareness but government investment would measurably amplify the ability to get awareness messages out and protect every child's heart in the UK.

3. We are calling for action to protect children's hearts with government investment in awareness campaigns to get Kawasaki Disease known.

References

1. RCPCH "Turning the Tide: Harnessing the power of children's research",
2. UK Health Research Analysis 2022 (UK Clinical Research Collaboration, 2023) <https://hrcsonline.net/reports/analysis-reports/uk-health-research-analysis-2022/>
3. Bishop, N. (2022) Research: if everyone does a little, together we can do a huge amount



Persistent fever



Cracked lips /
'strawberry' tongue



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands

A Manifesto for Kawasaki Disease continued...

There are currently 53 studies registered worldwide on the clinical trials database investigating aspects of Kawasaki Disease. Only 10 of these studies have any study sites in Europe, most of which are in France. There is one single study listed as involving the UK and that is a study on genetic determinants at University College London.

Societi Foundation catalysed, co-designed and continues to be involved with a Europe-wide study for Kawasaki Disease treatment (KD-CAAP). We need urgent research on all aspects of Kawasaki Disease from the cause through to long term complications. With around 1000 children affected EVERY year in the UK we must do more to promote research within a population that is relevant to our own.

4. We will campaign to create an NIHR call for Kawasaki Disease research and continue to do so until real progress has been made in tackling all aspect of this devastating illness.

Societi Foundation will bring together experts in Kawasaki Disease and key influencers in health to specify, and seek adoption, for standardised pathways for excellence in care for all families affected by Kawasaki Disease, wherever they live in the UK.

Societi Foundation has already brought together a writing group to create guidelines on lifetime management of patients with heart damage due to Kawasaki Disease. We need support from the government to ensure the infrastructure and funding for these guidelines to be adopted uniformly by every NHS Trust throughout the UK.

5. We will work to achieve clear and funded, standardised pathways for care for all those affected by Kawasaki Disease - removing the current unacceptable postcode lottery of provision.

We will continue to respond to clinicians and develop the highest quality resources in a range of formats to ensure doctors in both primary and secondary care are ready to see and treat quickly Kawasaki Disease and do so following best practice guidelines. We will use various formats to deliver high quality education to ensure we deliver specialist knowledge in away that works for doctors in their own training and in educating others.

6. We will continually introduce, review and update and improve resources for GPs and paediatricians so they have more time for training and specialised knowledge development to improve patient care.

28% of all children affected by **Kawasaki Disease** will suffer some heart damage

39% of infants under 1 year will suffer coronary artery aneurysms as a result of **Kawasaki Disease**

3% of untreated children will die from **Kawasaki Disease**



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