

Fundraising Launch for Kawasaki Disease Research

'Questions of the Heart'



Questions



Research



Improving outcomes



What's the plan?

Societi has launched a research fund for U.K. based research into Kawasaki Disease, designed to find answers to key questions. We will select our research questions working closely with families, focusing on an area or areas which will help improve long term outcomes and/or care for those affected by Kawasaki Disease, here in the U.K.

-  **What will we study and why?** - We will work with families affected by Kawasaki Disease to identify the key questions they wish to see investigated - including describing what benefits and outcomes we seek from our research
-  **How?** - We will carefully design investigations which respond to one or more question/enquiry areas (as resources allow)
-  **How will this be delivered?** - We will undertake research which enables our question(s) to be answered
-  **Who will we involve?** - We will work in partnership, with the active participation of our family/patient community throughout
-  **What will our impact be?** - We will actively translate our research findings into practical implementation

Partners These include Societi Foundation, families and adult patients, KSSG - with clinical leadership from Professor Robert Tulloh and Professor Paul Brogan. We will actively gather more partners as we progress.

How can I support this or donate? You can make a donation now through our website www.societi.org.uk or download information from our website on fundraising - to help raise the funds we will need.

How can I get involved? If you'd like to get involved, please contact us through the contact form on our website, giving as much information as possible on how you want to be involved. The support we need right away is in fundraising. Can you help?

Timescales Depending on the rate of fundraising, we could aim to have the project underway in 2019. Timescales will be kept under review as fundraising progresses.

How will key questions for investigation be identified? Possible research areas will be identified through a discussion process with affected families, Societi supporters and KSSG members. Societi will coordinate a comprehensive engagement process with an aim to secure input from a minimum of 100 families/patients. Clinicians will then discuss and prioritise possible enquiry areas developing a short list. We will work with families to look at these selected areas and together, finally determine our chosen investigation areas.

How will research be undertaken? Clinical research leadership will be provided by Professor Robert Tulloh and Professor Paul Brogan. Dedicated resources (PhD x1, Research Co-ordinator (families) x 0.5 fte) will be employed to direct and deliver the day to day work. A Research Administrator will be employed if resources allow, to increase the impact of the team. Technical support will be identified. The employed research team will work closely with families as volunteer research team contributors. We will integrate their input and expertise as a core component of the wider research team.

The full design of the enquiries and investigations needed to enable research will be determined once research questions have been agreed.

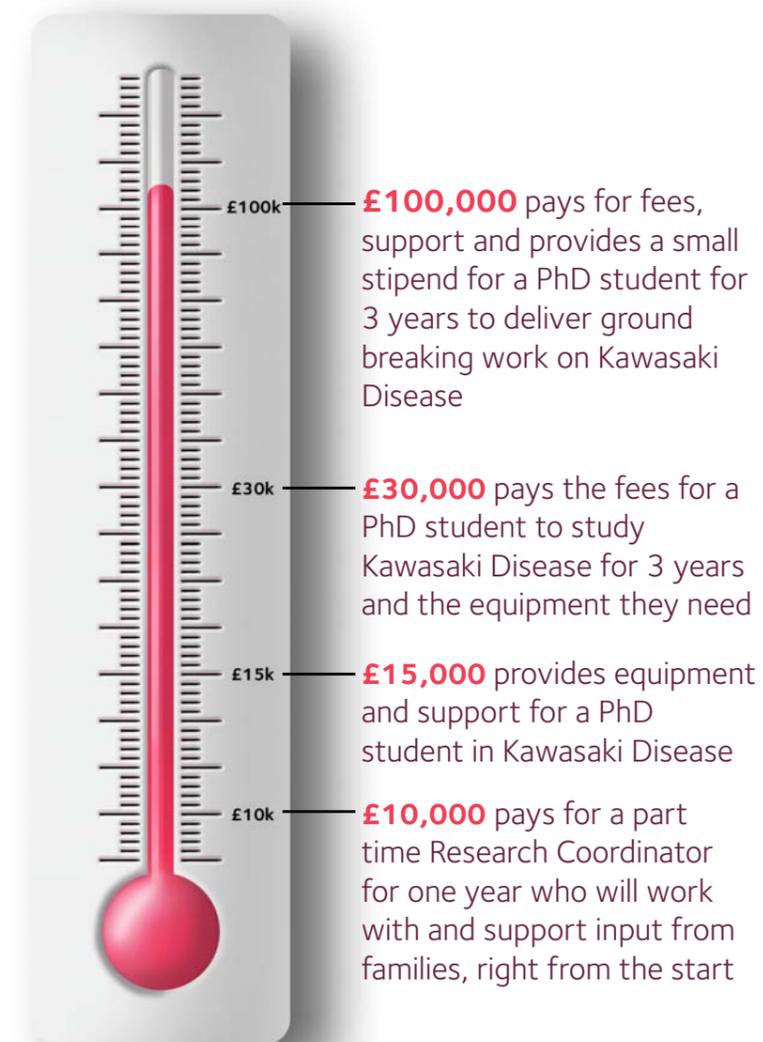
How will research be funded? We have launched this research fund for our project and as with all our work, we will need our supporters to raise the funds we need if we are to be successful. We will look for match funding opportunities too and apply for grants where we can, to help us reach our target.

Publishing findings We will be proactive and promptly publish interim and final research findings, with the aim of widely distributing data and key findings on an open access basis.

Translating findings - creating positive change quickly This research project will comprise much more than an academic enquiry into Kawasaki Disease with our questions being selected at the start with significant emphasis on potential to translate into actively improving clinical practice. An element of funding will be reserved to support translation activities.

How much money is needed?

How much funding we raise, and when we raise it will determine what we study and how quickly we make a start.



How can I stay informed? We will post regular updates on our fundraising campaign together with research project updates on our website, once we get underway!

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

...Together we will!

