



## Driving our UK Strategy for Kawasaki Disease



## Delivery Through Partnerships

### A Year in Societi

#### Key Partnership Milestones

Having worked to establish early partnerships with leading medics and key agencies, we quickly created a forward UK Strategy for Kawasaki Disease. This has framed our work in subsequent months and focused our energy. Our Achievements Timeline below summarises the many areas in which we have made real progress, and some of these project areas are described in a little more detail here.

#### Website - International Impact -

Identifying that there was no 'go-to' place for Kawasaki Disease, and much online information is out of date or incorrect

for a UK audience, we prioritised the development of the Societi website, working closely with the **UK Support Group KSSG**. Since its launch at the end of April 2016 we've already made an international mark; with visits from 26 countries, over 3,600 page views and more than 1,600 users. We continue to build and develop our web presence but opportunities exist, with investment, to create an even more powerful platform for awareness raising from our well established online foundation.

**National Clinical Trial** - With no major UK based research underway or planned, we

catalysed a discussion with leading medics to identify research requirements, linking these to changes which could then be pursued to benefit patients. A Clinical Trial working group, co-ordinated by Societi across three research centres is now underway with discussions well advanced with the British Heart Foundation for a possible major programme grant investment.

#### UK Kawasaki Disease Steering Group

– Appreciating the critical importance of a shared conversation across policy makers and funders, Societi brought together this group engaging senior officers from Public Health England, the NHS, the British

Heart Foundation, the BCCA, and leading clinicians. We are pursuing an agenda which changes the UK policy landscape for Kawasaki Disease care.

**E-Learning** – Given poor levels of medical understanding around Kawasaki Disease, developing training modules for clinicians quickly emerged as a priority project. The UK Steering Group endorsed our active pursuit of this and we are sourcing funds, which will allow us to develop the first two (of four) training modules – for Primary Care doctors and parents. We have successfully secured access to the NHS learning platform to support distribution.

### Our Achievements Timeline

Dec 2015 - Establishing Societi

Jan 2016 - Developing Partnerships

Feb 2016 - Establishing Societi's Scientific Advisory Board

Mar 2016 - A National Strategy for Kawasaki Disease

Apr 2016 - Societi is online

May 2016 - UK Research Project is outlined

Jun 2016 - A National Steering Group for Kawasaki Disease is Formed

Jul 2016 - Our National Agenda

Aug 2016 - Summer Newsletter

Sep 2016 - Join Twitter & work with the World Heart Federation

Oct 2016 - Advancing our E-learning

Nov 2016 - Sourcing E-learning funding

