

Rachael McCormack, Founder of Societi Foundation talks to Professor Damian Roland, Professor Paul Brogan and Professor Simon Kenny to discuss Kawasaki Disease.



Professor Damian Roland is a Fellow of the Royal College of Paediatrics and Child Health, a researcher in children's medicine, a leadership mentor and is hugely passionate about child health and sharing knowledge.



Rachael: A warm welcome to our World Heart Day podcast – bringing together influential clinical leaders from across the UK to talk all-things Kawasaki Disease.

I'm Rachael McCormack, Founder of Societi Foundation – and I'm delighted to be joined first by Professor Damian Roland.

Damian is a Professor of Paediatric Emergency medicine at University Hospitals Leicester – he's an active researcher and an unrelenting clinical educator.

Damian – I'm delighted you could join me.

Damian: Well, thank you so much for the invite. It's an absolute pleasure to be here.

Rachael: I'd like to start with a look ahead to this winter. Damian – with winter coming – and autumn and winter being the period in which we know most Kawasaki Disease cases can be seen.... in your busy Emergency Department, what will you be on the lookout for in terms of spotting Kawasaki Disease?

Damian: So, we've got a huge challenge. I can't underestimate how difficult the winter period is, for all conditions. So, from the parent who has someone with just a simple viral illness to those parents who have children with sepsis disease and especially those parents and carers with children who maybe have Kawasaki Disease – but no one knows it yet!

It's difficult and it's difficult because we have so many children presenting with fever, coughs, colds, being slightly unwell. And they all present at one time. Sometimes in my department, up to 30 patients an hour present all with very similar symptoms.

So the key thing that we try to instil in our staff is that you are literally trying to find a needle in a haystack. And you can do that by really listening to parents and taking good observations on those children.

Now, one of the things that does stand out with Kawasaki Disease... it's not in all cases, but parents will report how irritable and upset their child was. And that is a miserableness way out of proportion to a simple fever. These are the buzz words that I'm looking for.

When I'm taking a history from families, I particularly try to understand why the parent is concerned. Lots of families turn up because they're worried about a fever. They're worried about vomiting, they're worried about diarrhoea. I'm worried about none of those things because they're all just symptoms. What I'm worried about is why is the parent concerned. What it is about the child that has caused them to come here today. Because if they've literally only come because their child has a fever... actually it's really unlikely that child's unwell. For a child with Kawasaki Disease, it's likely because they can't control that fever, their child is so miserable even despite paracetamol or ibuprofen – where there's something just not quite right. And it's that 'not quite right' buzz word that we're looking for.

The other thing is – and this a real plea to parents out there – please take a temperature in a way that is approved. What we have is lots of families pitching up with forehead thermometers. These things you stick on your forehead. That's a disaster. It's completely unreliable. It tells you that you have a temperature when you haven't and it tells you that you haven't got a temperature when you have. The reason that's important is because fever is important for Kawasaki Disease. We know one of the definitions is 5 days [fever] or more. We also know that you can have Kawasaki Disease for less than 5 days of fever but you've still got a fever. If you present to the emergency department and you've just felt your child is warm – that doesn't really cut the mustard.

One of the problems we have during these bad economic times is making sure parents have access to thermometers and some of the basic advice and things they need to self care at home.

So, in summary, what I'm trying to do is listen to families. It's not just about the fever, it's about how people are feeling. But it's also, 'have you really had a fever?', 'how long have you had it for?' and maybe, what are some of the other associated symptoms that come with Kawasaki Disease, which I think Societi has been so good at promoting for so long.

Rachael: Thank you, Damian, some powerful insights shared, an invaluable aide memoir for doctors, on clues in diagnosing Kawasaki Disease – amongst the melee of bugs we know it tries to hide within! Thank you.

Rachael: My next guest is Professor Paul Brogan.



An expert in Kawasaki Disease, Professor Paul Brogan is Professor of Vasculitis and Honorary Consultant Paediatric Rheumatologist at Great Ormond Street Hospital. He brings strategic clinical direction to Societi Foundation as one of our clinical trustees.



Rachael: Paul is a Professor of Vasculitis within University College London's Institute of Child Health and is an Honorary Consultant Paediatric Rheumatologist at Great Ormond Street Hospital.

Paul is an undisputed expert in Kawasaki Disease, and leads a uniquely successful clinical and academic programme of work dedicated to the field of paediatric vasculitis – including Kawasaki Disease. Welcome Paul, thank you for joining me.

Paul: Thanks for having me.

Rachael: Paul, we've heard from Damian about some of the distinctive features of Kawasaki Disease. And we know thankfully, it's increasingly on the minds of doctors, which is hugely positive from the perspective of getting that all important rapid diagnosis. But this is in part linked to the emergence, during the pandemic of PIMS-TS and the challenges of differentiating, treating and following up these distinct illnesses. Could you share your thoughts? There are some key differences aren't there?

Paul: Thanks, Rachael. Yeah, I think that the important point to note is that, in the UK at least, I suspect that doctors have become very much better at differentiating the two, following the initial flurry of enthusiasm and perhaps confusion that there was a Kawasaki-like syndrome. It was very clear early on that the two syndromes are quite different.

Typically PIMS-TS or MIS-C as they call it in Europe and North America, affects older children, usually 8 to 15. Typically, we're looking at the epidemiological studies, abdominal pain seems to dominate the clinical picture alongside the hyperinflammation and the severely affected children are very shocked. And, whilst Kawasaki Disease can do that, it's much

less common. So older kids, the tummy pain and shock are very useful clinical rules of thumb to hang your hat on.

The other important point is that the pretest probability of having PIMS-TS – in other words, how common is it? – has gone way down. It seems that for probably various reasons, PIMS-TS is less common. Probably due to the fact that we are an increasingly vaccinated population including children. But perhaps also related to the mutations in the most prevalent strains of Omicron BA.4 and 5 that may be less immunogenic and with less potential to cause hyperinflammation.

Rachael: We know that Kawasaki Disease is often confused with other illnesses. Are there other things to look out for? Other characteristic markers that from a clinical point of view, we should be considering?

Paul: There is no diagnostic test for Kawasaki Disease. So the diagnostic criteria, as described initially by the Japanese and then by the American Heart Association stand true. So these are children who typically are under the age of five or it can affect all the children with a high unrelenting fever. You don't have to wait the full five days to make the diagnosis. C-reactive protein... simple blood tests available every hospital is very elevated. So beware of diagnosing a child with a viral illness in the context of a very high C-reactive protein.

Many infectious diseases can mimic Kawasaki Disease, toxic shock syndrome, measles, scarlet fever, other superantigen mediated types of diseases. And this has been the case right since the initial descriptions of the mucocutaneous lymph node syndrome. So, in order to make the diagnosis, you have to think of the diagnosis.

The key to making the diagnosis is to deeply understand that all of these clinical features such as rash and indurative oedema, lymphadenopathy, red lips and tongue, red eyes – may present sequentially. So remember to think about the diagnosis and then tick off the various features by asking the parents were they present? Even if they're no longer present. In particular, redness of the eyes can have been gone by the time they come to see a doctor. So it's like all of these things. If you think about the diagnosis, it's usually downhill from there.

Rachael: Thank you, Paul. Some expert and very valuable perspectives, which I'm sure will help colleagues facing diagnosis challenges and treatment decisions this winter. Thank you.

Rachael: And my final guest is Professor Simon Kenny.



Professor Simon Kenny is the National Clinical Director for Children and Young People at NHS England. Simon is an experienced Consultant Paediatric Surgeon with a demonstrated history of leadership in healthcare at hospital and national levels.



Rachael: Simon is a Consultant paediatric surgeon at Alder Hey Children's Hospital and an Honorary Professor at the University of Liverpool.

His global training – in the UK, US and Australia, together with wide ranging clinical practice including as Clinical Director of Surgery, Critical Care, Anaesthesia and Cardiac, positioned him perfectly for a key, national leadership role, which he also holds – as NHS England's National Clinical Director for Children and Young People. Simon – thank you for generously finding time to join me.

Simon: Hi Rachael. It's my pleasure. And really looking forward to this discussion.

Rachael: Thank you Simon. We've heard from Damian on challenges he anticipates in his Emergency Department in the coming very busy winter period, and we've also heard from Paul on the importance of keeping Kawasaki Disease high on the clinical radar as a potential diagnosis in children with persistent fever.

I wonder if you might offer some reflections on what you've heard, from a national perspective on what winter might hold?

Simon: Yes. You can tell the nights are drawing in now and the weather's starting to change. We've been through an incredibly challenging few years. And I'm sure that all parents, doctors and families would agree with that on a number of levels.

One of the things that has happened has been that there's very unusual patterns of disease, because of the non pharmacological interventions that took place with regards to

keeping children away from their normal social environments.

That caused a huge reduction in infections in 2020/21, which is having consequences. Some of the consequences are, there's a consequence of the reduced immunity of children because they've not been exposed to just the normal viruses we all see at school.

Some of it has caused disordered timing. So, we've seen viruses crop up that we normally see in these first few weeks in autumn – they've been cropping up in June and July. And so we've been responding to that.

From a national perspective, that response involves working really closely with the UK Health Security Agency and the Department of Education in terms of monitoring disease activity and responding to it. And last winter, we worked across government and with local authorities on a coordinated winter response, which I think kept children's services running last winter and reflects really the changes that we're seeing in terms of how health services are going to be organised in future.

What probably people don't see is our constant eye on data. So we have data sources running all the time in terms of what diseases are occurring. In particular with infections, but also with conditions like Kawasaki Disease. So since starting as National Clinical Director, we've been able to harness the power of electronic data so that we can now get a not quite real time, we have about a six week lag, but we start to see a picture of what's happening in terms of disease trends.

That was incredibly helpful during COVID, but its value is continuing. And I think strategically as we move forward as the health service, we need to leverage the power of data more.

From both clinicians and parents and family perspective, I think COVID is still around and it will still be there this winter and we can see those trends starting to develop again, slightly.

I think Paul's already touched on it, but just to emphasise that PIMS-TS, which is one of the conditions that can be confused with Kawasaki Disease, has almost vanished since the later variants of COVID. It's really not quite clear as to why that's happened, but it's certainly something that we're really happy about – not to see that disease.

I think that there may well have been some benefits in terms of promoting awareness around Kawasaki Disease by having that new disease, because it helped us spread the message about how we might think about children who have an unusual patterns of symptoms, and what might be going on.

Moving forwards, we continually monitor data and tragically look at things like child mortality trends, and not just the trends, but the stories underneath. And one of the things we do when we're looking at that data is to try and show what missed opportunities we have to promote earlier diagnosis.

Fortunately, I've not seen those trends in Kawasaki Disease at the moment, but I'd just like to assure people if we did see that, we would be very rapid in responding if we saw any emerging trends. I hope what we see is earlier more timely diagnosis of Kawasaki Disease and so that we can minimise

the consequences for children as they live the rest of their lives.

Rachael: *Thank you, Simon. Understanding how your national priorities and programs are underpinning delivery of better outcomes for children is, frankly, inspiring.*

There's clearly a huge momentum behind creating a step change in children's health under your leadership. And on behalf of the community I represent, I'd like to say thank you.

*And thank you to all those listening to our World Heart Day podcast on Kawasaki Disease. For more information, do check out the clinician's area on our website societi.org.uk. And let's keep Kawasaki Disease on the radar this winter because **together we can help to protect tiny hearts. Thank you.***

