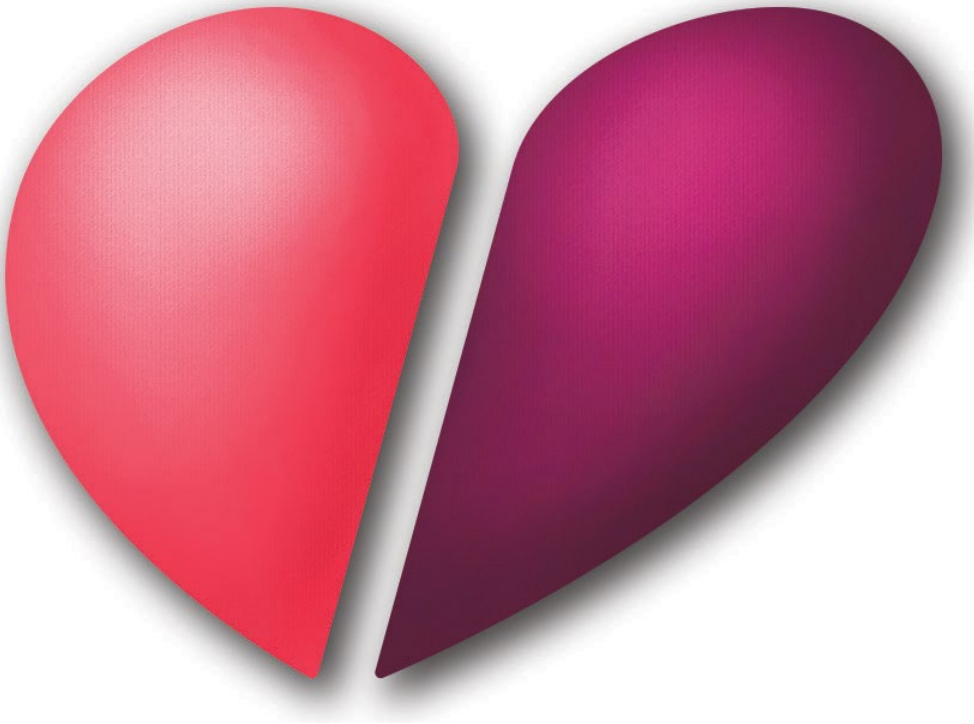
societi the UK Foundation for Kawasaki Disease

Kawasaki Disease

Awareness raising posters & leaflets pack



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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

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Awareness raising posters and leaflets

Click to donate

Donate

Please consider a donation to Societi Foundation. It's quick and simple to make a donation via JustGiving.

Thank you for downloading our awareness raising posters and leaflets pack. Raising awareness of Kawasaki Disease is the best way to ensure affected children are diagnosed and treated early. This WILL reduce the rate of life long heart damage in our children - THANK YOU!

We've created this poster pack to make it easy for you to download and print Kawasaki Disease information that can be handed out or displayed in your local community.

Click the red bars below to go straight to the resource or scroll though the pack to see all our posters. If you're unable to print out the information in this pack but would still like to raise awareness in your area, please do get in touch and we can send you the resources you need.

And... whatever you do to raise awareness – and wherever you do it – please do let us know! We'd love to promote what you're doing!

TEMPERS information leaflet

Our TEMPERS information leaflet includes a handy nmemonic to help you easily remember the symptoms of Kawasaki Disease. It also includes lots of other useful information too and is great for raising awareness either at events with your friends, family, at work or at school.

General awareness raising poster

Pin this poster in any busy place – from your place of work or school to your local Post Office – and help us let people know about Kawasaki Disease.

Clinician's information poster

This poster is designed to give clinician's some of the important facts about Kawasaki Disease. Why not pop some over to your local GP surgery or A&E department?

Kawasaki Disease Myths & Facts

Developed following many 'Kawasaki Conversations' with doctors and families who have experienced a Kawasaki Disease diagnosis, it's clear that there is out dated information in circulation about Kawasaki Disease which we're keen to help move on.

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Kawasaki Disease is predominantly a childhood illness though it can affect people of any age. Its cause is unknown. **Kawasaki Disease is the leading cause of acquired heart disease in children**. Awareness of Kawasaki Disease is currently low and it is often mistaken for other common childhood illnesses, leading to misdiagnosis and delayed treatment. Children who go untreated or who are treated later face higher risks of developing complications including life long heart damage.

Early diagnosis and treatment are key to better outcomes

...for our children

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The UK Foundation for Kawasaki Disease

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Kawasaki Disease?
Remember TEMPERS
Children with **Kawasaki Disease** *are characteristically irritable!*

Temperature - **Persistent high fever**

Erythema - reddened hands and feet with swelling

Mouth - dry, sore mouth, cracked lips, 'strawberry tongue'

Pace - **Treat early** to reduce potential heart damage

Eyes - bloodshot, non-sticky conjunctivitis

Rash

Swollen glands in neck, often just one side

If a child has a **PERSISTENT FEVER** *and two or more of these symptoms* **THINK KAWASAKI DISEASE!**

Kawasaki Disease
is the **#1** *cause of acquired heart disease in children in the UK...*

...help us change this.

Kawasaki Disease - who does it affect?
It is mostly a childhood illness with over 75% of those affected being under 5 years old but it affects older children too.

Kawasaki Disease - what's the issue?
In the UK awareness of Kawasaki Disease is low. Currently UK diagnosis and treatment times are too slow. **39%** of babies (under one year) treated for Kawasaki Disease develop serious heart problems. **28%** of diagnosed children experience heart complications. Overall, **19%** of children treated develop serious heart damage. For a few children every year Kawasaki Disease is fatal ...help us change this. We need everyone to know Kawasaki Disease as early diagnosis and treatment can prevent heart damage. (Data from BPSU Study, Kawasaki Disease UK & Ireland 2013-2015)

Kawasaki Disease - how common is it?
Hospital admissions in England for Kawasaki Disease have increased fourfold in the last ten years. It's more common than some types of meningitis. About 1 in 10,000 children are currently diagnosed each year and very poor levels of awareness mean many more children may be affected.

Kawasaki Disease - what can I do?
Know the symptoms and remember, symptoms may not appear all at once. Not all children present with all symptoms so - if a child has a **PERSISTENT FEVER** for 5 DAYS or more with 2 or more of the symptoms overleaf THINK Kawasaki Disease and seek URGENT medical advice. **You** could save a child's heart.

Kawasaki Disease is serious! Awareness is urgent!
Today, most people haven't heard of Kawasaki Disease. That's one of the biggest challenges we face. Help us get it known because Kawasaki Disease is increasingly common in the UK. Too many children and young people today have lifetime heart damage because of Kawasaki Disease ...help us change this. For more information visit societi.org.uk

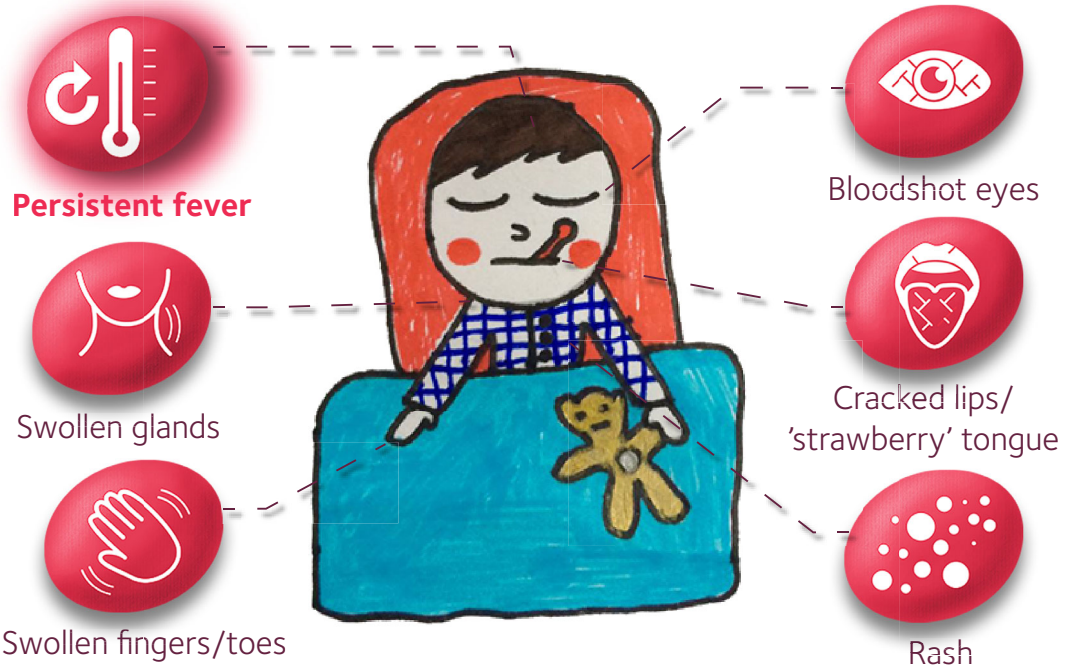
Endorsed by
RCPCH
Royal College of Paediatrics and Child Health
Leading the way in Children's Health

THINK 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

Kawasaki Disease Symptoms:



Kawasaki Disease is **increasingly common** in the UK

If a child has a **persistent high fever** for 5 days or more, with TWO or more of these symptoms please **THINK Kawasaki Disease**

Kawasaki Disease can be present with some or all of these symptoms

Please **EXPECT** to see it, be **READY** to treat it!

Societi Foundation is a registered charity in England and Wales (no. 1173755)

EARLY TREATMENT IS KEY ...PLEASE DON'T DELAY

Children diagnosed and treated in **less than 7 days** from onset of fever have a much reduced risk of life long heart damage

Kawasaki Disease is predominantly a childhood illness. Its cause is unknown. **Kawasaki Disease is the leading cause of acquired heart disease in children**. It is often mistaken for other common childhood illnesses, leading to delayed treatment. Children who go untreated or who are treated later face significantly higher risks of developing serious complications including life long heart damage. Babies under one year are at greatest risk of serious heart damage **Early diagnosis and treatment is critical.**

Current UK & Ireland Outcomes for Kawasaki Disease

7+ days — The current average diagnosis time for Kawasaki Disease is 7.8 days **This is too slow!**

39% — 39% of babies with Kawasaki Disease develop coronary artery aneurysms **This is too high!**

19% — 19% of children overall develop coronary artery aneurysms **This is too high!**

28% — 28% of children overall have some heart damage **This is too high!**

TOGETHER WE CAN CHANGE THIS!

Poster data from Tulloh et al, Kawasaki Disease: a prospective population survey UK & Ireland 2013-15

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THINK Kawasaki Disease...

...for our children

Kawasaki Disease *is the leading cause of acquired heart disease in UK children...*

...faster diagnosis and treatment can change that!

Symptoms

Remember **TEMPERS**

Children with **Kawasaki Disease** *are characteristically irritable!*

If a child has a **PERSISTENT FEVER** *& two or more of these symptoms* **THINK KAWASAKI DISEASE!**

T Temperature - **Persistent high fever**

E Erythema - reddened hands and feet with swelling

M Mouth - dry, sore mouth, cracked lips, 'strawberry tongue'

P Pace - **Treat early** to reduce potential heart damage

E Eyes - bloodshot, non-sticky conjunctivitis

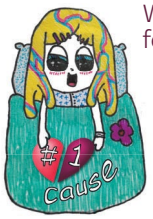
R Rash

S Swollen glands in neck, often just one side

Case History

Case history is important in **Kawasaki Disease -** *symptoms can appear over time. Not all symptoms appear in all children*

Differential Diagnosis



When ruling out the many other causes of fever in children...

...please **THINK Kawasaki Disease**.

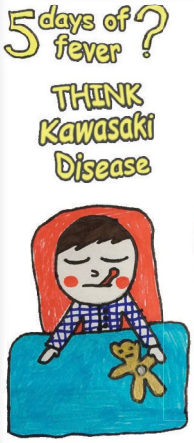
~~*Virus?*~~ ~~*Scarlet Fever?*~~

~~*Meningitis?*~~ ~~*Tonsillitis?*~~

Please...THINK Kawasaki Disease

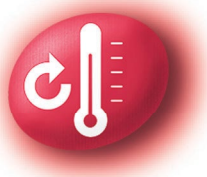
~~*Slapped Cheek?*~~

~~*Strep Throat?*~~ ~~*Measles?*~~



Acute **Kawasaki Disease** *is always an* **emergency!**

Persistent Fever

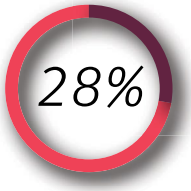


Kawasaki Disease *should always be considered in any child with unexplained* **persistent fever**

Increasingly Common

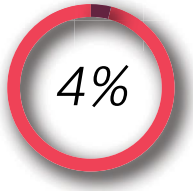
Hospital admissions increased in England **FOURFOLD** *in the last decade -* **EXPECT** *to see it,* **BE READY** *to treat it*

Heart Damage*



Where we are today of treated children with heart damage

This is too high!



Where we need to be (or less) of treated children with heart damage

Treatment Time*

Refer URGENTLY to paediatrician for **treatment within 5 days** *from onset of fever*

BPSU study findings show children treated early had a lower risk of lifetime heart damage than children treated later.

EARLY TREATMENT IS KEY *to reduce risk of heart damage*

...PLEASE DONT DELAY!

Numbers to Remember*

39% *of treated infants develop coronary artery aneurysms*

19% *of treated children overall develop coronary artery aneurysms*

#1 *cause of acquired heart disease in UK children*

**BPSU survey Kawasaki Disease, UK and Ireland 2013-2015*

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About this leaflet

This leaflet has been written for parents and carers of children who have been affected by Kawasaki Disease. The information it contains has been reviewed by doctors from Societi Foundation's Scientific Advisory Board. It is designed for parents and can also be shared with school teachers or care givers to explain more about some of the longer term issues which some children with Kawasaki Disease may experience.

See a doctor if you have concerns!

This leaflet **does not provide medical advice.** It is intended to be a guide for general information purposes only. If you have concerns about your child, please contact your usual doctor or GP.

Important points:

1. Whilst you'll read about a range of possible longer term issues in this leaflet, following Kawasaki Disease most children experience just one or two, if any of these issues.

2. It's important to know that the majority of longer term issues will resolve within one to two years or well before then, on their own without additional treatment for most children. If you have concerns, please see your usual doctor or GP.

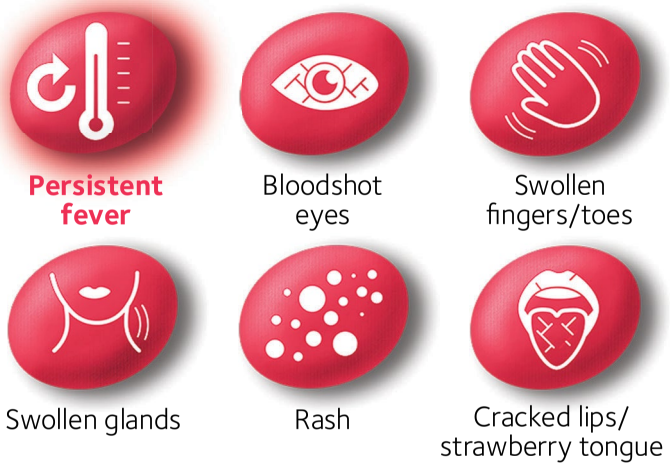
3. If a child has serious, lasting complications following Kawasaki Disease, a medical care and action plan should be put in place at school / nursery. If this is necessary, your child's doctor will provide guidance for this.

If you would like more information please visit www.societi.org.uk

societi.org.uk

About **Kawasaki Disease**

Kawasaki Disease is a serious disease which affects hundreds of children in the UK each year. Most children affected are under 5 years but about 25% of patients are older children. Kawasaki Disease has a range of symptoms including:



Persistent fever

Bloodshot eyes

Swollen fingers/toes

Swollen glands

Rash

Cracked lips/ strawberry tongue

Kawasaki Disease can be present with some or all of these symptoms. **If a child has a persistent fever with any two** or more of these symptoms please **THINK** Kawasaki Disease.

Most of these symptoms occur in the first few days of the illness, although they are often not all present at the same time. There are sometimes other symptoms too - loss of appetite, diarrhoea, tummy ache, vomiting and jaundice. Typically, children with Kawasaki Disease are very irritable.

Kawasaki Disease is a serious illness as it can cause coronary artery damage – damage to the blood vessels in the heart. Early treatment is key to reduce the risk of lifelong serious heart damage. **Kawasaki Disease is the leading cause of acquired heart disease in children in the UK.**

THANK YOU

If you have found the information in this leaflet helpful, please consider making a donation to Societi Foundation. Your donations support our work to share information about Kawasaki Disease and protect children's hearts.

Societi is a registered charity in England & Wales (no.1173755)

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The UK Foundation for Kawasaki Disease

Kawasaki Disease

Understanding some of the possible longer term issues

A short guide for parents & carers of children affected by **Kawasaki Disease**

societi.org.uk

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Eczema & skin peeling

After Kawasaki Disease, some children have ongoing problems with occasional dry skin areas and skin peeling. Dry lips can be treated with Vaseline, this does help. Creams such as E45 can be used on dry, peeling skin if it is uncomfortable. Whatever cream you choose to use, pick one without antibiotics or perfumes as these ingredients can irritate the skin. Do discourage children from picking the affected areas too, as this could lead to infection.

Exercise

All children can exercise after Kawasaki Disease, in fact regular exercise is important! Children may be advised by their doctor to avoid certain types of exercise if they have very serious heart damage. This would include those children taking blood thinning medicines like warfarin and clexane where a doctor may advise that they should not take part in contact sports, for instance. If there need to be any restrictions on exercise, your child's doctor will advise you in detail. If you have any questions about exercise after Kawasaki Disease, discuss these with your doctor.

Joints

Nearly half of children affected by Kawasaki Disease have some initial issues with joint pain or swelling in the first few weeks. Areas most affected include large joints - elbows, knees or ankles. This can be quite painful but over the counter children's painkillers can be given to help (ibuprofen should be avoided in children who are already taking aspirin.) Very occasionally joint pain can continue for longer – if this happens, discuss it with your doctor.

Tummy pain

Many children complain of tummy pain and possibly have vomiting and/or diarrhoea when first ill with Kawasaki Disease - this doesn't usually last long. Ongoing tummy pain could however be linked to other issues, for instance it can sometimes be caused by some types of medicines (see also *Treatments & precautions*). Speak to your doctor if this is a concern.

Behaviour

Some children will have difficulty concentrating, be more restless or have trouble sleeping for a short time after Kawasaki Disease. Some will experience anxiety linked often to awareness of a difficult period in hospital and older children may be alert to having been seriously unwell. This can lead to worries about health or a more generalised anxiety. This shouldn't present lasting difficulties for most children and studies show that this improves, with almost all children recovering within 1 to 2 years. If other mental health issues emerge, these are probably not linked to Kawasaki Disease and a doctor should be consulted.

Tiredness

Having been seriously ill with Kawasaki Disease, many children experience tiredness and for some this can last a few weeks or months. After Kawasaki Disease, the recovery process will be different for each child and some may have low levels of energy for some time after being initially unwell. If tiredness is not improving and is affecting school (for instance) discuss it with your doctor.

Treatments & precautions

The main approach to treating Kawasaki Disease initially is with two medicines called immunoglobulin and aspirin. After treatment with immunoglobulin, your child's doctor will advise that for a period of 6 months, they will need to avoid having live vaccinations. This is simply because the antibodies in immunoglobulin may mean that vaccination might not be effective.

All children with Kawasaki Disease will also be treated initially with low dose aspirin for about 6 weeks. After 6 weeks an echocardiogram (ultrasound of the heart) will be done to check for any damage to the heart. Aspirin will be stopped in children with no lasting heart damage.

In children who develop lasting heart damage, low dose aspirin may be continued longer term.

Some children may experience side effects whilst taking aspirin long term; these can include headaches, tummy pain and tiredness. Medicines to protect the tummy are often given with aspirin to limit side effects (see also *Bruising*).

Parents will be advised if a child is taking aspirin long term, following their initial illness with Kawasaki Disease, to stop this for a few days if there is a high fever (39°C+) This is to reduce the risk of Reyes syndrome, a rare but potentially very serious illness.

Other treatments

Other medicines may also be given to those with the most serious heart damage, for instance children with giant coronary artery aneurysms. Treatments may include warfarin or clexane to help thin the blood. For these children, precautions may be needed such as safety helmets for playtimes, which help to avoid knocks to the head and for older children, avoiding contact sports (see also *Exercise*).

Bruising

Following Kawasaki Disease, if a child is taking aspirin and blood thinning medicines, they may bruise much more easily. It is important that nursery/school is aware of this and it is noted in the child or young persons individual record.

A repeat of some symptoms?

Many children will experience repeated symptoms or "reactivation". This might happen when they have a cold, and they get a very high fever, red eyes or a rash, or peeling skin. This happens very frequently in children who have had Kawasaki Disease but almost always, it is not another episode of Kawasaki Disease. It's the child responding differently to a bug or infection after Kawasaki Disease. These symptoms can be worrying for parents even though it's not Kawasaki Disease.

It's important to know that actually getting Kawasaki Disease again is very rare - and only happens in 2% of children. Speak to your doctor if you have concerns.

Flexibility & support

After a serious illness like Kawasaki Disease, children and their families may need support as normal routines such as nursery and school are resumed. Some flexibility will be essential to help children settle back in - especially if there are significant adjustments now needed, like protective safety helmets mentioned above or regular medication.

Some children will need routine follow up medical appointments and may miss school / nursery because of this.

Working together between schools and families is important to help minimise any negative impact of necessary changes like these.

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Think you know **Kawasaki Disease***?*
Here are some common clinical **myths** *and the* **facts** *behind them!*

This "Myths and Facts" summary has been prepared for clinicians with input from Professor Robert Tulloh, internationally recognised expert in Kawasaki Disease. These myths hamper care and delay diagnosis - and so adversely affect outcomes for children. Please contact us if you know of other myths and we'll help debunk those too!

Symptoms & Treatment

Myth: A characteristic symptom of Kawasaki Disease essential for diagnosis is peeling of fingers/ soles of feet

Fact: If skin peeling occurs - and it only appears in some patients - this will only occur after 10-21 days. **Never** dismiss a case on the basis of skin peeling being absent

Myth: There is a treatment window for IVIG of 10 days

Fact: There is no "window" or cut off point for IVIG. If clinical benefits are possible and inflammation is ongoing (fever, elevated CRP) - TREAT!
And **do not delay** IVIG assuming a 10 day window for effective treatment. Current treatment times are too slow. Aim to treat at 5 days (ASAP) after fever onset - early treatment is key to reduce risk of heart damage!

Myth: Kawasaki Disease has no characteristic symptoms

Fact: The strongest defining symptom which should always trigger suspicion of Kawasaki Disease is a persistent, high unremitting fever for 5 days

Myth: IVIG reduces heart damage from 25% to 5%

Fact: **19%** of all children develop permanent damage and **39%** infants develop coronary artery aneurysms despite IVIG - linked to delayed treatment. Early treatment is critical!

Heart Damage

Myth: Kawasaki Disease rarely causes heart damage

Fact: In the UK, 28% of affected children have heart damage, 19% have lasting coronary artery aneurysms. 39% of infants develop coronary artery aneurysms. Late treatment is linked to poorer outcomes

Who & How Many?

Myth: Child is too young / too old for Kawasaki Disease

Fact: You **will** see Kawasaki Disease in very young and older children. It can be most severe in infants (under 1yr) and c.25% of those affected are older than 5 years.

Myth: Kawasaki Disease is very rare, you'll never see it

Fact: Kawasaki Disease is **increasingly common**. Cases are doubling globally every 10 years. In England, hospital admissions for Kawasaki Disease increased fourfold in the last decade. It's more common than bacterial meningitis and measles. Please EXPECT to see it and be READY to treat it

Diagnosis

Myth: Echocardiograms are a useful way to confirm a Kawasaki Disease diagnosis

Fact: Echo is very useful to confirm heart damage but Kawasaki Disease if treated early, does not always lead to heart damage. Echo can help diagnose an atypical case. **Never delay treatment** awaiting access to an echo if Kawasaki Disease is suspected

Myth: Persistent fever plus all 5 symptoms must all be present to confirm a diagnosis of Kawasaki Disease

Fact: **47% of UK/Ireland cases are incomplete** i.e. do not have all symptoms. Kawasaki Disease can be diagnosed with fewer symptoms - **not all patients exhibit all symptoms** and symptoms can appear in series. If a child presents with persistent fever and 2 or more Kawasaki Disease symptoms, always THINK Kawasaki Disease

Impacts

Myth: The only lasting damage from Kawasaki Disease is to the heart

Fact: Kawasaki Disease is a systemic disease and effects can be wide ranging. It can affect hearing, sight, kidneys, joints and cause hydrops of the gallbladder. It can also cause behavioural issues. See Societi Long Term Effects leaflet*

Long-Term Care

Myth: After coronary artery aneurysms have 'resolved', patients can be fully discharged from care

Fact: All patients with heart damage which persist beyond the acute phase (even if it 'resolves' later) require **lifelong specialist care** and are at increased risk of major cardiac events (see NHSI PSA 5/2016*)

Myth: There are no known future health risks for patients

Fact: Patients with lasting cardiac damage are known to be at **higher risk of artery stenosis** and calcification. Lifetime specialist care is essential. See Lifetime cardiac management guidance for clinical follow up regime

Myth: A past patient history of Kawasaki Disease is an irrelevant clinical consideration later in life

Fact: **Adverse cardiac events** with atypical presentation can occur in patients with a past history of Kawasaki Disease and this history should always inform clinical care - see NHSI Patient Safety Alert May 2016*

Please see societi.org.uk - Resources - For Clinicians - Here you will find the Lifetime cardiac management guidance , Societi long term effects leaflet and the *May 2016 NHSI Kawasaki Disease Patient Safety Alert

Kawasaki Disease?
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