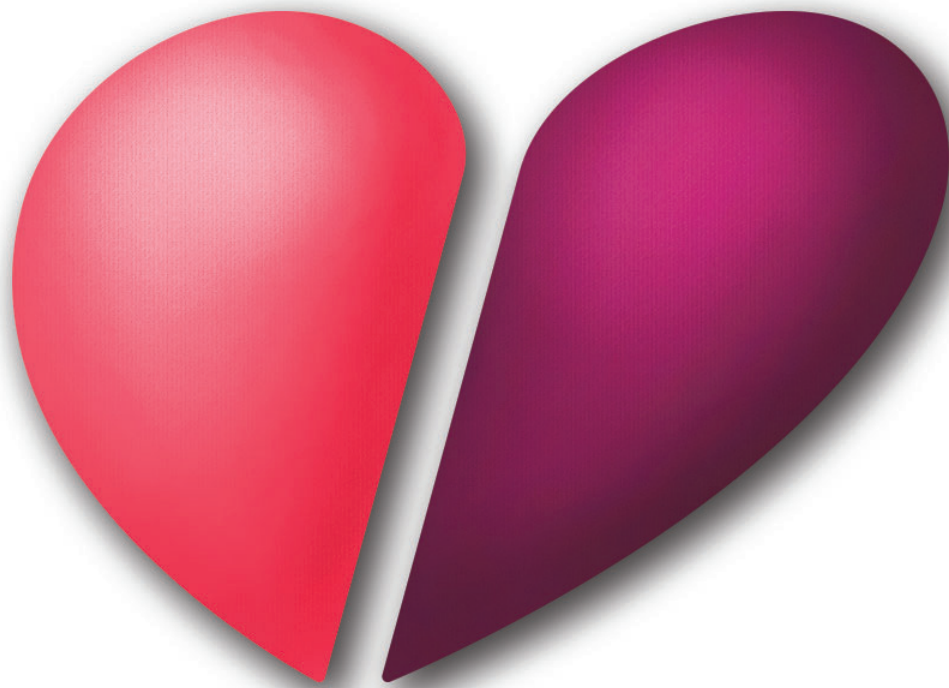


societì *the UK Foundation
for Kawasaki Disease*

Kawasaki Disease
School's Information Pack



societì
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*

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

...**TOGETHER** we will.

Dear Head Teacher

Kawasaki Disease School's Information Pack

I am writing to ask if you would consider raising awareness of Kawasaki Disease within the school and to send you a Kawasaki Disease information pack which has been developed by Societi, the UK Foundation for Kawasaki Disease. I think you'd like to know about Kawasaki Disease - why? Because it's a very serious children's disease which is more common than measles and bacterial meningitis. Yet not many parents, carers or doctors know it. Kawasaki Disease is increasingly common in the UK and today it is the **leading cause of acquired heart disease in children in the UK**. Raising awareness of the disease is extremely important, as recognising the symptoms and treating early could save a child's heart from life-long damage.

Little known but increasingly common, Kawasaki Disease presents with symptoms, many of which mirror those of other common childhood diseases such as Scarlet Fever. This can lead to misdiagnosis and a delay in treatment, which severely affects outcomes. In the UK, 39% of infants (children under one) develop coronary artery aneurysms - this is very serious heart damage and has been linked to delay in treatment. 28% of children overall suffer some heart damage after being affected by Kawasaki Disease. Heart damage may be avoided if treated early.

Kawasaki Disease has a range of symptoms including a characteristic and distinctively persistent high fever for five days or more and two or more of the symptoms opposite.

Kawasaki Disease can be present with some or all of these symptoms. A persistent high fever is the one defining symptom which will always be present. The symptoms of Kawasaki Disease can also appear in series (i.e. not all at once) over a few days.

I have enclosed an information pack which I hope you will find helpful. You'll find information leaflets to share with parents and general awareness posters suitable for display in your classrooms. The pack also includes a longer-term issues leaflet which provides helpful information to carers of children affected by Kawasaki Disease. If you have any questions, please do get in touch. If you'd like any further copies of the information provided in the pack, printable copies can be downloaded from the Societi website at www.societi.org.uk - or simply get in touch via their website or email info@societi.co.uk.

Thank you in advance for your help in raising awareness - it is so very important everyone knows Kawasaki Disease so that we can help protect our children's hearts.

Yours sincerely,

Enc. Kawasaki Disease School Information Pack



Persistent fever



Cracked lips /
'strawberry' tongue



Rash



Swollen fingers/toes



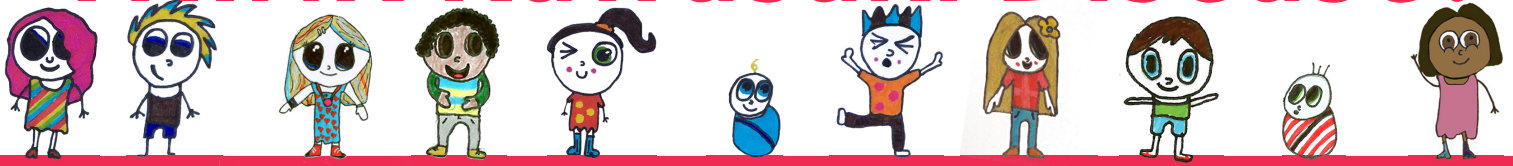
Bloodshot eyes



Swollen glands



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:

- Persistent fever** (Icon: Thermometer with a circular arrow)
- Bloodshot eyes** (Icon: Eye with red veins)
- Swollen glands** (Icon: Neck with swollen lymph nodes)
- Cracked lips/ 'strawberry' tongue** (Icon: Mouth with cracked lips and red tongue)
- Swollen fingers/toes** (Icon: Hand with swollen fingers)
- Rash** (Icon: Skin with white spots)

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** these symptoms

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

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

EARLY TREATMENT IS KEY
PLEASE DON'T DELAY! Children diagnosed and treated in **less than 5 days** from onset of fever have a **much reduced risk** of life long heart damage

BABIES UNDER 1 YEAR
 can show **fewest symptoms** but have the **highest risk** of serious heart damage

Kawasaki Disease is mostly a childhood illness and there's no known cause. It's **the leading cause of acquired heart disease in UK children.**

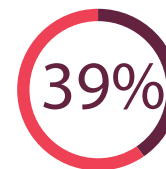
It's **often mistaken** for other common childhood illnesses, leading to delayed treatment. Children who are untreated or who are treated later face a much higher risk of developing serious complications, including life-long heart damage.

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



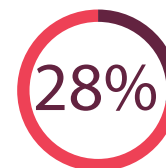
The current average diagnosis time for Kawasaki Disease is 7.8 days
This is too slow!



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



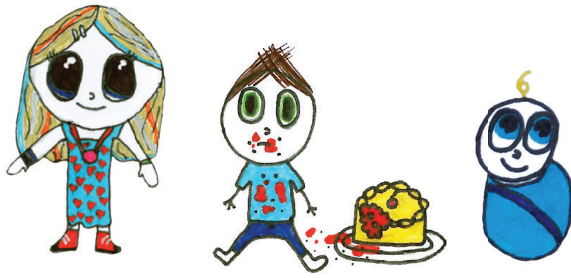
19% of children overall develop coronary artery aneurysms
This is too high!



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

TOGETHER WE CAN CHANGE THIS!

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



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

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



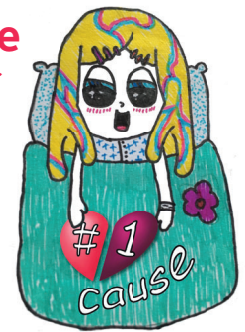
Swollen glands in neck, often just one side

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

5 days of fever?
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

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



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)

societi
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.

societì Non Uniform Day! for Kawasaki Disease Awareness!

We're having a Non Uniform Day!
Join us and help protect tiny hearts!

Location:.....

Date:..... Time:.....



Would **you** know the symptoms?

Kawasaki Disease is the leading cause of acquired heart disease in children in the UK - we want every parent and doctor to be able to recognise the symptoms and help protect tiny hearts!
If a child has persistent fever plus any two or more of these symptoms, please THINK Kawasaki Disease!



Persistent fever



Cracked lips/'strawberry' tongue



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands

societì Super Hero Day! for Kawasaki Disease Awareness!

We're having a Super Hero Day!
Join us and help protect tiny hearts!

Location:.....

Date:..... Time:.....



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Would **you** know the symptoms?



Persistent fever



Cracked lips/'strawberry' tongue



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands

societi Wear Red Day !

for Kawasaki Disease Awareness

Kawasaki Disease is the leading cause of acquired heart disease in children in the UK - we want every parent and doctor to be able to recognise the symptoms and help to save tiny hearts



Write your details here

Would **you** know the symptoms?



Persistent fever



Cracked lips/'strawberry' tongue



Rash



Swollen fingers/toes



Bloodshot eyes



Swollen glands

www.justgiving.com/societi

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The UK Foundation for Kawasaki Disease

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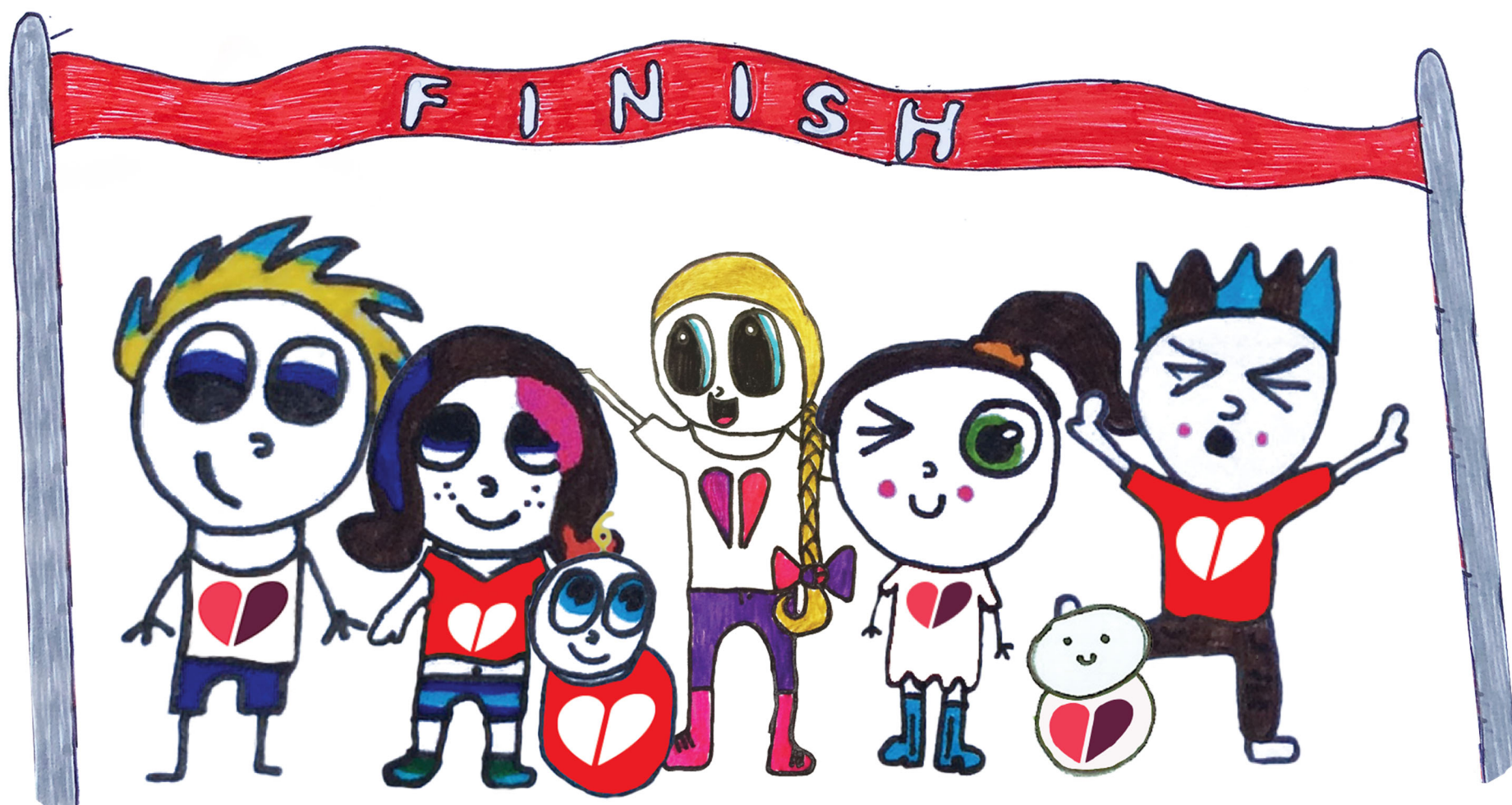
societi.org.uk

societì Fun Mile! for Kawasaki Disease Awareness!

We're holding a Fun Mile!
Join us and help protect tiny hearts!

Location:.....

Date:..... Time:.....



Would **you** know the symptoms?

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