Kawasaki Disease In Hospital Instructions

What is Kawasaki disease?

- Also known as Mucocutaneous Lymph Node Syndrome
- In 20% of children the blood vessels in the heart grow larger than normal.
- In some children the blood vessel grows so big it forms coronary aneurysms.

Why does it happen?

- No reason has been found
- Doctors have looked at many different things: bacteria, viruses, chemicals or things in the house or school. These are not the reason.
- Some doctors think that the child's body is trying to fight something and it makes the body's parts fight themselves.
- The child's genes may be part of the reason.

What are the signs?

- a fever for 5 or more days
- a skin rash of various types
- swollen, dry, cracked lips
- red, swollen tongue (called "strawberry tongue")
- red (red of the white part) eyes without any drainage
- swollen lymph nodes in the neck (occurs only in 50 to 75% of the cases)
- swelling and redness of the hands and feet. Later on the skin of the hands and feet peels.

How is it diagnosed?

- Your child will be checked for other illness that have some of the same signs or symptoms
- There is no one blood test for Kawasaki Disease
- If your child has a fever for many days and also has 4 or 5 of the other signs from the list then they will probably be diagnosed with Kawasaki Disease.
- Your child also may have "Incomplete Kawasaki Disease" if your child has a fever and less than 4 of the signs.
- Children less than 1 years old are more often diagnosed with the "Incomplete" form of the Disease
- It is very important to make the diagnosis within 7-10 days of the start of the fever and begin the treatment to have the best chance of preventing the heart problems.

What are the complications of Kawasaki disease?

When untreated, Kawasaki disease can cause many serious problems including:

- Swelling and irritation of the coronary arteries in the heart. Coronary arteries are the blood vessels that carry blood to the muscle of the heart.
- Weak, swollen (bulging) areas of the coronary arteries are called aneurysms. Blood can clot in an aneurysm and block the blood flow. When the blood flow is blocked to the heart, the heart muscle can be damaged (heart attack).
- About 25% of the children who get Kawasaki Disease and are not treated, will get coronary artery aneurysms.

Less serious problems that usually resolve with time include:

- Weakening of the heart muscle (myocarditis) causing the heart muscle to pump blood poorly.
- Joint swelling (arthritis) and refusing to walk
- Poor digestion
- Diarrhea
- Gallbladder problems
- Irritability (very whiney and crying)
- Not liking bright lights

What is the treatment?

- Child needs to be hospitalized
- If the disease is treated in the first 5-10 days of the beginning of the fever, that is the best chance of stopping the complications of Kawasaki Disease
- Your child will receive aspirin by mouth and gamma globulins (IVIG) through a vein (IV).
- These medicines help reduce the chance of heart problems, especially the coronary artery aneurysms
- In about 15% of cases, other treatments such as steroids or other immune system medications may be needed if the IVIG does not work the first time
- When your child goes home from the hospital you will be instructed to give low dose aspirin and will keep giving this until the cardiologist (a special doctor who takes care of children's hearts) says it is okay to stop.
- The usual amount of low dose aspirin is one half to one full 81mg tablet one time every day
- Your child should have an appointment with the cardiologist in 2 to 3 weeks after discharge in the Kawasaki Clinic.
- At the follow up visits in the Kawasaki Clinic your child will have testing, an echocardiogram and ECG, to look at the coronary arteries in the heart and to look at how well the heart is squeezing. These are the same tests your child had while in the hospital.
- Your child will also have lab (blood) tests.
- The pictures of the heart and the blood test help the doctor to see how the inflammation or irritation is going away

- If your child has coronary artery aneurysms, your child may need to be on more medication and be seen more often by the cardiologist to monitor their heart.

Reye Syndrome & Vaccinations after Kawasaki's Disease

- Low-dose aspirin does not cause Reye Syndrome.
- Ibuprofen (motrin, advil) generally should be avoided while taking aspirin as it can bother the stomach and can make the aspirin not work as well.
- Live virus vaccinations (measles and chickenpox) should be delayed for 11 months after receiving IVIG because they will not work as well. Other vaccines are okay to give. If your child is exposed to chickenpox or measles the primary care provider may give the vaccination and then repeat it again after 11 months.
- All children ≥6 months and their family members should be given a seasonal FLU vaccine every year. The FLU season usually begins in November.

When should I call my child's doctor?

During the first 8 weeks after going home from the hospital, you may need to call your child's doctor.

Call immediately if:

- Your child has a temperature of 100.5 or higher.
- Your child has any of the signs of Kawasaki Disease (rash, red eyes, crankiness, red or puffy hands and feet, red lips/tongue/throat, swollen glands in the neck).
- Your child is acting very sick.
- Your child is having chest pain, color changes and/or shortness of breath.
- Your child is on a blood thinner please see separate instructions.

Call during the day if:

- You would like more information about Kawasaki disease.
- You have questions about your child and their health.

Weekdays (Monday through Friday, 8:00-5:00 PM)
call the Heart Institute Kawasaki Nurse Care Manager at (323) 361-8638 or (323) 361-4622

Weekends, evenings, and holidays
call the hospital operator (323) 660-2450 and ask to speak with the cardiologist on call.

Sources:

. "Diagnosis, Treatment, and Long-Term Management of Kawasaki Disease: A Scientific Statement for Health Professionals From the American Heart Association." *American Heart Association.* **2017.**