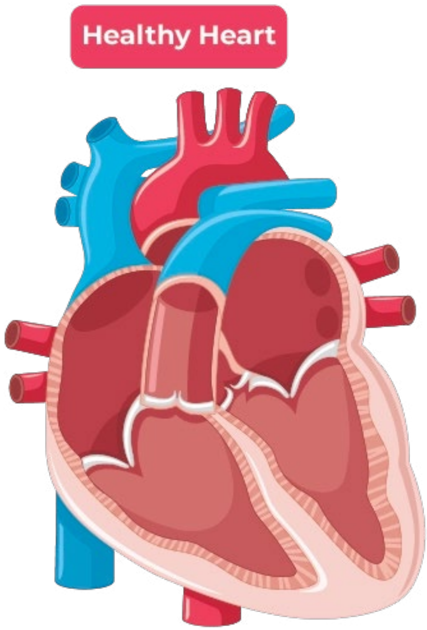
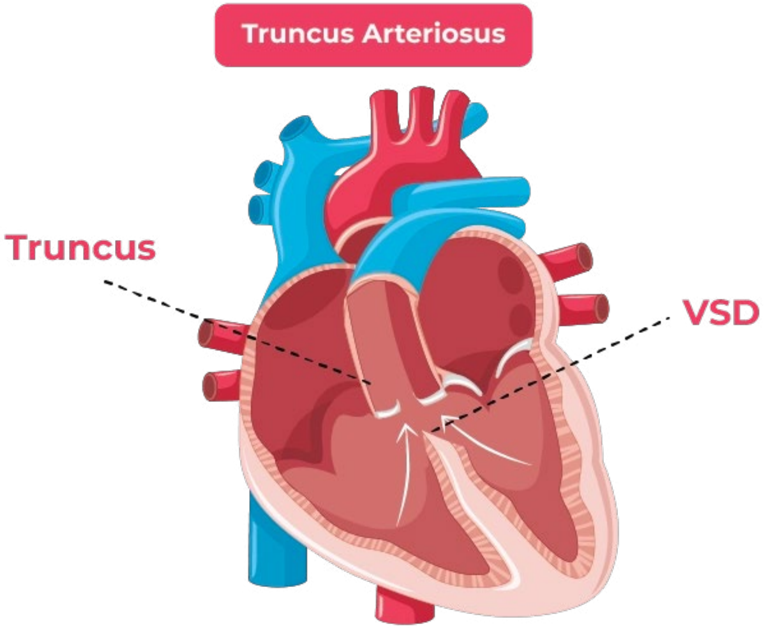
PARENT GUIDE:

TRUNCUS ARTERIOSUS





WHAT IS TRUNCUS ARTERIOSUS IN CHILDREN?

Truncus Arteriosus is a rare congenital heart defect in children that causes the child to be born with a large single blood vessel instead of two separate vessels.

In a normal heart, there are two blood vessels. One comes out of the left ventricle and carries blood around the body, the other carries blood to the lungs and comes out of the right ventricle. These are called the “Great Vessels of the heart”.

With Truncus Arteriosus, the heart only has one large blood vessel, meaning oxygen-rich and oxygen-poor blood is able to mix and flow from the heart to the body and lungs.

THE SIGNS AND SYMPTOMS OF TRUNCUS ARTERIOSUS

A baby born with Truncus Arteriosus may show a variety of different symptoms, such as:

- A blue or purple tint to the skin
- Fast or laboured breathing
- Difficulty feeding
- Issues with gaining weight
- Increased tiredness
- Increased sweating, often while feeding
- Heart murmurs

A child born with Truncus Arteriosus may not look sick straight away, but if they do show any of the signs or symptoms listed above, you should always consult with your child's doctor. Often, issues with the heart will present themselves in very similar ways, which is why it is important to get a diagnosis as soon as possible.

HOW IS TRUNCUS ARTERIOSUS DIAGNOSED?

Doctors will usually find Truncus Arteriosus before birth through a fetal echocardiogram, which is a test that uses sound waves to create a moving picture of the heart. This test allows doctors to see how the baby's heart looks and to check if it is functioning the way it should be while in the womb.

Truncus Arteriosus is not always diagnosed prenatally and detection can be missed due to various factors. The condition may be discovered after birth, such as if a newborn shows signs of cyanosis (bluish skin), difficulty breathing or heart murmurs.

A pulse oximetry may also be used, which is a simple, non-invasive test that measures the amount of oxygen in the baby's bloodstream.

If an issue is detected, further tests such as heart ultrasounds **(transthoracic echocardiogram)** will be performed to determine the issue in the heart. This test **confirms the diagnosis** by showing a single large artery instead of separate pulmonary and aortic arteries.

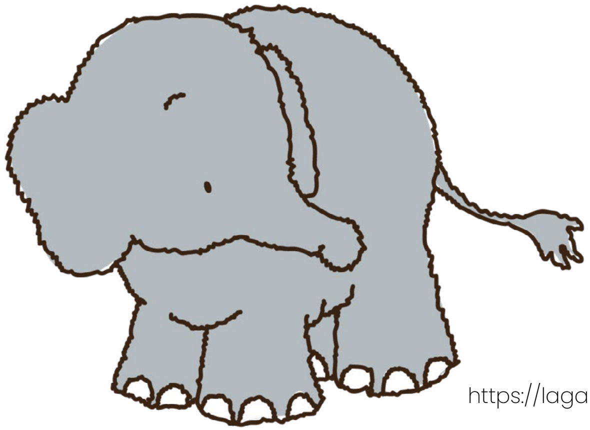
HOW IS TRUNCUS ARTERIOSUS TREATED?

Truncus Arteriosus requires surgical repair in early infancy to prevent severe complications like heart failure and high blood pressure in the lungs (pulmonary hypertension). Without surgery, the condition is life-threatening.

During the surgery, the aorta and pulmonary artery are separated in order to create a pathway for the blood to travel from the right ventricle out to the lungs. These are connected using a tube with a value. If your child also has a Ventricular Septal Defect, this will be closed with a patch to ensure oxygen-rich blood is pumped efficiently to the body.

After the surgery, your child will need to stay in hospital in order to recover correctly. They also may need additional surgeries as they grow.

Open heart surgery is an extremely effective method of treating Truncus Arteriosus, with over 90% of children receiving the surgery going on to live healthy and happy lives.



ARE THERE ANY OTHER CONDITIONS ASSOCIATED WITH TRUNCUS ARTERIOSUS?

Yes, in fact almost all children born with Truncus Arteriosus are also born with a Ventricular Septal Defect (VSD).

A VSD is a hole in the wall between the right and left ventricles. This hole allows oxygen-rich blood to mix with the oxygen-poor blood and go through the single artery to the lungs. As a result of this, the lungs can get too much flowing into them.

Other conditions that may be, but not always, associated with Truncus Arteriosus include:

Atrial septal defects- This is a hole in the heart wall that separates the heart’s two upper chambers.

DiGeorge Syndrome- A birth condition caused by a small part of chromosome 22 being absent.

Patent Ductus Arteriosus- A persistent opening between the two major blood vessels that lead away from the heart.

Atrioventricular Septal Defect (AVSD)- Complete AVSD occurs when there is a hole in the centre of the heart and partial AVSD occurs when there is a hole either between the atrial or the ventricular wall.

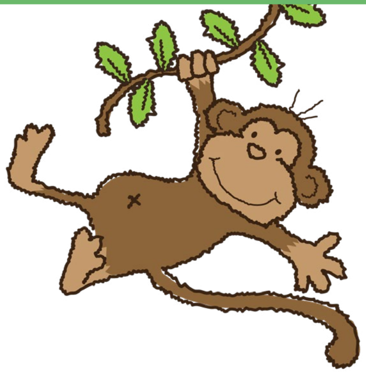
WHAT HAPPENS AS YOUR CHILD GROWS UP WITH TRUNCUS ARTERIOSUS

If the Truncus Arteriosus is not treated effectively through surgery when your child is young, most babies will not survive.

Surgery is one of the most effective ways to treat Truncus Arteriosus, and most babies will recover well and go on to live normal, healthy lives. However, some children may need further surgeries as they grow older, as well as regular appointments with their doctor to prevent any further issues.

At Lagan's Foundation, we provide **specialist respite care and short break services** for children with congenital heart defects, such as Truncus Arteriosus.

We know how hard it can be for parents and carers, which is why we offer individual and flexible care services to families who have children with congenital heart defects. Not only does this ensure your child gets the best care and support they need, but it gives you a well deserved break.



Respite and support of any kind is invaluable.

Lagan's Foundation, a Charitable Incorporated Organisation in England and Wales (1154208) aims to physically help support families who have infants and children up to 19 years old, diagnosed with complex health conditions specialising in heart defects and feeding difficulties. Lagan's Foundation's purpose is to provide unique at home and in hospital care to support parents in their caring role.

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