

Fontan Clinic - A Family Guide

What to expect when you come to the Fontan Clinic



What is the Fontan Clinic?

Thank you for choosing Children's Hospital Los Angeles for your child's heart care. Welcome to the Fontan Clinic. Our team helps patients with Fontan circulation achieve their best health and wellness (body, mind, and social well-being.)

Why do patients visit this clinic?

Children born with a single ventricle heart get an operation called the Fontan surgery. This surgery does not "cure" the heart problem but makes living with it possible. Fontan circulation affects the heart and other organs in the body. It is important to check these organs regularly. Our clinic has specialists who can help find and treat concerns quickly.

Who are the Fontan Clinic Team Members?

Our Fontan Clinic team includes different professionals. We focus on different areas of your child's health. This is called a multidisciplinary approach to health care. Each team member will check for health problems related to having the Fontan circulation. We will come up with specific advice for managing your child's Fontan care. Our team members include:

- **Cardiologist (heart doctor) and Cardiology Nurse Practitioner (advanced practice nurse):** Heart specialists who focus on caring for patients with the Fontan circulation.
- **Hepatologist:** A doctor who specializes in liver disease related to the Fontan circulation.
- **Pulmonologist:** A doctor who manages lung disease related to the Fontan circulation.
- **Psychologist:** A professional who focuses on emotions, behavior, and health. They check how patients and families are dealing with their medical condition.
- **Clinical Social Worker:** A professional who assesses and provides supportive services to patients and families as related to their medical condition
- **Dietitian:** A professional who checks the patient's nutritional health and develops a tailored plan to keep a healthy diet
- **Nurse Care Manager:** A nurse who plans the patient's visit and coordinates care after the visit. They are the link between the team members and the patient.

What are some problems that may happen after the Fontan Procedure?

Although the Fontan procedure can save your child's life, there are risks for developing problems. In this clinic, we regularly check for these problems.

- Anxiety or depression (Intense worry or sadness)
- Decreased lung function (Lungs do not work well)
- Kidney dysfunction (Kidneys do not work well)
- Learning difficulties (Trouble with learning)
- Liver dysfunction (Liver does not work well)
- Malnutrition (Poor nutrition and growth)

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- Plastic bronchitis (Hard plastic-like pieces blocking airways in the lungs)
- Protein losing enteropathy (Low protein in the body)
- Weak bones

What to expect for your visit

How do I prepare for my child's visit to the Fontan Clinic?

After you schedule your child's appointment, the nurse care manager will call you before the visit. They will review your child's health history, explain what to expect, and how to prepare for the clinic day. You can ask questions or talk about any worries you have before the visit. We plan the visit for your child's needs.

What happens on the day of the visit?

On the day of the clinic, it is very important to arrive at your visit on time. You will meet with many members of the Fontan Clinic team. Each member will meet with you for about 30 minutes. Your child may also need to do some tests to check the health of their organs. These tests may include:

- Lab studies (blood, urine, and stool)
- 6-minute walk – to measure how well they can do light exercise
- Zio Patch – to check their heart rhythm throughout the day
- Chest x-ray – to check their lung health
- Echocardiogram – to check how well all parts of their heart are working
- Electrocardiogram (EKG) - to test their heart rhythm

What happens after the clinic visit?

Our team will meet to go over our findings. We will contact you to discuss advice for your child's future care. Both you and your primary cardiologists will receive a letter with this information. We may suggest referrals to other specialists, more testing, or new medicines. Please call our nurse care manager to help schedule those appointments.

Request for Participating in Research

Welcome to the Children's Hospital Los Angeles (CHLA) Fontan Clinic. As part of our commitment to providing the best care to children, our clinic and many of its members take part in scientific research. We gather information for patients who get Fontan surgery.

- During your clinic visit, a member of our research team may talk to you if your child is eligible for a study.
- If your child is eligible for more than one study, our research team may approach you at a future visit.
- Participation in these studies is voluntary. Your decision to take part in research will not change your child's care in any way.

We hope you will consider taking part in our research studies as it may help other children in the future. Whether you do or do not take part, we will always give the best possible care to your child while you are here at CHLA.

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