

CARDIAC SURGERY

Family Handbook

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INTRODUCTION

- Heart Diagram
- Health Record
- Outpatient Care Team

CHECK THIS OUT! Here's How Your Heart Works!



HEART DIAGRAM

For patients who need more in-depth record keeping forms, please visit the Forms section of the Special Needs Resource Directory at <u>www.cincinnatichildrens.org/special-needs</u>.

l was born on	//
	I was born on

See how I'm growing!

Date		
Height		
Weight		

Here are some procedures that I have had:

Procedure	Date	Surgeon

My baseline oxygen saturation is ____%

I have a few special needs including_

HEALTH RECORD

Outpatient Care Team

Cardiologist:

	PH: 513	
Surgeon:		
	PH: 513-636-4770	
Social Worker:		
	PH: 513-636-4711	
Dietitian:		
	PH: 513	
For questions during the week, please call:		
Cardiology Clinic (C4)		
Monday-Friday, 8 am to 4 pm		

513-636-4432

For questions after hours or on the weekend, please call:

513-636-4200 or 800-344-2462 and ask for the Cardiology Fellow on call.

For any emergency, call 911 immediately.





HOSPITAL RESOURCES

- Preparing for Your Visit
- Phone Directory
- Campus Locations
- Concourse Map
- Hospital Resources

Welcome to Cincinnati Children's Heart Institute

When you/your child faces the diagnosis of a heart condition, nothing but the best, most knowledgeable care will do. With our family centered care, we work with you to develop the best care plan for you/your child. Together we can change the outcome.

This handbook contains resources to aid you during your/your child's stay. In addition to this information, we invite you to visit our website for information on your/your child's heart condition, details about Heart Institute programs and how to prepare for a clinic visit, surgery or hospital stay.

Heart Institute: www.cincinnatichildrens.com/heart

Preparing for Your Visit: www.cincinnatichildrens.org/patients/visit/prepare/default

Visiting Cincinnation	INCINNATI CHILDREN'S / PREPARE FOR YOUR VISI	T.	Recommend 🖂 Email 🔒 Print
Visiting Cincinnati Children's Locations & Directions Prepare for Your Visit Schedule an Appointment Prepare for Your Outpatient Visit Prepare for Your Overnight Stay Prepare for Surgery Interpreter Services Concierge Scheduling Services for Traveling Patients	 Prepare for Your Visit Whether you're coming to our Burnet Camp at Cincinnati Children's wants the experience you and your child. We can help guide you through each step of about: Your Outpatient Visit Your Overnight Stay Your Child's Surgery 	t us or one of our neighborhood locations, the tea e to be as smooth and comfortable as possible i the way during your child's visit. Learn more	for
During Your Visit			
After Your Visit	Traveling Families	Interpreter Services	Patient Orientation
International Patients and Families	Many of our patients come to us from across the country and around the globe. We can help with your travel plans, appointments and lodging. > TRAVELING FAMILIES	We assist families who do not speak English as their primary language. Qualified medical interpreters are provided for you at no cost. > INTERPRETER SERVICES	Watch a video of insights and tips that will help you and your child understand the hospital and some of the people you'll meet. > PATIENT ORIENTATION VIDEO

Parking

Follow the medical center's main entrance off Burnet Avenue and turn right into the underground visitor garage.

• Please allow up to 15 minutes to park

Parking validation is available at any welcome center (Locations A, B and C) for the visitor garage.



Phone Directory

General Information	
Local calls.	513-636-4200
Toll-free	800-344-2462
A6 Central	.513-636-1920
Billing and Financial Assistance	
Billing Customer Service	513-636-4427
Financial Family Advocate	513-636-2670
Cardiac Intensive Care Unit	.513-636-4007
Cardiac Surgery	513-636-4770
Cardiothoracic Nurse Coordinator (6:30 am - 6:30 pm)	513-315-0634
Cardiothoracic Surgery NP/PA "Wound Phone" (6:00 am – 6:00 pm)	513-429-8130
Center for Special Needs	.513-636-3000
Chaplain	513-636-4376
Guest Services	
Local calls	513-636-5009
Toll-free	888-894-1374
Family Relations	513-636-4700
Family Resource Center	513-636-7606
Pharmacy (Main Campus)	513-636-8808
Protective Services Obtain escorts to your car or Ronald McDonald House	513-636-4204
Ronald McDonald House	513-636-7642
Same Day Surgery/Post Anesthesia Care Unit	513-636-4517

PHONE DIRECTORY



CAMPUS LOCATIONS



CONCOURSE MAP

Hospital Resources

Welcome Cer	513-636-2030	
Concierge Servi	ces at Locations A, B and C can help with:	
•	International Patient Care needs	
•	Travel Arrangements	
•	Answer Questions	
•	Provide discounts to local attractions	
Guest Services		513-636-5009
Call Guest Servi	ces for needs including:	
•	Financial Assistance	
•	Hotels and Lodging	
•	Interpreter Services	
•	Pastoral Care	
•	Special Needs Resource Directory	
Meals		513-636-3663
Room Service (c	delivery within 45 minutes)	
Full Menu	ı 6:30 am - 8:00 pm	
Evening N		
Cafeteria		
Open 24/		
Location I		
Food Delivery	513-636-5009	
Call Gues	st Services for restaurants that deliver to the hospital.	
Wireless Net	work (Wi-Fi)	866-536-7676
Network ID: chm Password: childr	nc-guest rens	
Call customer su	upport for assistance using customer code 9-617.	

HOSPITAL RESOURCES

Hospital Resources (continued)

Family Resource Center

We encourage our families to utilize the Family Resource Center (FRC) for medical and community resources including:

- Customized information packets for health conditions
- Parent to parent networks
- School resources
- Free, personalized <u>CarePages</u> to keep loved ones updated

You can also visit the Family Resource Center on A1 to relax and unwind:

- Private office
- Computer and internet access
- Living room fireplace
- Outdoor patio



HOSPITAL RESOURCES

513-636-7606



SUPPORT & EDUCATION

- Heart Encyclopedia
- Child Life Services
- Support Networks
- Heart Family Activities

Heart Encyclopedia

The Heart Encyclopedia provides easily accessible information on pediatric heart defects and disorders including videos and graphic summaries.

To learn more about your child's condition, view the Heart Encyclopedia at: www.cincinnatichildrens.org/heart-encyclopedia.



Ebstein Anomaly

Ebstein anomaly is an abnormality in the tricuspid valve. The tricuspid valve separates the right atrium (the chamber that receives blood from the body) from the right ventricle (the chamber that pumps blood to the lungs).

Contact the Heart Institute

For more information, contact the Heart Institute at 844-205-8826 or via our online form.



> View 2-D graphic summary.

Heartpedia

Heartpedia is an interactive, 3D app featuring anatomically accurate images of congenital heart defects and repairs of those defects for you and your child to explore together.



Download for **free** on your Apple and Android devices!





HEART ENCYCLOPEDIA

Child Life Services

Our child life specialists provide emotional support and teach techniques to help your child cope and relax.

Ask your child life specialist for more information about:

- Preoperative tour for the family
- Preparing your child for medical procedures
- Family movie night
- School program via our hospital school
- Medical play in the inpatient activity center
- Music therapy



Cincinnati Children's offers unique, uplifting activities for your child.

Family Pet Center

• Your child can visit with the family dog or cat at the Family Pet Center.

Seacrest Studios/WKID33

- Tune in to channel 33 on the inpatient room TV to watch videos and interviews.
- Call 3-3333 from your room to request songs and play games!

CHILD LIFE SERVICES

Support Networks

Being diagnosed with a congenital heart defect for the first time is overwhelming—causing incredible emotional stress on patients and their families. The Heart Institute collaborates with these groups to connect patient families for support.

Mended Little Hearts of Cincinnati

Mended *Little* Hearts of Cincinnati provides families, caregivers and patients with heart defects and heart disease an outlet through which they can find answers, education, resources and access to local-based peer-to-peer support. With Mended *Little* Hearts, patients with congenital heart defects (CHD) and their families find strength and understanding from those who share similar experiences. The Cincinnati chapter is run by local Heart families and CHD patients, who can truly relate to the concerns of Congenital Heart Disease.

Visit <u>www.cincinnati.mendedlittlehearts.net</u> to learn more and connect with MLH families on Facebook at <u>www.facebook.com/MLHCincinnati</u>.

For more information, please contact:

Lisa Butler, Lead Coordinator Phone: 513-518-3621 Email: <u>mlhcincinnati@gmail.com</u> Leslie Sams, Co-Coordinator Phone: 859-559-5580 Email: <u>mlhcincinnati@gmail.com</u>



Adult CHD Survivors of Cincinnati

Adult CHD Survivors of Cincinnati is a collaboration effort to provide Adult Congenital Heart Disease (ACHD) patients, family and friends with a support and educational program. We provide one-onone support, community outreach/fundraising opportunities, educational opportunities, social events and advocacy for CHD families. We are based in Cincinnati and directly serve patients at Cincinnati Children's; however, we provide online support through email and social media to patients outside the Cincinnati area.

Join us each month for the Adult CHD Survivors meetings at Cincinnati Children's and connect with us on Facebook at www.facebook.com/SurvivingCHDofCincinnati.

For more information, please contact:

Danielle Fritsch, Coordinator Phone 513-884-0601 Email: <u>survivingchd@gmail.com</u>

SUPPORT NETWORKS

Heart Family Activities

The Heart Institute strives to partner with families to provide the best care for your child. We also look to provide fun and educational opportunities for patients and their families outside the hospital. For more events and information, please visit <u>www.cincinnatichildrens.org/heart-families</u>.

Fit Hearts Marathon Training Program

The Heart Institute partners with the Cincinnati Flying Pig Marathon to offer our congenital heart patients to take part in a progressive marathon training program. The seven-week program allows participants to complete a progressive full marathon by crossing the finish line at the Flying Pig!

Family Camp Weekend

Family Camp Weekend is designed specifically for families of children affected with heart disease. The weekend is full of fun family activities, informational sessions for parents and sharing with other families who have had similar experiences.

Camp Joyful Hearts

Camp Joyful Hearts is a residential summer camp for kids and teens with heart disease. Camp Joyful Hearts offers many exciting camp activities such as swimming, high ropes, campfires and more! A pediatric cardiologist and cardiac nurses are onsite 24 hours a day.

Family Education Day

The Heart Institute Family Education Day is an all-day conference designed for parents, guardians and caregivers of children with all types of heart disease. This event brings them together with medical care providers for a casual day of education, information and hands-on learning.



ACTIVITIES FOR THE HEART



SURGICAL CARE TEAM

- Inpatient Care Team
- Cardiac Surgeons

Inpatient Care Team

We take a unique multidisciplinary approach to providing the best possible care for you/your child. Our cardiothoracic surgeons, cardiologists, intensivists, anesthesiologists, pharmacists and other team members conduct rounds and host briefings together, ensuring that you/your child's unique care plan is crafted by a diverse team of experts.

Your inpatient care team will consist of the following providers:

Surgery

- Cardiac Surgeons
- Cardiac Surgery Fellow
- Physician Assistants and Nurse Practitioners
- Cardiac Nurse Clinician
- Perfusionists
- Cardiovascular Operating Room Nurses
- Scrub Technologists
- Cardiac Anesthesiologists

Cardiac Intensive Care Unit (CICU)

- Cardiac Intensivists
- Cardiology Fellows
- Nurse Practitioners
- CICU Nurses
- Pharmacists*
- Respiratory Therapists*
- Dietitians*
- Child Life Specialists*
- Physical and Occupational Therapists*

A6S Stepdown Unit and Follow-up Clinic

- Cardiologists
- Cardiology Fellows and Residents
- Nurse Practitioners
- Cardiology Nurses

*These members are a part of the care team throughout your entire stay.

INPATIENT CARE TEAM



Dr. James Tweddell

Executive Co-Director, Heart Institute Surgical Director, Heart Institute Professor, Surgery



Dr. David Morales

Chief of Cardiovascular Surgery, Heart Institute Clark-Helmsworth Chair of Cardiovascular Surgery Professor, Pediatric Surgery



Dr. David Lehenbauer

Attending Surgeon, Heart Institute Assistant Professor, Pediatric Surgery

CARDIAC SURGEONS



PREPARING FOR SURGERY

- Cardiology Visit
- Surgical Consult Visit
- Pre-Operative Screening
- Staph Testing
- Pre-Admission Testing
- Lab Testing Locations

Before surgery is recommended, you or your child will be seen by a cardiologist. A cardiologist will help diagnose you/your child with his or her heart disease.

My/my child's Primary Care Doctor: _	
My/my child's Cardiologist:	

Last **visit**: ______ Last **ECHO**: ______

Other **related studies** (imaging, lab): _____

Once you or your child has a diagnosis, they will be presented at a conference with an entire team of physicians and surgeons, where the best course of action will be discussed for you or your child. Once a plan has been made, it will be presented to you at the Cardiothoracic Surgery Consult Visit.

If surgery is considered the next step in you/your child's plan of care, a surgical scheduler will contact you to set up a consult visit. At this visit, you will meet with the surgeon and an advanced practice provider (APP) to discuss surgery, have a history and physical and sign consent.

The next chapter, Your Child's Stay, provides detailed information on what to expect.



CARDIOLOGY VISIT

Surgical Consult Visit

After receiving a diagnosis, a team of physicians and surgeons will review you/your child's case and determine a course of action. We will present this plan to you at the Cardiac Surgery Consult Visit. You will meet with the surgeon and advanced practice provider (APP) to discuss surgery, have a physical and sign consent.

1. Who should come?

- The patient
- Parents/guardians: Those who will be active in the child's care before, during and after surgery

2. What should we bring to the visit?

- Binder
- · List of medical history and medications
- Dental clearance letter (if already seen by the dentist)
 - The letter should state that there are no dental issues preventing the patient from having cardiac surgery.
- Activities to help keep your child busy, if needed, while you talk with the surgeon

3. How long will the visit be?

- Visits usually last 2 4 hours
- If there is an emergent surgical case, your appointment may be rescheduled

Location: C4

Running late? Please call **513-636-4770**.



SURGICAL CONSULT VISIT

Pre-Operative Screening

The following routine pre-operative screening processes improve patient care and outcomes. We ask you to help us facilitate these measures.

1. Dental Clearance

All cardiac surgery patients who are one year old and older must be seen by a dentist within six months of scheduled surgery. We ask that you take yourself/your child to be seen either by a local dentist or contact our h o s p i t a l's dental clinic at 513-636-4641. A dental clearance letter is required before surgery can be performed.



2. Staph Testing

All cardiac surgery patients undergo screening for the presence of Staph infection within 6 weeks of surgery, with the results received at least 2 weeks prior to surgery. Testing is usually done during the pre-op CT Surgery Clinic visit. Special arrangements may need to be made for those who live a distance from Cincinnati. Your nurse will talk with you in more detail if this is the case.

3. Thyroid Testing in Patients with Down Syndrome

Patients with Down syndrome who are scheduled for elective cardiac surgery require thyroid screening (Free T4 and TSH) at least six weeks prior to surgery. A normal newborn thyroid screen is not adequate, as hypothyroidism can develop later. We ask that you obtain these tests at least six weeks prior to scheduled surgery so that, in patients who are discovered to have hypothyroidism, there is adequate time for effective replacement therapy (approximately four weeks) prior to the scheduled surgery date. In children older than 12 months of age, a screen within 6 months of surgery is adequate.

4. Vaccinations

All vaccinations may be given up until 4 weeks/1 month prior to cardiac surgery.

Please note the following exceptions:

- The influenza (Flu) vaccination and Synagis injections can be given up until the time of surgery.
- While the flu mist may be given up until 4 weeks/1 month before surgery, it should not be given to anyone coming in close contact with the patient for 2 weeks before surgery.

PRE-OPERATIVE SCREENING

Staph Testing

Please tell your nurse if your child or any family member has a history of staph or MRSA.

What is Staph?

- Staph is a germ that lives on skin or in moist areas on the body.
- Up to 1/3 of all people have staph on their skin; it usually does not cause problems.
- A positive test for staph does not mean the person is dirty. Anyone can carry staph.

What is MRSA/ORSA?

• MRSA/ORSA is a type of staph aureus that needs to be treated with certain antibiotics.

Prevent Spread in your Family

(if someone in your family has a staph infection)

- Everyone should wash their hands often with an antibacterial soap.
- Take showers instead of baths.
- If your child is too young for a shower, bathe them alone.
- Use separate towels and washcloths for each person.
- Clean bath toys often.
- Avoid bath toys that cannot be cleaned well.

Why Test for Staph?

- Staph is a germ that lives on skin or in moist areas on the body.
- Your/your child's surgery will result in an incision. If you/your child have staph, it can enter the body and cause an infection.
- Testing will help us give medicine to keep you/your child healthy before and after surgery.



STAPH TESTING

Staph Testing (continued)

What Will the Test be Like?

- The test is done in one of our labs or in the clinic during an office visit. The surgeon's office will
 let you know.
- Two areas of the body are swabbed for staph. One is the inside of both nostrils. The second is the top of the crease of the buttocks.
- There is no pain with the test.
- A parent or guardian can stay with a child while the test is done.
- You/your child will not need to undress.

When Do You Test for Staph?

• The best time to test for Staph is two to six weeks before the surgery date.

Is Any Follow-up Care Needed?

- If the test is positive for staph or MRSA, a nurse will tell you how you can help prevent infection.
- A positive test does not mean you/your child has an infection. It just means that staph is living on the skin.
- You/your child will be asked to shower with a special soap and to swab the inside of both nostrils with special ointment.
- Make sure to follow all instructions given to you by the nurse or doctor.



STAPH TESTING

Pre-Admission Testing

Who should be present?

- The patient
- Parents/guardians: Those who will be active in the child's care before, during and after surgery

What to bring to the visit?

- PAT letter instructing you where/when to go for testing
- Binder

Timeline

- Approximately 3 hours
 - If you arrive late, the appointment may take longer due to scheduling.
- Same Day Surgery (B3) You will go here first to be evaluated by the CT Surgery NP/PA and anesthesia physician. You will also have an EKG completed here.
- Radiology (B1) For chest X-ray. Head here after you are finished in same day surgery.
- Test Referral Center (A1) for all pre-operative lab work (ideal to save for last if you are worried about your child getting upset with lab draws)

Location

- There are two Testing Referral Centers, located on A1 or C2. You may use either center.
- Radiology is located on B1
- Same Day Surgery is located on B3

Running Late? Please call 513-636-4770.



PRE-ADMISSION TESTING

Pre-Admission Testing (continued)

After chest x-ray and lab testing, please report to Same Day Surgery (SDS) at Location B3.

Pre-Admission Testing (PAT)

- 1. History and Physical
 - What to Expect
 - Questions regarding you/your child's history, medications including blood thinners, allergies and physical exam
 - Who to Expect
 - Cardiothoracic Advanced Practice Provider (APP): A physician assistant or nurse practitioner
 - o Cardiac Anesthesiology
- 2. Review Results
 - Femoral Ultrasound | Radiology Location B1
 - If your child is above a certain weight and has had surgery before, he/she will need a femoral ultrasound.
 - Chest X-Ray | Radiology Location B1
 - All patients need chest x-rays before surgery.
 - Lab Testing | Test Referral Center (TRC) Location A1 or C2
 - All patients need labs 24-72 hours before surgery. This gives us a baseline and shows us any imbalances your body may have.
 - EKG | Same Day Surgery (SDS) Location B3
 - All patients need an EKG before surgery. This shows us a baseline of your heart's rate and rhythm.

Discussion Points at PAT

- 1. Food and Drink Restrictions
- 2. Bathing Before Surgery
- 3. Arrival Time Day of Surgery
- 4. Aspirin, ibuprofen or Plavix needs to be stopped prior to surgery. Regarding when to stop aspirin or other anti-coagulants (Plavix, Coumadin, Eliquis for example), call Cincinnati Children's Cardiac Surgery NP/PA phone at 513-429-8130. If you have vascular stents, please DO NOT stop your medication without the approval of your healthcare provider. Please contact the NP/PA at 513-429-8130 if you have not spoken with anyone regarding your medications.

Lab Testing Locations

Laboratory testing is available at the following Cincinnati Children's locations:

Location	Monday- Friday	Saturday	Sunday
Burnet Campus Test Referral Center	7 am-8 pm	8 am-3 pm	10 am-2 pm
Anderson	8 am-11 pm	8 am-7 pm	Noon-7 pm
<u>Eastgate</u>	8 am-6 pm	closed	closed
Fairfield	8 am-6 pm	8 am-noon	closed
Green Township	8 am-11 pm	8 am-7 pm	Noon-7 pm
<u>Liberty</u>	7 am-8 pm	8 am-3 pm	10 am-2 pm
<u>Mason</u>	8 am-11 pm	8 am-7 pm	Noon-7 pm
Northern Kentucky	8 am-6 pm	8 am-noon	closed

Schedule an Appointment

The Scheduling Center at Cincinnati Children's is committed to helping families quickly schedule appointments, procedures and testing.

Please call our Scheduling Center for information:

Phone: 513-636-3200 Monday - Thursday: 7:30 am to 6 pm

Friday: 7:30 am to 5:30 pm



LAB TESTING LOCATIONS



MY NOTES

YOUR CHILD'S STAY

- Day of Surgery
- Visitor Policy
- Wound/Incision Care
- Discharge/Going Home

Day of Surgery

Risk of Cancellation

Although infrequent, there are several reasons your/your child's surgery may need to be delayed or cancelled, including: if the patient is sick, if patient has eaten or drank after instructed NPO time, or if our team must perform an emergency surgery such as a transplant.

A member of the cardiothoracic surgical team will notify you and your family if surgery must be delayed or cancelled for any reason. If surgery is cancelled due to illness, we typically wait 4-6 weeks to reschedule the surgery. If surgery is cancelled due to an emergency (for instance, if a transplant surgery needs to be done), we will reschedule at that time.

What to bring:

- Binder and pen
- Insurance cards, proof of guardianship (for court appointed guardians), list of medications
- Cell phone and chargers
- Activities to help pass time
- Blankets and/or pillows depending on length of case and timing

Where to go:

- Arrive at least 90 minutes before your scheduled surgery time.
- Check in for surgery on B3 in Same Day Surgery (same as PAT).
- Running late or need to reschedule? Please call Same Day Surgery at (513) 636-8896.

Waiting during surgery:

- You will be escorted to the family waiting area where you will sign in and receive a photo name badge to access the Cardiac Intensive Care Unit (CICU).
- The nurse coordinators will provide you updates approximately every 1¹/₂ hours.
- The surgeon will come speak with you immediately following the surgery.
- The nurse coordinators will then escort you to the CICU waiting area where you will wait until the CICU staff is ready for you to visit your loved one.
- CICU limits visitors to 4 people at one time. You may rotate in and out of the room and wait in the family lounge.

DAY OF SURGERY

Visitor Policy



Hospital-Wide Visitor Policy

- All visitors should be healthy: free from fever, cough, colds or stomach virus symptoms
- Up to 4 primary support persons (such as parents, guardians, spouse) ages 18 and up may receive 24-hour access to the patient room. Up to two primary persons may stay overnight.
- Up to 6 secondary support persons (such as siblings, family members, friends) may be identified to visit. Consider virtual visits for additional family and friends.
- Children in waiting areas must be always supervised.
- **During peak times of illness in the community** (such as flu/respiratory illness from December to March)
 - Young children (under age 14) are requested not to visit the ICUs.
 - Only children seeking evaluation or treatment should be brought to outpatient appointments.

Visiting Cardiac Inpatient Units

- **CICU** limits visitors to 4 people at one time. You may rotate in and out of the room and wait in the family lounge.
- Stepdown Unit—A6 South follows the general hospital-wide year-round visitor policy.

VISITOR POLICY

Wound/Incision Care

Unless you receive special instructions, incision(s) may be left open to air upon discharge. Allow steri-strips to fall off on their own.

If your child tends to drool or spit up, keep the incision covered to minimize breakdown (can cover with layers of clothing, bibs, etc.).

Bathing

In the first 4 weeks, soap and water may run over the incision but the incision should not be submerged under water. Shower stream should not be allowed to hit the incision directly. Pat dry.

Incision(s) may be submerged in water (bath, pool, etc.) 4 weeks after surgery if fully healed (no openings or drainage).

Lotions, Oils, etc.

Please do not apply anything to incision unless specifically instructed by your provider for the first 4 weeks.

Sun Protection

It is very important to keep the incision protected from sunlight for the first year after surgery to minimize scarring. Keep the incision/scar covered with sunscreen and/or a UPF sunshirt. Seeing "UPF" on the label means the fabric has UV protection and will protect the incision/scar.

Call if the incision is:

- More red or swollen
- Draining any type of fluid
- Pulling apart

During normal business hours, call 513-636-4770.

On nights/weekends, call 513-636-4200 or 800-344-2462 and ask for the cardiology fellow on call.

Do I need stitches removed?

- White stiches will dissolve and fall off; usually -8 weeks
- The blue or clear stiches (knots) at the ends of the incision should be clipped at time of you first cardiology follow up visit after surgery Blue stitches will also dissolve, but the ends may need to be clipped if the skin becomes irritated
- Black stitches (if present) need to be removed
 - ♦ This will happen at your cardiology follow up visit

Discharge/Going Home



What to expect at discharge?

- All medications will be reviewed, and prescriptions given if necessary.
- A member of the care team will review instructions for home care plan prior to discharge, including sternal precautions and incision care instructions.

Activity restrictions

- You should restrict yourself/your child from any activities that might pull the incision apart or have a risk of hitting the chest. Example activities include throwing/catching a ball, wrestling and playing basketball.
- Going back to school/daycare/work—it is best to prevent any activity that could impact the chest for the first 4 weeks. Please discuss with your cardiologist at the time of discharge.

Follow up visit

- You will follow up with your cardiologist 10-14 days after discharge from the hospital.
- Appointment will be arranged in hospital prior to discharge.







ABG—arterial blood gas.

Acyanotic—skin color is not blue (cyanosis).

Aneurysm—a bulging of the wall of a vein or artery due to weakening of the wall by disease or a problem present at birth.

Angiocardiogram—X-ray exam of the heart and great vessels. A dye is injected into the blood stream for this exam.

Anomalous venous return—oxygen rich blood returning from the lungs goes to the right side of the heart and into the right atrium.

Anticoagulant—a drug that delays blood clotting.

Aorta—the main artery that gets blood from the lower left chamber of the heart.

Aortic arch—the part of the aorta or large artery that leaves the heart and curves up like the handle of a cane over the top of the heart.

Aortic stenosis—narrowing of the valve opening between the lower left chamber of the heart and the large artery (aorta).

Aortic valve—valve located where the aorta and the lower left chamber of the heart meet.

Apex—the blunt, rounded part of the heart that points downward, forward and to the left in most people.

Arrhythmia—any change in the normal rate or rhythm of the heart.

Arterial blood—oxygenated blood. The blood gets oxygen in the lungs before it goes to the left side of the heart via the pulmonary veins. It is then pumped by the left side of the heart into the arteries that carry it to all parts of the body.

Artery—blood vessels that carry blood away from the heart to the rest of the body.

Atrium—either of the two upper chambers of the heart.

Atrial septum—the muscle that divides the left and right upper chambers of the heart (atria).

Atrial septal defect (ASD)—an abnormal opening between the left and right atria.

Atresia—the lack of an opening where one should be located.

Atrio-ventricular valves—the two valves, one in each side of the heart, between the upper and lower chambers.

Auscultation—listening to sounds in the body, usually with a stethoscope.

AV canal—atrioventricular canal.

AV node—a small mass of muscle fibers. It is at the base of the wall between the two upper chambers of the heart. It is part of the conduction system of the heart that allows impulses to go from the upper chambers of the heart to the lower chambers.

Bacterial endocarditis (BE)—a swelling of the inner layer of the heart that is caused by bacteria.

Bicuspid valve—a valve made up of two cusps or leaflets.

Blood pressure (BP)—the measurement of the blood pressure flowing in the arteries.

Bradycardia—an abnormally slow heart rate.

BT shunt—Blalock-Taussig shunt.

Bundle of His—muscle fibers of the conduction system of the heart. They run from the AV node to the lower chambers of the heart.

Capillaries—very narrow tubes that carry blood (and form a network) between the arterioles and veins.

Cardiac—referring to the heart.

Cardiac cycle—one total heartbeat. It includes contraction and relaxation.

Cardiac output—the amount of blood pumped by the heart in one minute.

Cardiovascular (CV)—referring to the heart and blood vessels.

Catheter—a thin, hollow tube that is inserted into a blood vessel.

Catheterization—a process to examine the heart. A thin tube is inserted into a vein or artery that then goes into the heart.

CBP—cardiopulmonary bypass.

Chordae tendineae—cords of fiber that hold down the valves between the upper and lower chambers of the heart.

Circulatory—referring to the heart, blood vessels and the circulation of blood.

Coarctation of the aorta—narrowing of the aorta.

Collateral circulation—circulation of the blood through nearby smaller vessels when a main vessel has been blocked.

Compensation—a change in the circulatory system that makes up for some abnormality.

Congenital anomaly—an abnormality or problem present at birth.

Congestive heart failure—the heart is unable to pump out all the blood that returns to it. This causes a backup of blood in the veins leading to the heart.

Coronary arteries—arteries that bring blood to the heart.

CVP—central venous pressure.

Cyanosis—blueness of the skin caused by low oxygen in the blood.

Decompensation—the heart cannot keep enough blood flowing.

Defibrillator—an agent, such as an electric shock, that may help to restore a normal heart rhythm.

Dextrocardia—a condition in which the heart is rotated and lies in the right side (instead of the left) of the chest.

Diastole—in each heartbeat, the period of relaxation of the heart.

Dilation—the heart's blood vessels are stretched or larger than normal.

Diuretic—a medicine that promotes the flow of urine.

Ductus arteriosus—a vessel that connects the artery leaving the left side of the heart (aorta) and the artery leaving the right side of the heart (pulmonary artery).

Dyspnea—hard or labored breathing.

Echocardiogram (ECHO)—a recording of sound waves in the heart. It makes moving pictures of the inside of the heart.

Edema—swelling due to large amounts of fluid in the tissues of the body.

Electrocardiogram (EKG or ECG)—a recording of the electric currents of the heart.

Endocardium—the inner lining of the heart.

Epicardium—the outer lining of the heart.

Etiology—the cause of the disease.

ET-Tube—endotracheal tube (breathing tube).

FiO2—percentage of oxygen being given to a patient.

Foramen ovale—an oval hole between the left and right upper chambers of the heart.

Heart block—interference with the electrical impulses of the heart.

Heart-lung machine—a machine that supplies oxygen to the blood and circulates blood in the body during surgery.

Hemoglobin—the oxygen-carrying red pigment of the red blood cell.

Hemorrhage—loss of blood from a blood vessel.

HIV—human immunodeficiency virus.

HLHS—hypoplastic left heart syndrome.

Hypertension—high blood pressure (hyper means high).

Hypertrophy—tissue or organ that is larger than normal.

Hypotension—low blood pressure (hypo means low).

Hypothermia—the body temperature is lowered so the body tissues need less oxygen.

Hypoxia—lower than normal oxygen level in the organs and tissues of the body.

Incompetent value—a value that does not close tightly and leaks blood back in the wrong direction.

Innominate artery—one of the largest branches of the aorta. It supplies blood to the right arm and head.

Insufficiency—when a valve does not work like it should.

Inter-atrial septum—a muscular wall that divides the left and right upper chambers of the heart.

Inter-ventricular septum—a muscular wall that divides the left and right lower chambers of the heart.

Ischemia—a decrease of blood in some part of the body.

LA—left atrium.

Lumen—the passageway inside a tubular organ.

Mitral stenosis—a narrowing of the valve opening between the upper and lower chambers in the left side of the heart.

Mitral valve—a valve with 2 flaps between the upper and lower left side of the heart. It is sometimes called the bicuspid valve.

Mitral valvulotomy—an operation to widen the opening in the valve between the upper and lower chambers in the left side of the heart (mitral valve).

ml—milliliter (5ml = 1 teaspoon, 30ml = 1 ounce)

Murmur—a heart sound that may or may not be normal.

MVO2—mixed venous oxygen saturation.

Myocarditis—swelling of the heart muscle.

Myocardium—the muscular wall of the heart.

NPO—may not have anything to eat or drink.

Pacemaker (artificial)—a small, battery-operated device that controls the beating of the heart. It sends electrical impulses to the heart muscle.

Palpitation—a fluttering of the heart or an abnormal rate or rhythm of the heart.

Papillary muscles—small bundles of muscles in the wall of the lower chambers of the heart. Chords leading to the cusps of the valves are attached to the muscles.

Pericarditis—swelling of the thin membrane sac that surrounds the heart and roots of the great vessels.

Plasma—the liquid part of the blood.

Pulmonary artery—the large artery that carries unoxygenated (venous) blood from the right lower chamber to the lungs.

Pulmonary circulation—the blood flow from the right lower chamber of the heart (right ventricle) through the lungs, back to the left upper chamber of the heart.

Pulmonary edema—an abnormal amount of fluid that accumulates in the lungs and makes it hard to breathe.

Pulmonary hypertension—a higher than normal pressure within the blood vessels of the lungs.

Pulmonary valve—the valve where the pulmonary artery and the right lower chamber of the heart (right ventricle) meet.

Pulmonary veins—four veins, two from each lung, that carry oxygenated blood from the lungs to the left upper chamber of the heart.

Regurgitation—the backward flow of blood through a defective valve.

Renal—referring to the kidney.

SA node—a small mass of cells in the right upper chamber of the heart. It helps the heart to contract at the right time.

Semilunar valves—cup-shaped valves that prevent back flow of blood. The aortic and pulmonary valves are semilunar valves.

Septum—a dividing wall in the heart.

Shunt—a passage between two blood vessels or between the two sides of the heart.

Stenosis—a narrowing of an opening.

Sympathetic nervous system—a part of the autonomic nervous system or involuntary nervous system. It controls tissues not under voluntary control, such as blinking our eyes or breathing.

Syndrome—a set of characteristics that occur together and are given a particular name.

Systemic circulation—the blood flow through all parts of the body except the lungs.

Systole—in each heartbeat, the period of contraction of the heart.

Tachycardia—a faster than normal heart rate.

Thrombosis—the formation or presence of a blood clot (thrombus) inside a blood vessel or cavity of the heart.

Tricuspid valve—a valve consisting of three cusps between the right upper and lower chambers of the heart.

Vein—any of a series of vessels of the vascular system. Veins carry unoxygenated blood back to the heart. The exception is the pulmonary veins, which carry oxygen-rich blood back to the heart.

Vena cava—a large vein that carries blood back to the heart (there is inferior and superior).

Venous blood—unoxygenated blood.

Ventricle—either of the two lower chambers of the heart.

Ventricular septum—a muscular wall between the two lower chambers of the heart.

Ventricular septal defect—an abnormal opening between the right and left ventricle.

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