



Heart Surgery Guide



DOERNBECHER
CHILDREN'S
Hospital



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Welcome

Welcome to OHSU Doernbecher Children's Hospital. Thank you for trusting us with your child's heart surgery.

Our world-class heart team will give your child excellent care and make your stay as comfortable as possible.

This guide will help you know what to expect during your child's surgery and recovery. You will find information on:

- How to prepare for your child's hospital stay.
- How to help your child cope with surgery.
- What happens after you go home.

Your care team is always here to answer your questions. Please call us if we can help in any way: 503-418-5750 or 1-800-822-9996.



Doernbecher
Children's
Hospital



ROOD FAMILY PAVILION

3411

Preparing for the hospital



Preparing for surgery and a hospital stay can be stressful. We will support you at every step. We'll also connect you with resources to make it a little easier.

Our goal is to ease your stress so you can focus on your child.

Where to stay

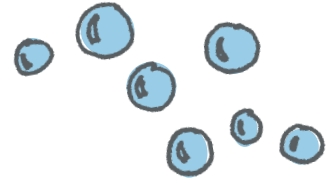
If you live outside the Portland area, you may need a place to stay while your child is in the hospital.

Many families can stay for free at OHSU's Rood Family Pavilion on our South Waterfront campus. This guest house, run in partnership with Ronald McDonald House Charities of Oregon & SW Washington, provides a

home away from home for Doernbecher children and their families who live more than 30 miles away. It has easy access to Doernbecher via the Portland Ariel Tram, and offers public and private spaces devoted to your well-being. Details are at ohsu.edu/health/rood-family-pavilion.

A number of hotels near the hospital also offer discounted rates for Doernbecher families. We may be able to provide vouchers to help you pay for your hotel stay.

Please note that one or two parents/guardians can spend the night in a child's hospital room after surgery, but siblings are not allowed overnight. It's important to make plans for your other children. If you need help, please let us know.



What to pack

We provide everything your child needs in the hospital, so you don't need to bring much. We suggest you pack an overnight bag with only the essentials for yourself, as well as a few comforting items for your child. Please wash or clean anything you bring from home.

We recommend bringing:

- A cellphone and charger
- Comfortable clothes
- Toiletries
- Your child's favorite clean toy, stuffed animal or blanket
- A credit card or a little cash for food and the gift shop; please leave other valuables at home

Don't worry if you forget something. We have extra toiletries and other supplies. Just ask.

Staying healthy

It's important to help your child stay as healthy as possible before surgery. We may have to delay the procedure if your child is sick.

To lower the risk of illness, we recommend:

- Washing your hands frequently.
- Avoiding sick people.
- Covering your cough with your elbow.
- Getting plenty of sleep.
- Following food safety guidelines.

Please let us know if your child isn't feeling well within two weeks of your scheduled surgery. We will determine whether they are healthy enough for surgery and anesthesia on the day before surgery at your preoperative appointment.



Meet your team

Your child's heart surgery team will provide leading-edge care in the comfort and safety of our top-ranked children's hospital, recognized among the best in the nation by *U.S. News & World Report*.

Our two surgeons, Dr. Irving Shen and Dr. Ashok Muralidaran, have more than 25 years of combined experience. They offer exceptional skill in repairing complex heart conditions.

In addition, they are part of a dedicated team of children's heart specialists who are trained to understand the needs of babies, children and teens. We use the latest technology and techniques in our child-focused operating room and intensive care units.

Our team works with specialists from across OHSU to plan the most effective surgical care for your child.

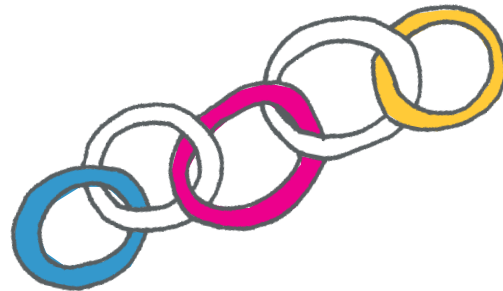
Your child's team may include:

- **Two children's heart surgeons:** Dr. Shen and Dr. Muralidaran usually operate together, sharing their knowledge and skills to give your child the best possible results.
- **Cardiologist:** Your child's heart doctor plays a key role in planning your child's surgery and follow-up care.
- **Physician assistants, nurse practitioners, nurses, technicians and respiratory therapists:** Everyone on your child's team specializes in caring for children. Respiratory therapists help your child during the post-operative recovery period.
- **Anesthesiologists:** We have five children's anesthesiologists who specialize in taking care of children during cardiac surgery available 24/7.

- **Perfusionists:** Heart-lung machine specialists (perfusionists) monitor your child throughout the procedure.
- **Radiologists:** Imaging specialists create high resolution images of your child's heart.
- **Intensivists:** Doctors certified in children's intensive care give your child the highest-quality care around the clock in our pediatric and neonatal intensive care units.
- **Rehabilitation specialists:** Speech-language pathologists, registered dietitians, and physical and occupational therapists help your child eat, speak and move as well as possible, as soon as possible after surgery.

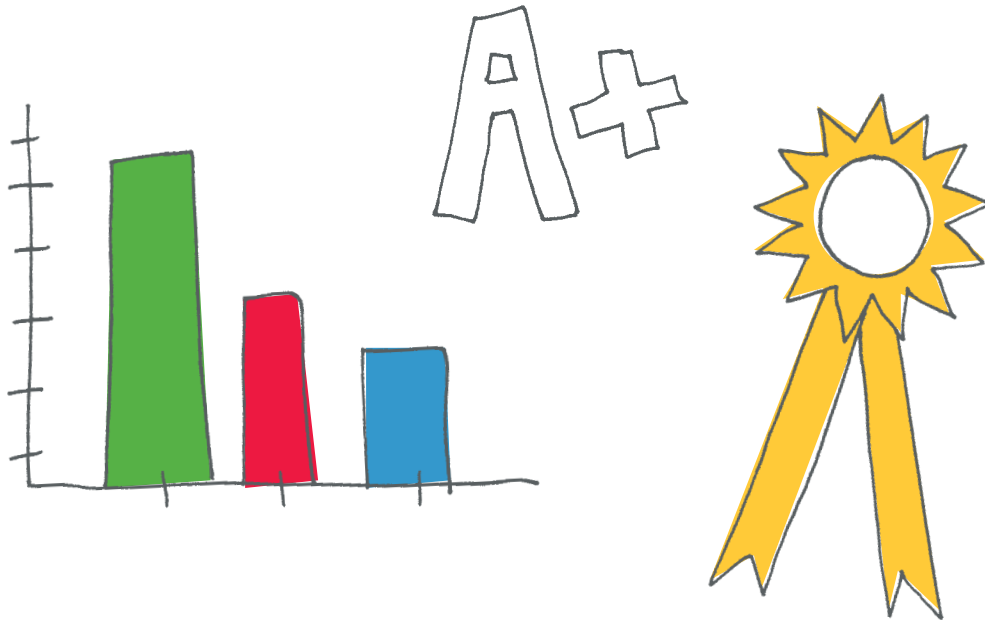
- **Certified child life specialists:** Experts in children's well-being help you and all the children in your family cope with being in the hospital through play, education and creative activities.
- **Social workers:** Our licensed clinical social workers provide emotional and social support.

Our team works with specialists from across OHSU to plan the most effective surgical care for your child.



Quality and outcomes

At Doernbecher, we're proud of our quality and outcomes. We're members of the National Pediatric Cardiology Quality Improvement Collaborative. We also voluntarily report our heart surgery outcomes to the Society of Thoracic Surgeons, and we share them on our website. Learn more at ohsu.edu/doernbecher/pediatric-heart-care-quality-and-outcomes.





Day before surgery

On the day before your child's surgery, you will come to OHSU Doernbecher for a preoperative appointment with your care team. Here's what to expect:



Health evaluation: Our nurse practitioner or physician assistant will give your child a physical exam and go over your child's health history and any concerns. They will talk with you about the next day's schedule and how to prepare.



Talk with your child's surgeon: One of our children's heart surgeons, Dr. Irving Shen or Dr. Ashok Muralidaran, will meet with you to talk about your child's surgery and ask for your consent.



What to bring: You don't need to bring any special financial or insurance documents; we've usually taken care of these matters by this point. You may want to bring small toys, games, videos, books or snacks to comfort or entertain your child.



Tests: After you meet with the surgeon, you will go to our lab for a test to confirm your child's blood type. Other tests may include:

- **Echocardiogram:** This safe, painless ultrasound test creates moving images of your child's heart as it pumps. Your child may be sedated for this test. In that case, we will call you the day before with special instructions.
- **Duplex study:** This is another ultrasound test that helps us look closely at the structure and blood flow in your child's veins and arteries.



Tour of Pediatric Intensive Care Unit (PICU): A child life specialist or nurse can arrange a tour of our PICU. A tour can help you know what to expect when you arrive for surgery. Please let your care team know if you'd like a tour.



The night before surgery: Your child can eat and drink normally until midnight. After that, please follow our instructions for eating and drinking. These rules are important for the safety and health of your child. If you don't follow them, the surgery may be delayed or canceled.

Before bed, you should:

- Make sure your child has a bath or shower.
 - Remove any makeup, nail polish, jewelry or contact lenses. (Your child should wear glasses to the hospital, if needed.)
 - Gently wipe your child's skin with SAGE antiseptic cloths to reduce bacteria and the risk of infection. We will give you these cloths at your pre-operative visit.
 - Dress your child in clean pajamas or clothes.
-

Day of surgery

On the day of surgery, you will check-in to OHSU Doernbecher and your child's care team will help to prep them surgery. Once your child is in surgery, we will keep you up to date with their progress, and our surgeons will speak directly with you after the surgery.



Arrival: The day before surgery, we will give you a hospital check-in time. The time varies for each child, but it is usually early in the morning. Check in at the OHSU Doernbecher lobby, and then go to the eighth-floor maple leaf sign.



Surgery prep: Your child's skin will be cleaned again with SAGE antiseptic cloths. We will also swab their nose with another antiseptic to reduce the risk of infection. You will then meet with the anesthesiologist and nurses who will care for your child during surgery. We may give your child medication to relax at this time. You may stay with your child until we go to the operating room, but you may not accompany your child into the operating room.



Communication: During surgery, nurses in the operating room will call or page you with updates every 1-2 hours. Please bring your cellphone, fully charged, and a charging cable. We will give you a pager.



In the operating room: It can take up to two hours to get your child ready for surgery. Here's what we do before the procedure starts:



- The anesthesiologist gives your child medication to fall deeply asleep. After that, your child will not feel any pain or be aware of anything.



At this time, the anesthesiologist will place a breathing tube.



- We place several thin, flexible tubes (intravenous catheters or IVs) in your child's arms, legs, neck and wrist. These IVs give your child fluid and medications, including pain medications, and measure their blood pressure.

- Another thin, flexible tube (Foley catheter) is placed in your child's bladder to drain and collect urine. We monitor the urine levels throughout the procedure.

- We place an ultrasound probe in your child's food pipe (esophagus) to see moving images of their heart from the inside. We do this test before and after surgery.



Transfer to the PICU: It takes about one hour after your last update for your child to be transferred from the operating room to the intensive care unit. Dr. Shen or Dr. Muralidaran will come to the eighth-floor waiting room as soon as possible to talk with you about the surgery.

After surgery

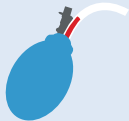
It can be overwhelming to see a child after surgery when they are swollen and connected to tubes, wires and monitors. It's impossible to truly prepare you, but we hope to give you an idea of what to expect.



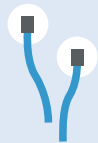
Surgery site: A pink dressing will cover the surgery site on your child's chest.



IVs and catheters: Your child will still have various IVs for medications and a Foley catheter to drain urine.



Chest tubes: These long tubes come out from under your child's rib cage. They collect and drain fluid from around the heart and lungs. The drainage might be bloody at first, but it will change to a straw-colored fluid over the next few days.



Pacer wires: Temporary pacemaker wires will be on both sides of your child's surgery site under the rib cage. Sometimes after heart surgery, children can have a fast, slow or irregular heartbeat. A pacemaker controls heart rate until it normalizes.



Removal of chest tubes and pacer wires: During surgery, the surgeon stitches the chest tubes and pacer wires into place. We remove them at your child's bedside about a day before going home from the hospital.



Breathing tube: Your child may still have a breathing tube in their throat, or we may have taken it out in the operating room. This is the first tube we remove. The timing depends on how fast your child processes the anesthesia and the type of cardiac surgery. Often children have the breathing tube removed in the operating room. Others will come to the pediatric intensive care unit with the breathing tube still in. The breathing tube will be removed when the team decides your child is ready.



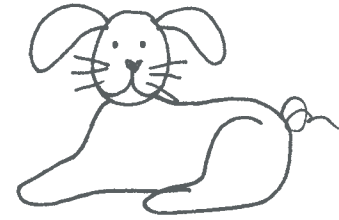
Deep breathing: As soon as the breathing tube is removed, nurses will work with your child to take deep breaths. If your child is old enough, the nurses will ask them to blow bubbles and inhale deeply. We use a device called an incentive spirometer to encourage deep breathing. Most importantly, we will help your child get out of bed and start walking. Taking deep breaths through movement and other activities helps children recover faster.



Pain control: During the procedure, your child has a continuous dose of pain medication through an IV. The level can be turned up or down to control pain. After your child is back to the PICU, the providers use a variety of pain medications to keep the child as pain free as possible but not so sleepy that they are not taking deep breaths. Doctors use IV medication, either continuous or as an individual dose every couple of hours as needed. Usually after 12 hours they add non-narcotic pain medication, a non-steroidal through the IV, and Tylenol. This combination helps us to decrease the amount of narcotics we use but also keep your child comfortable. After your child is awake enough to eat and drink, we will switch to pain medication taken by mouth, usually in a liquid. You will be given a prescription for pain medication to take home. Within a few days, most children can use Tylenol or Motrin alone to control pain.



Staying with your child



After your child's surgery, you can stay with them at all times. We encourage you to spend the night in your child's room. Siblings are not allowed to spend the night.

Pediatric Intensive Care Unit (PICU, eighth floor): Your child first goes to the PICU to recover from surgery. PICU rooms have an extra twin bed, toilet and sink. A shower is down the hall. At first, there is a two-visitor limit per child. Visitors younger than 12 usually aren't allowed. If your child has a young sibling who would like to visit, please check with your care team.

Main pediatric floor (ninth floor): Your child moves to the main pediatric floor after their breathing tube has been removed and he no longer needs continuous IV medications. These rooms are little bigger, and the atmosphere is more relaxed than in the PICU. Each room has an extra twin

bed, a chair bed, bathroom and shower. Visitors under age 18 must be with an adult at all times.

Hospital amenities: We offer services and spaces to make your stay more comfortable, including:

- Free laundry facilities and detergent
- Indoor and outdoor play areas
- Child life specialists and animal-assisted therapy
- Family lounges with refrigerators and microwaves
- Free Wi-Fi
- Meditation room
- Interpreter services
- Family Resource Center in the lobby
- Lactation rooms with breast pumps

Leaving the hospital

Many families ask, "How long will my child be in the hospital?" The length of a child's stay depends on the speed of recovery. Some children stay for only a few days, and others are here for a few weeks or longer.

We follow your child's lead. Children can typically go home after reaching these milestones:

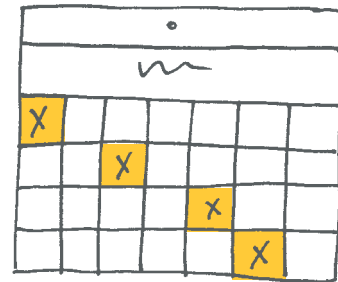
- The breathing tube has been removed.
- Extra fluid from the surgery has drained, and the chest tubes are out.
- Your child is taking all medications and fluids by mouth, and the IV tubes are out.
- Pain is controlled with medications taken by mouth.
- Your child can move in an age-appropriate way.
- Final imaging tests (usually an X-ray and echocardiogram) are done.

Recovery at home

Before you go home, we will give you instructions on how to care for your child's incision, how to give medications and how active they can be. A nurse will call you within a week to check on how things are going.

You will have two follow-up appointments for your child:

- In one week with your primary care provider
- In two weeks with your child's heart doctor





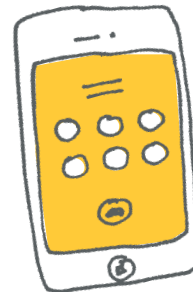
When to call your doctor

We are here for you any time. If you have any questions or concerns, please call us at:

- **503-418-5750** during business hours
- **503-294-8311** after hours

Please call right away if your child has:

- A fever of 101 degrees or more
- Severe irritability or inconsolable distress
- An incision that is red, bleeding or draining fluid
- An opening or separation in the incision
- Noisy, congested, rapid or difficult breathing
- Poor appetite, feeding or weight gain
- An irregular or racing heart rate
- Vomiting or diarrhea that may lead to dehydration
- Sleepiness and lack of energy
- Chest discomfort



Emotional care

Children are resilient. Most cope well, grow and mature from their hospital experience with support.

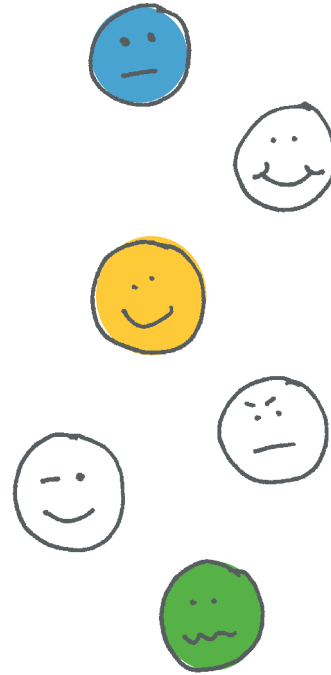
In the first four to six weeks after leaving the hospital, some children may have behavior changes, such as:

- Withdrawal
- Anger
- Depression
- Bad dreams
- Discipline problems
- Regression in skills
- Difficulty separating from you.

Try not to be overprotective, overly harsh, too strict or too permissive.

Siblings also may feel neglected or responsible for your child's illness. Try to give them special attention so they feel noticed and loved.

If you have any concerns about your child's emotional recovery, please talk with your care team.





Supporting your child

Children often feel anxious about the unfamiliar people, places and procedures in the hospital. Helping your child cope with stress and feel more comfortable can make their stay and treatments easier.

Our child life specialists can help you find the words to explain what's happening in a way your child will understand. They can show you ways to distract, comfort and relax your child.

To prepare, you can:

- Talk with your child's care team about what will happen.
- Ask questions about any concerns.

- Take care of yourself. Eat and sleep regularly.
- Ask family and friends to give you breaks.

The OHSU Doernbecher Family Resource Center in the hospital lobby has children's books and resources on health, child development and coping with illness.

The following pages include common issues at each developmental stage, plus tips for helping your child prepare for surgery. You can contact the Child Life Therapy team for more ideas at **503-418-5388**.



Infants

Common issues

- Separation from parents
- Many caregivers
- Disrupted routines
- Interrupted sleep
- Strange sights, sounds and smells
- Day and night confusion

How you can help

- Keep your baby's routine the same before the day of surgery.
- Talk with your care team about your baby's routines, including sleep and eating habits.
- Make sure you, your baby and your family are well-rested.

- Bring your baby's favorite blanket, pacifier, stuffed animal or other security items.
- Play soothing music and dim the lights.
- Plan for at least one family member to be with your baby as much as possible so he always has a familiar touch, voice and smile present.
- Relax your facial expressions, gestures and body language to soothe your baby.

Reactions to surgery

- Before surgery: It's normal for your baby to be hungry and irritable before surgery. Try to comfort your baby with rocking, walking, singing or talking.
- After surgery: Your baby may not be easily consoled. This is normal. Rocking, quiet music and dimming the lights may help.





Toddlers and preschoolers

Common issues

- Thinking they are in trouble or being punished
- Blurring of imagination and reality
- Fear of:
 - Being alone or away from family and home
 - Needles, shots and pain
 - The dark
 - Strangers and unfamiliar places

How you can help

- One to two days before surgery, explain what will happen and why.
- Answer questions in a simple, honest way.
- Ask your child to tell you what's happening. Correct any misunderstandings.
- Emphasize that being in the hospital is not a punishment. Explain that doctors and nurses are helpers.
- Take a tour of the Pediatric Intensive Care Unit with your child.
- Read books with your child about going to the hospital.

- Allow your child to help pack a suitcase.
- Bring favorite blankets, stuffed animals and photos of relatives and pets.

Books

- "Curious George Goes to the Hospital," by Margret and H.A. Rey
- "Going to the Hospital," by Anna Civardi
- "A Visit to the Sesame Street Hospital," Random House/Children's Television Workshop
- "Pooh Plays Doctor," by Kathleen Weidner Zoehfeld
- "One Bear in the Hospital," by Caroline Bucknall
- "Going to the Hospital," by Fred Rogers
- "Franklin Goes to the Hospital," by Paulette Bourgeois and Brenda Clark
- "Corduroy Goes to the Doctor," by Don Freeman and Lisa McCue
- "Little Critter: My Trip to the Hospital," by Mercer Mayer

School-age children

Common issues

- Being away from school and friends
- Thinking they have been bad or are being punished
- Anxiety about body changes or injuries
- Fear of waking up during surgery
- Loss of control or privacy
- Fear of needles, shots and pain

How you can help

- Talk with your child about what to expect at the hospital.
- Tour the hospital and Pediatric Intensive Care Unit before surgery.
- Ask your child to tell you what is going to happen. Correct any misunderstandings.
- Read books with your child about going to the hospital.

- Tell children they haven't done anything wrong and aren't being punished.
- Explain the benefits of the surgery in words your child can understand.
- Encourage your child's friends to visit the hospital, to call or to send cards and emails.
- During a test or procedure, hold hands and take deep breaths together. Distract your child with books, toys, videos and counting backward. Take an imaginary trip together.
- Affirm your child's feelings: "I know this is hard, and I know you can do it."

Books

- "The Hospital Book," by James Howe
- "Let's Talk About Going to the Hospital," by Marianne Johnston
- "What's Inside a Hospital?" by Sharon Gordon





Teens

Common issues

- Loss of independence, privacy and control
- Being away from school and friends
- Reluctance to say they don't understand
- Body changes or injuries
- Worry about what others will think about them
- Fear of:
 - Surgery and its risks
 - Pain
 - The unknown
 - Waking up during surgery



How you can help

- Allow your teen to help make care decisions.
- Encourage your teen to make a list of questions for the care team.
- Be honest when answering questions.
- Explain the care plan in different ways.
- Bring favorite items from home, such as music, videos, photos, books and journals.
- Ask teens if they would like visitors. Encourage them to stay in contact with friends by email, text, phone or social media.
- During a test or procedure, you can:
 - Help your teen find a comfortable position.
 - Do breathing exercises together.
 - Play music or videos.
 - Affirm your teen's feelings: "I know this is hard, and I know you can do it."

Resources

Doernbecher offers a full range of support services for children and their families. Please talk with your care team if you are interested in learning more about any of these services:

Social workers: Our licensed clinical social workers are here to provide you with social and emotional support both in and out of the hospital. They can help connect you with resources related to food, housing, transportation, financial assistance, safety and other hospital or community services. If you would like to talk to a social worker at any time, please let us know.

Bridges Pediatric Palliative Care Program: Our children's palliative team can support your child and your family at all stages of your child's care. Palliative specialists can help you through difficult decisions and procedures. They can also coordinate services, provide counseling and improve communication with your care team.

Monthly support group meetings: Heart to Heart Family Connections, our support group, gives families and caregivers of children with heart conditions a place to meet and share stories. The group meets at 6:30 p.m. on the first Thursday of each month. Please email Kristine Gutshall, R.N., at gutshall@ohsu.edu to RSVP and receive location details.

Parent mentors: When your child is diagnosed with a serious heart condition, we can connect you with other parents who have gone through similar experiences. Mentors are available to talk with you and offer support throughout your child's care. Please tell your care team if you would like to meet another family with a child who has a serious or similar heart condition.

Cardiac rehabilitation: Our children's heart rehab program encourages children with heart conditions to become active in a safe, supervised and fun way. A children's

cardiologist (heart specialist), physician assistant and physical therapist will work with you and your child to assess your child's fitness level, and to set and reach goals.

Family Resource Center: You'll find copy and fax machines, computers with internet access, and weekly activities for parents. The center also offers books and information on child development and health topics, and resources in Spanish and other languages. The center, in Doernbecher's lobby, is open 8 a.m. to 7 p.m. weekdays.

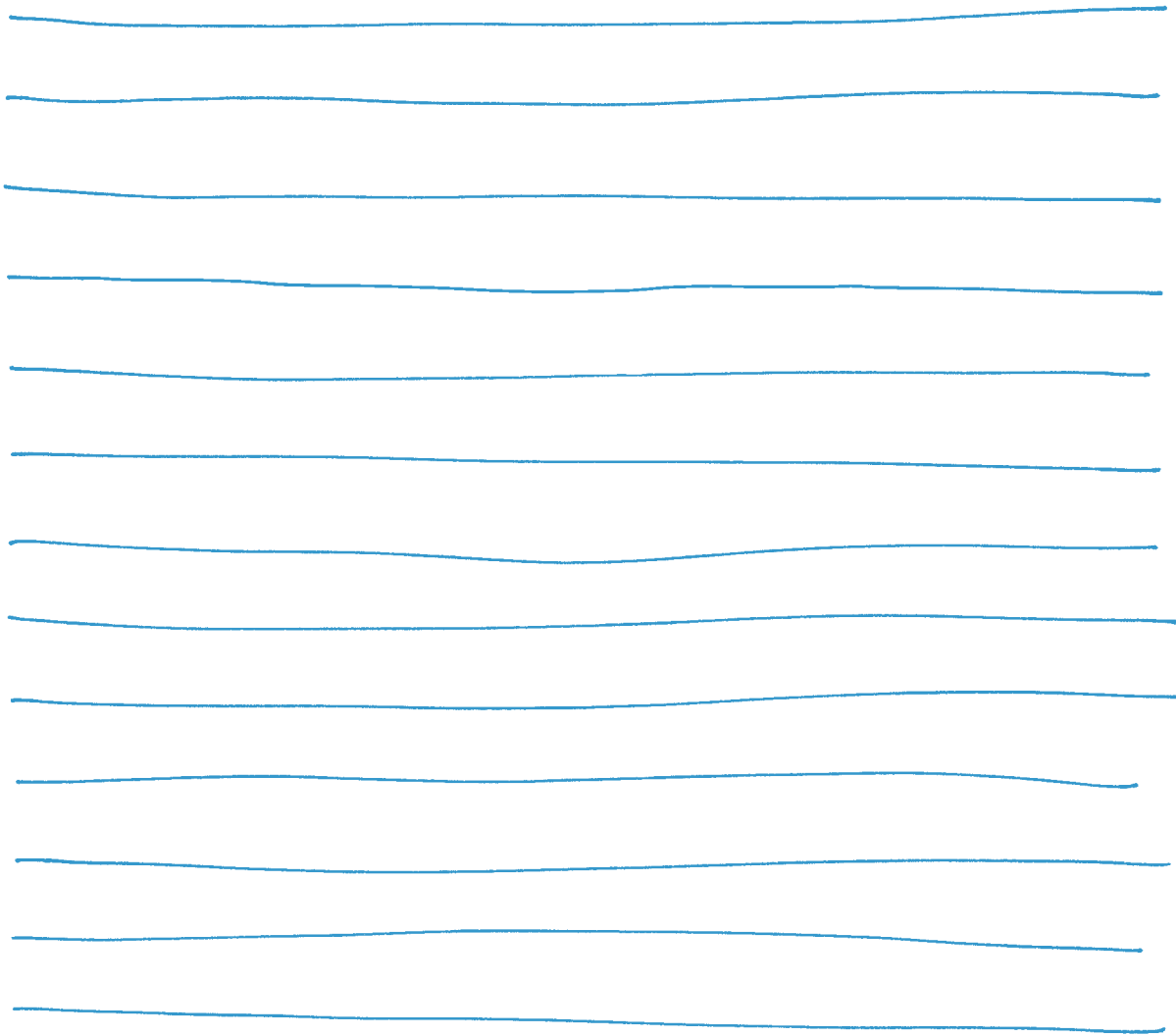
Important phone numbers

	Phone Number	Hours
Children's Heart Care Team	503-418-5750 or 1-800-882-9996	8 a.m. - 4:30 p.m. weekdays
General OHSU number	503-294-8311	After hours and on weekends. Ask for the pediatric cardiologist on call.

Notes / questions



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ohsu.edu/doernbecher



DOERNBECHER
CHILDREN'S
Hospital

OHSU accepts most major health plans.
OHSU is an equal opportunity, affirmative action institution.
DCH 21632339 5/20