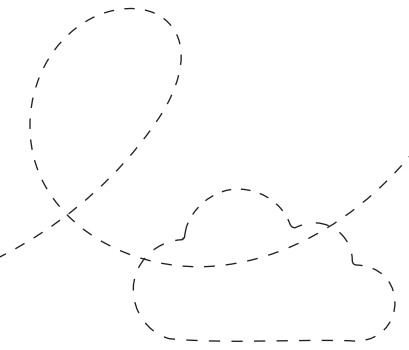
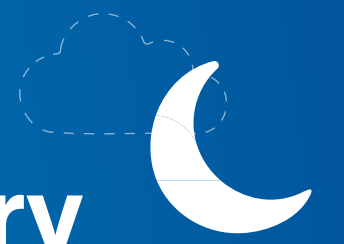


Guide to Your
Child's Heart Surgery
at Mount Sinai
Kravis Children's Hospital



This book belongs to:

Medical Record Number _____

Date of Birth: _____

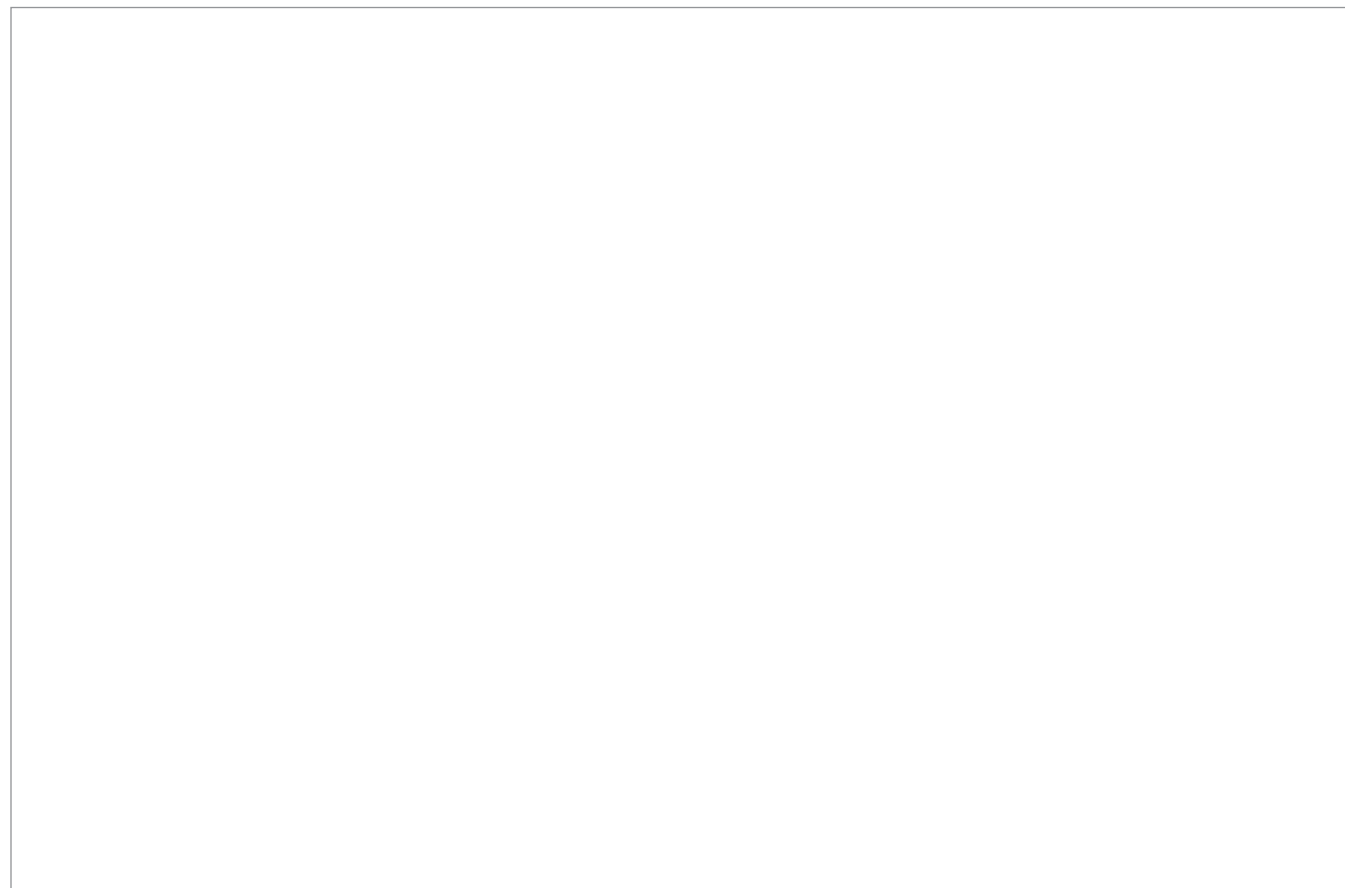
Contact information: _____

Cardiologist: _____

Date of Surgery: _____

Surgeon: _____

This is a drawing of me or one of my favorite things:



About me



My favorite color is _____

My favorite animal is _____

My favorite thing to do is _____

My favorite food is _____

Foods I don't like are _____

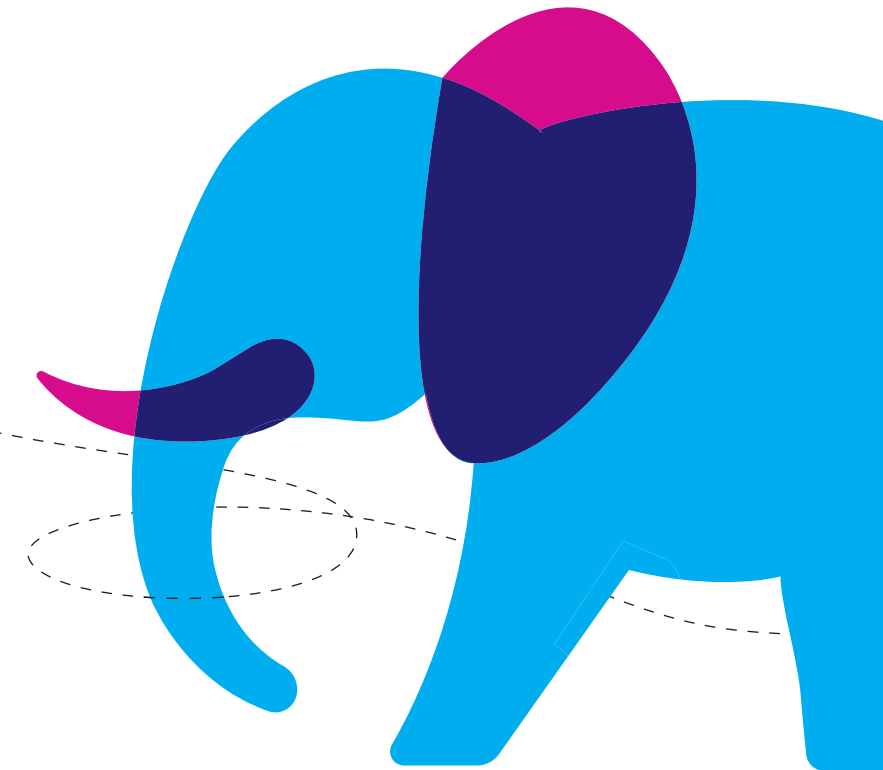
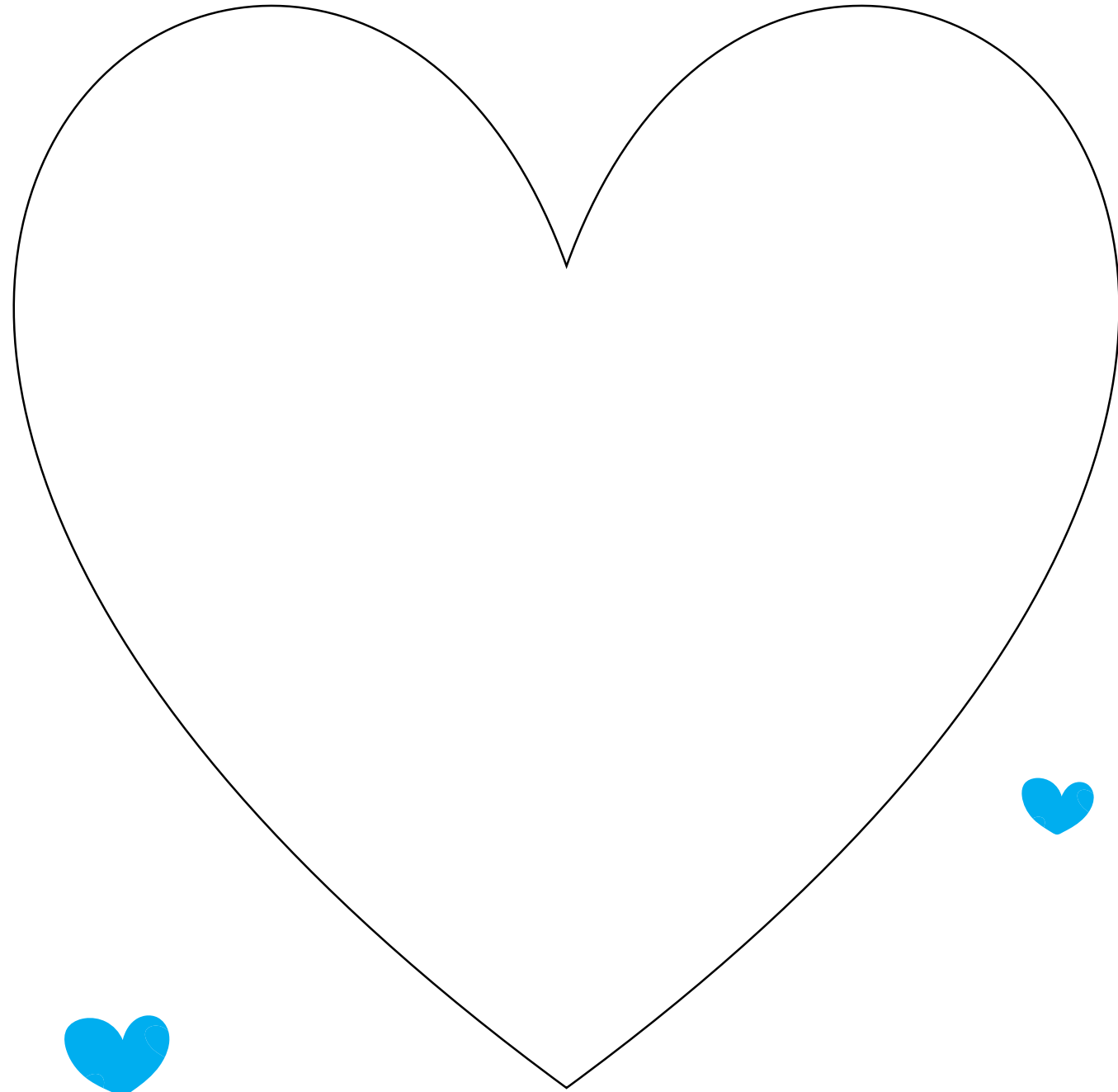
Dietary restrictions _____

MEDICATIONS			
Daily Medications	Dose	Amount/Route	Frequency
As Needed Medications	Dose	Amount/Route	Frequency

Allergies _____

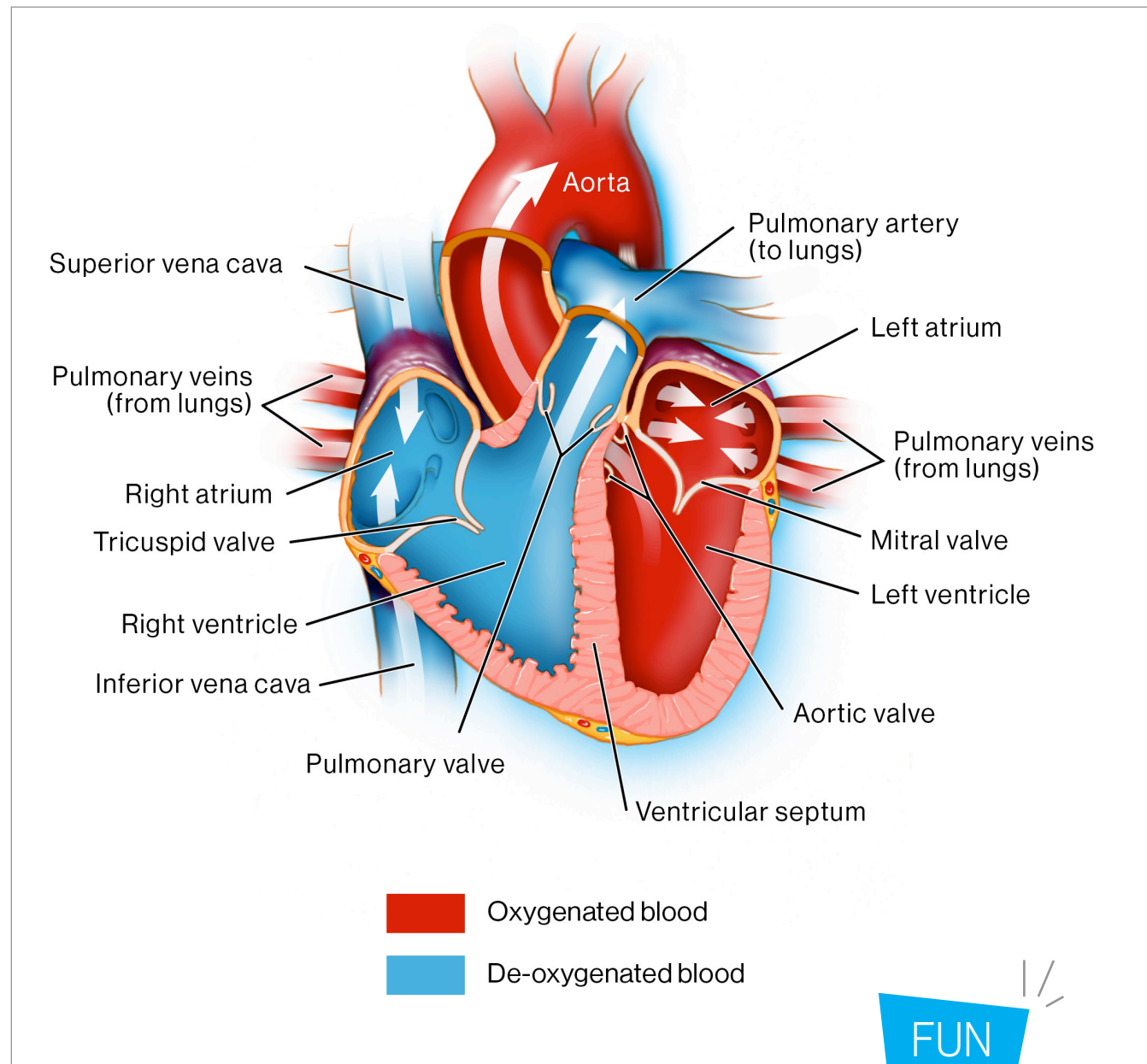
My heart

This is a drawing of me or one of my favorite things:



Typical heart anatomy

This is what a heart really looks like.



Your heart is about as big as your fist.

My heart anatomy



A note from

Robert Pass, MD | Peter Pastuszko, MD | Ali Zaidi, MD

Directors of the Mount Sinai Children's Heart Center

As you prepare your child for heart surgery, we want to assure you that you are in the right place. Our entire Children's Heart Center team is dedicated to providing the best care for your child. We understand what you are going through, and we appreciate your trust.

The idea of surgery can be overwhelming, but we are here to support you every step of the way. The Children's Heart Center brings world-class expertise to you and your child in order to address complex conditions in even the tiniest of hearts.

This guide has been developed by our physician assistants and social workers based on the feedback of families who have been standing where you are now. In the pages that follow, you will find information on what to expect in the weeks leading up to surgery, on the day of preadmission testing, the night before surgery, and the day of surgery.

Please remember that we are here for you. Do not hesitate to reach out with any questions or concerns.

Sincerely,

Robert Pass, MD

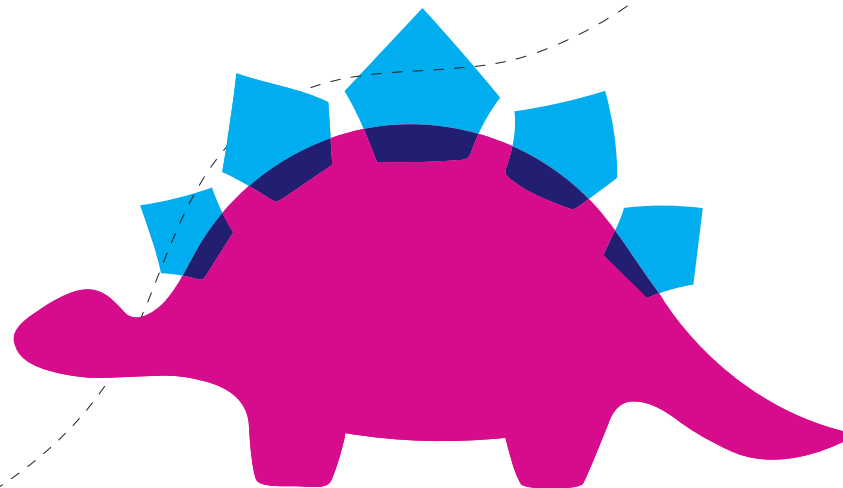
Chief, the Division of
Pediatric Cardiology

Peter Pastuszko, MD

Chief, Pediatric
Cardiovascular Surgery

Ali Zaidi, MD

Director, Adult
Congenital Heart Disease



Peter Pastuszko, MD

Chief of Pediatric Cardiac Surgery
Director of Pediatric Cardiovascular Services
Co-Director of the Children's Heart Center



Peter Pastuszko, MD, is Chief of Pediatric Cardiac Surgery and the Director of Pediatric Cardiovascular Services at the Mount Sinai Health System and Co-Director of the Mount Sinai Children's Heart Center. He has extensive experience in treating the entire spectrum of congenital heart disease, from newborn to adult congenital, having performed several thousand successful surgeries over the course of his career.

Clinical Expertise

Dr. Pastuszko has expertise in the surgical treatment of complex neonatal heart defects, including Hypoplastic Left Heart Syndrome (HLHS), Transposition of Great Arteries (TGA), Truncus Arteriosus, Ebstein's Anomaly, and many others. He has extensive experience, with a high success rate, performing some of the most complex neonatal surgical procedures such as the Norwood operation, neonatal Ross procedure, and neonatal Ebstein's repair. In the five years prior to his move to Mount Sinai, he performed more than a thousand operations for congenital heart disease. In addition to treating newborns, infants, and children, Dr. Pastuszko is also experienced in the area of adult congenital, thoracic, and vascular surgery.

Dr. Pastuszko is a strong proponent of collaboration among diverse disciplines in order to ensure the best possible outcomes for his patients. Similarly, Dr. Pastuszko strongly believes in open communication and partnership with families to ensure that they make sound, informed choices about their treatment options. In order to ensure that all of their questions are answered and concerns addressed and to establish meaningful relationships, he routinely meets with expectant parents whose babies have been diagnosed with heart defects.

Education and Work Experience

Dr. Pastuszko received his medical degree from the Perelman School of Medicine at the University of Pennsylvania and did his residency at Thomas Jefferson University in Philadelphia prior to completing his congenital training at the Children's Hospital of Philadelphia under the mentorship of Thomas Spray, MD.

He is a Fellow of the American College of Surgeons. In addition, he belongs to the American Medical Association, the Society of Thoracic Surgeons, the Southern Thoracic Surgical Association, the Western Thoracic Surgical Association, and the Congenital Heart Surgeons' Society. He is board certified in both congenital cardiac as well as thoracic and cardiovascular surgery.



Meet the team



Pediatric Cardiologist:

As experts in cardiology, pediatric cardiologists collaborate closely with the surgeons and pediatric cardiac intensivists to create a plan as your child is recovering from surgery. They review and assess telemetry, EKGs, echocardiograms, and other key information.

Pediatric Cardiac Surgeon:

Pediatric cardiac surgeons and their team perform your child's surgery. Afterward, they work with pediatric cardiologists and the pediatric cardiac intensivists to make any major decisions. Pediatric cardiac surgeons make daily rounds in the pediatric cardiac intensive care unit (PCICU) and are available 24/7.

Pediatric Cardiac Intensivist:

These doctors are experts in pediatric cardiac intensive care. They provide highly specialized and individualized treatment for your child in the PCICU and are available on site 24/7. You will see them on rounds every morning and frequently throughout your child's stay at Mount Sinai.

Pediatric Cardiac Anesthesiologist:

These experts provide anesthesia to children who need heart surgery. An anesthesiologist will meet you and your child just before surgery. They will give your child medicine to keep your child asleep and comfortable throughout surgery. After, the anesthesiologist will bring your child to the PCICU.

Critical Care Nurse:

These nurses offer specialized cardiac nursing care. They have in-depth knowledge of and deep appreciation for the complexities of children with congenital heart disease. Nursing assistants (NAs) support the nursing staff.

Social Worker:

Our social workers meet with every patient and family. They offer emotional support and connect you to resources. They can also help with challenges your family may face after surgery. This might include getting home services, mental health support, sibling support, and transportation. They can also assist with any financial concerns.

Patient and Family

Child Life Team:

These specialists provide developmentally appropriate support while your child is in the hospital. They offer bedside play to help your child feel comfortable. They also help provide your child support in preparation for tests, procedures, and surgery. Child life specialists use language your child can understand.

Physician Assistant (PA)/ Nurse Practitioner (NP):

PAs and NPs are licensed health care professionals who provide direct patient care. The ICU team is comprised of PAs and NPs, all of whom will play an integral part in your child's care. Our surgical team is comprised of PAs, who are highly trained in the special care needs of congenital cardiac patients and will play an essential role in your child's care during and after surgery and after discharge.

Registered Dietitian/Nutritionist:

Our dietitians develop a personal diet plan for your child. They meet with you to complete a nutrition assessment. They are happy to help with any special diets or needs.



Two weeks before surgery

Your child should continue their normal daily activities. There are no restrictions in activities.

It is important for your child to remain healthy and avoid contact with people who may be sick. If your child feels sick in the days before surgery and experiences any of the symptoms below, please call us at **212-241-8213**.

- Fever over 101°F
- Cold symptoms (cough, runny nose)
- Vomiting or diarrhea
- Exposure to anyone with flu-like symptoms or any form of contagious illness such as COVID-19, chicken pox, or measles

Your child should not receive any vaccines during the two weeks before their surgery. It can be hard to tell if certain symptoms are a reaction to a vaccine or a cold.

What to Bring

A change of clothing for you and your child

- We provide children's pajamas and slippers, diapers, soap, and shampoo, but you may want to bring your own.
- Be sure to label all personal items.

General items

- Insurance and/or medical assistance information (including subscriber and access cards)
- List of medicines your child takes
- Name and phone number of your family physician, as well as any others involved in your child's health care
- Phone charger
- Phone numbers of friends and relatives you may need to call
- Things to do while you're waiting during your child's surgery, such as a book, a needlework project, or word puzzles

For infants and younger children

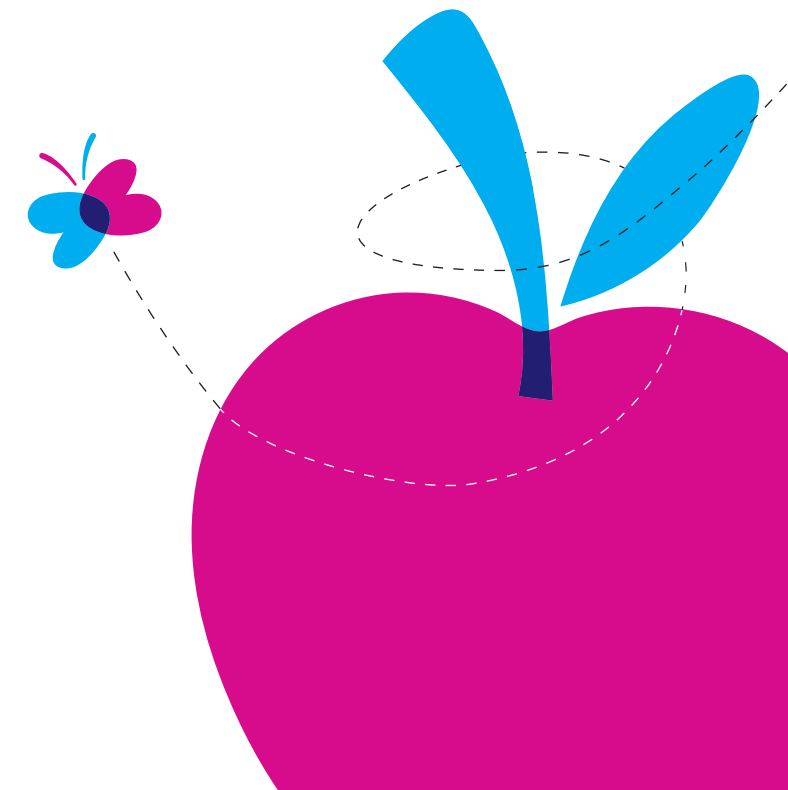
- One or two security items, such as a favorite stuffed animal, blanket, or pacifier
- An empty bottle or sippy cup to use after the surgery

For school-age children and teens

- One or two small toys or other items from home
- Books and magazines
- School work
- Bathrobe or sweatshirt with full-length front zipper

Don't bring:

- Large items. These can be a safety/fire hazard.
- Medications. Unless your child's physician specifically requests that you bring them, leave them at home.
- Remove all jewelry (including earrings and other piercings), nail polish, and synthetic nails prior to the morning of surgery.



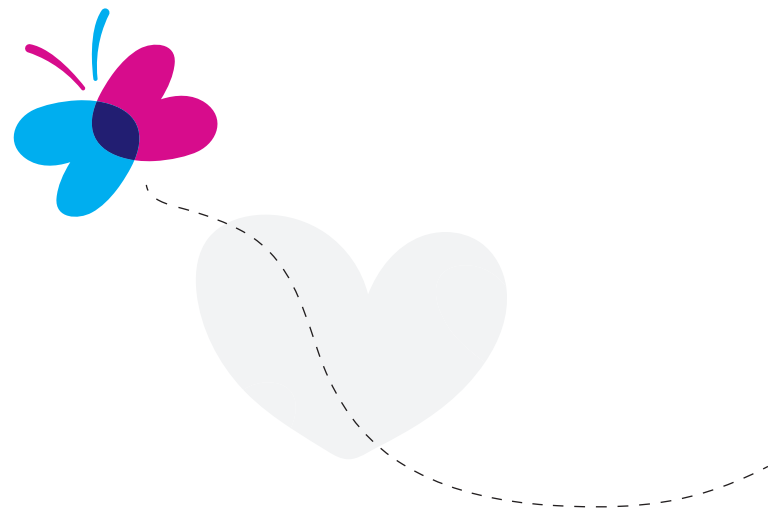
Talking to your child about surgery

Talking to your child and their siblings about surgery can be difficult. What and when you tell your child can vary based on developmental stage and age. We are here to guide you through these conversations and are happy to be as involved as you'd like. We offer the following advice, but you know your child best. We encourage you to communicate and comfort your child in the way you feel is most appropriate.

- **Infants to age three:** You can support your young child by bringing familiar, comforting items from home, such as a pacifier, blanket, doll, stuffed animal, music, or a sound machine. Your child will sense how you feel. You can help your child by remaining calm and being reassuring.
- **Toddler/preschool (three to five):** Use simple language to give your child a general sense of what to expect. Describe what your child will hear, see, feel, and experience. Explain that the surgery will help your child. For example, you can say, "The doctor is going to fix your heart here" (and point to the area). Children of this age use concrete thinking. Try to avoid using the term "put to sleep" when talking about anesthesia. Instead, you might want to say, "The doctor will help you fall asleep with special medicine."

There are many good books about going to the hospital for this age group. A few of our favorites are: *Riley's Heart Machine*, *Curious George Goes to the Hospital*, and *Franklin Goes to the Hospital*. You might want to bring a few familiar items your child will find comforting, such as special pajamas, toys, music, or a doll.

- **School age (5 to 12):** Your child is likely able to understand some details about what they will see, hear, and feel during and after surgery. Ask your child what they think and how much information they want. It is okay if you do not have all the answers. Prepare your child that they may feel some discomfort or aches and emphasize that the nurses and doctors will be there to give medicine to help. You can explain that, "Anesthesia is a medicine that will help you stay asleep during the surgery so you won't feel anything and when you



wake up surgery will be over." Try to encourage your child to tell you or the nurse if something hurts or seems scary. This will help give your child a sense of control and purpose.

- **Teenage (13-18):** With teenagers, the best approach is to be as honest and open as possible from the very beginning. Allow your teen the opportunity to meet with the medical team on their own at different stages. Encourage them to write down questions and get answers before and after surgery. If possible, allow your teen to have some control and make choices while you remain supportive.

It's best if your child doesn't think about surgery too heavily in the days leading up to it. Our general rule of thumb is one day notice for each year of life (for example, talk to your five-year-old five days before surgery).

Our Child Life Specialists can help speak to your child and their siblings about surgery. You know your child best, so do what feels right and let us know how we can assist.

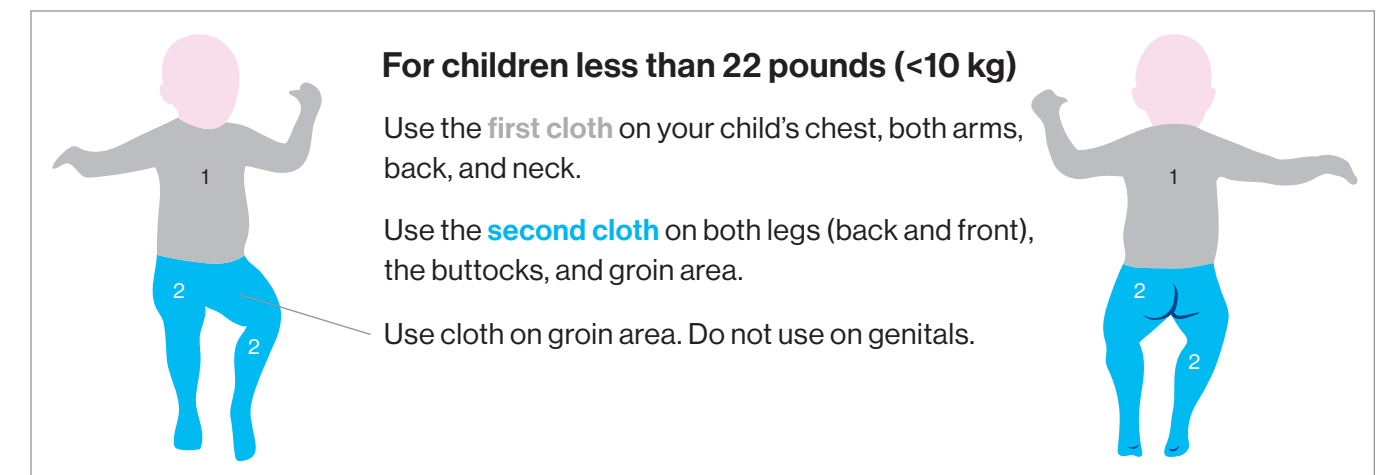
The night before surgery

Bathing and skin preparation

It is important that your child's skin is as clean as possible before you arrive for surgery. Use the provided special disposable cloths moistened with two percent chlorhexidine gluconate (CHG) antiseptic solution to help prepare your child's skin for surgery.

Please read and follow these instructions for bathing and skin care the night before surgery. **If you have any questions, please contact Pediatric Cardiac Surgery (212-241-8213).**

- Have clean, freshly laundered bed sheets, towels, and pajamas ready for use the evening before surgery.
- The night before surgery, your child should shower or bathe with regular soap and warm water and wash his or her hair.
- Remove nail polish, synthetic nails, and jewelry, including pierced earrings and other piercings.
- If you would like to warm wipes before use, place the unopened packet in a bowl of warm water at bathwater temperature. **Do not microwave.**
- Your child should be completely dry before applying the wipes.
- Open the package. Discard the foam piece.
- For each package, remove one cloth at a time and place onto a clean surface.
- Wipe your child's skin below the jaw line and down the body to the feet. Please follow the diagram for the proper use of cloths based on your child's weight.
- **DO NOT USE CLOTHS ABOVE THE NECK. Avoid contact with eyes, ears, mouth, internal genitalia, and any cuts or open areas of the skin.**
- Discard wipes in trash can.
- After using the wipes, **let skin air dry.** Your child's skin will feel sticky until dry due to the aloe in the wipes.
- **Do not rinse CHG off the skin before surgery.** After applying CHG wipes, your child may not shower, bathe, or apply lotions, moisturizers, or other personal care products.
- Put on clean pajamas and sleep in clean sheets.





For children between 22 and 66 pounds (10-30 kg)

Use the **first cloth** on your child's chest, both arms, and neck.

Use the **second cloth** on back and buttocks.

Use the **third cloth** on both legs (front and back).

Use the **fourth cloth** on your child's groin area.

For children more than 66 pounds (>30 kg)

Use the **first cloth** on your child's chest, both arms, and neck.

Use the **second cloth** on the RIGHT leg.

Use the **third cloth** on the LEFT leg.

Use the **fourth cloth** on the back.

Use the **fifth cloth** on the buttocks.

Use the **sixth cloth** on your child's groin area.

Eating and drinking

- No solid foods after midnight the night before surgery.
- No formula, milk, or opaque liquids after _____.
- No breast milk after _____.
- Your child may have one to two ounces of clear fluids until _____ am.
 - Clear fluids are any liquid you can see through, including water, pedialyte, and apple juice
 - This does NOT include citrus juices. Please do NOT give your child any citrus juices (such as orange juice, lemonade, etc.) on the morning of surgery.
- **Nothing by mouth after _____ am.**
 - If you don't follow these eating and drinking guidelines, your child's surgery may be delayed.

Medications

Unless otherwise instructed by your doctor or nurse:

- You may give your child's scheduled medications the night before surgery.
- Do NOT give any medications to your child on the morning of surgery.

In case of illness

If your child feels sick the night before surgery, let us know as soon as possible. If any of the following occur, please call us at 844-733-7692 and tell the operator that your child is having heart surgery. You will be directed to the cardiologist on call.

- Fever over 101°F
- Any cold symptoms such as runny nose or cough
- Any episodes of diarrhea or vomiting
- If you have reason to believe that your child has been exposed to anyone with flu-like symptoms or any form of contagious disease such as COVID-19, chicken pox, or measles



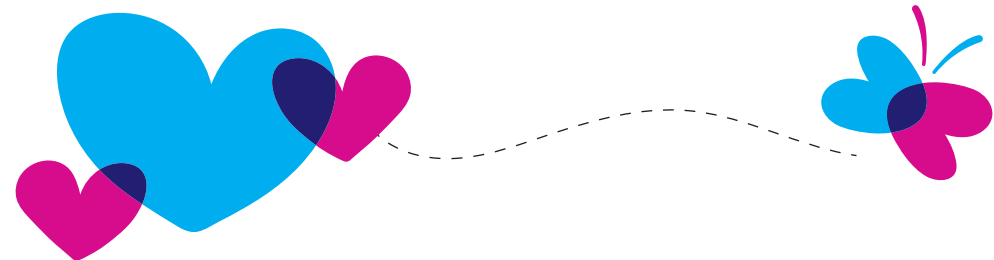
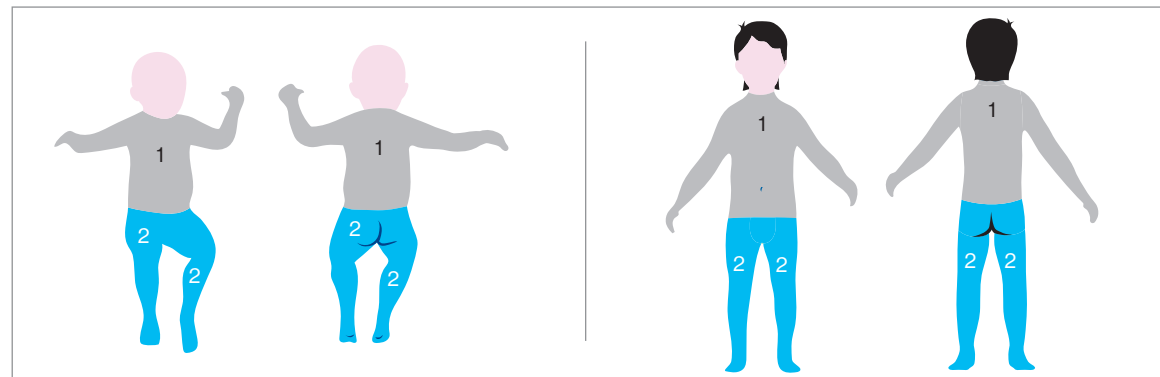
Morning of surgery

Repeat skin preparation

- Do not shower, bathe, or apply lotions, moisturizers, or other personal care products.
- Open the package of wipes. Discard the foam piece.
- On the morning of surgery, skin preparation instructions are the same for all children regardless of weight. Following the diagram below, use the first wipe to wipe your child's skin below the jawline down to the waist focusing on the chest area and then the back and both arms.
- Use the second wipe to wipe your child's lower half of the body, waist down, front and back, to the toes.

- **DO NOT USE CLOTHS ON THE FACE. Avoid contact with eyes, ears, mouth, internal genitalia, and any cuts or open areas of the skin.**
- Discard wipes in trash can.
- After using the wipes, **let skin air dry**. Your child's skin will feel sticky until dry due to the aloe in the wipes.
- **Do not rinse CHG off the skin prior to surgery.**
- Put on clean clothes.

Instructions for Children of All Ages on the Morning of Surgery



Arrival at Mount Sinai



Remember **NOTHING** to eat or drink after _____ am

Check in Time: _____ am

Check in Location: Pediatric Registration and Assessment Area, Seventh Floor

Mount Sinai Kravis Children's Hospital
1184 Fifth Avenue, between East 98th and 99th Streets
New York, NY 10029

Please plan to arrive at least a half-hour before your scheduled check-in time. This will allow enough time for possible travel delays and parking. At your scheduled check-in time, go to the Pediatric Registration and Assessment Area located on the Seventh Floor of Mount Sinai Kravis Children's Hospital.

Be sure to bring your photo ID, your child's insurance information, contact phone numbers, and any other important information.

Directions: Enter through the Mount Sinai Kravis Children's Hospital main entrance located on Fifth Avenue, between East 98th and 99th Streets. Take the elevator to the Seventh Floor. Head south off the elevators. Look for the butterfly signs that will direct you to the Pediatric Registration and Assessment Area.

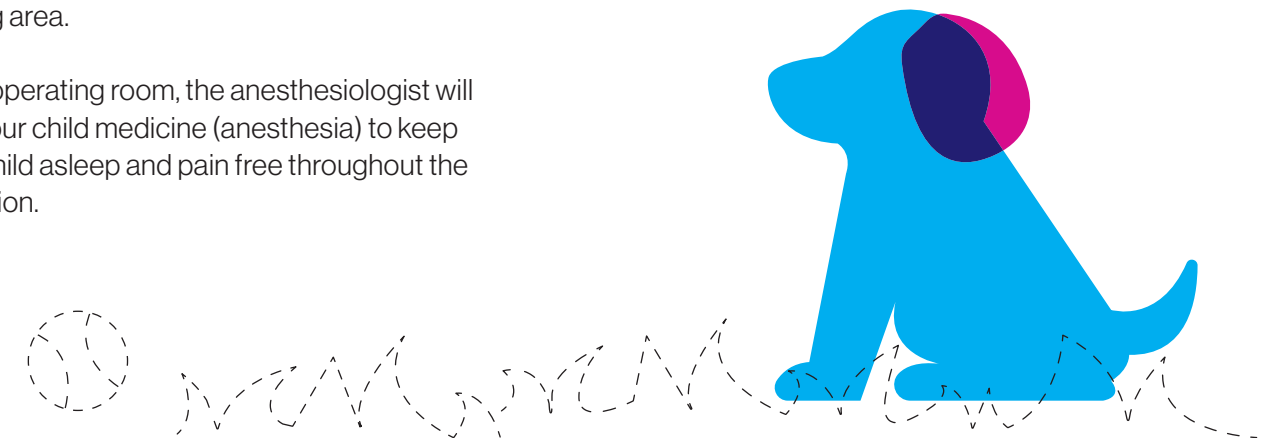
Check-in and preparation

After you check in, you will go to the Pediatric Registration and Assessment Area waiting room where you can complete any remaining paperwork. We will then accompany you and your child to the holding area, which is adjacent to the operating room. You will meet with your child's cardiac anesthesiologist to ask any questions you may have. Once all questions are answered, we will bring your child to the operating room and show you to our family waiting area.

In the operating room, the anesthesiologist will give your child medicine (anesthesia) to keep your child asleep and pain free throughout the operation.

During surgery

The length of the procedure depends on your child's heart condition and the type of surgery. Your child's surgeon can give you an estimated time. We understand, that waiting for your child during surgery is worrying, and we want to make it as stress-free as possible. Members of your child's medical team will provide regular updates about the progress of the surgery, either in person or by phone.



What to expect during your child's hospital stay

After surgery

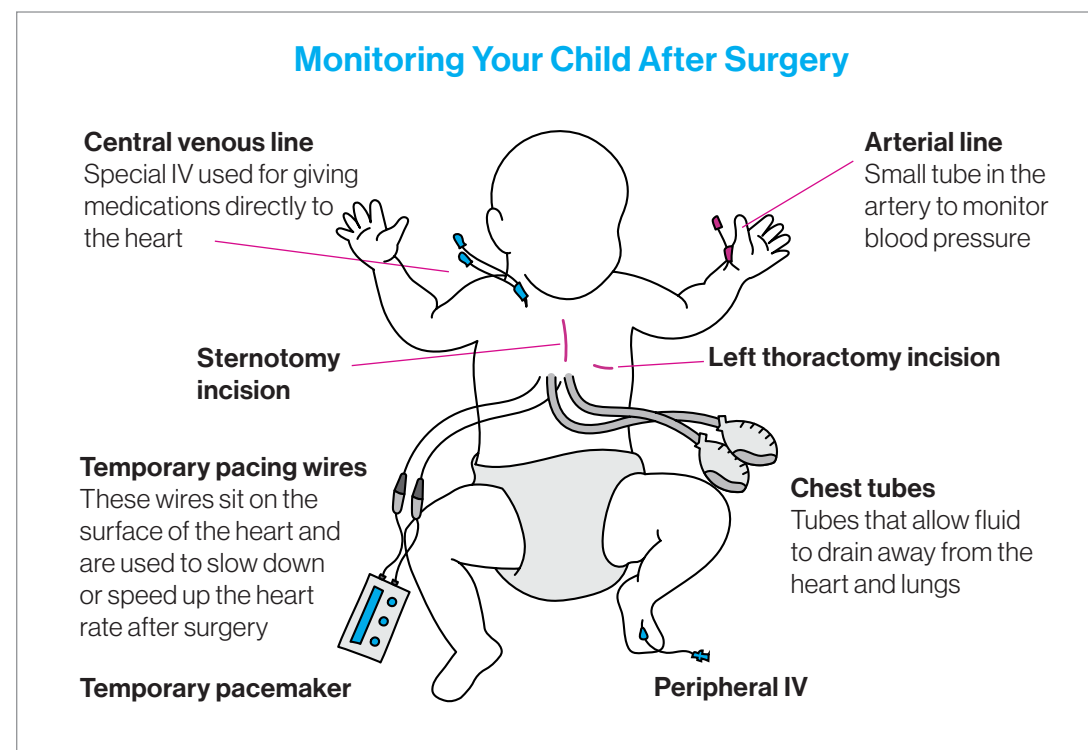
Your child's heart surgeon will come to see you in the family waiting room when the surgery is completed. After that, we will bring your child to the pediatric cardiac intensive care unit (PCICU) on the Fourth Floor of Mount Sinai Kravis Children's Hospital. In the PCICU, specially trained doctors, physician assistants, nurses, and technicians provide medical care in collaboration with your child's surgeon.

We understand that you will be very eager to see your child after surgery. You will be able to see your child as soon as possible after we complete the necessary postoperative tests (such as an electrocardiogram or chest X-ray). When your child is ready for visitors, a member of your child's medical team will meet you in the family waiting room. They will bring you to your child's bedside in the PCICU. You will be able to meet members of your child's inpatient team and ask any additional questions you may have.

Remember to wash your hands or use hand sanitizer every time you enter or leave the PCICU to help ensure a safe recovery. Hand sanitizer dispensers are located conveniently throughout the PCICU. Hand hygiene plays an important role in preventing infection.

Many monitoring lines and tubes are used to monitor and ensure the safety of your child. As your child recovers and gets stronger after surgery, the lines and tubes will slowly be removed. Typically, your child will be ready to eat and drink the day after the breathing tube comes out. Young babies might be fed through a tube in the nose (nasogastric or NG tube).

By the time your child leaves the PCICU and moves to a regular hospital room, most of the tubes and wires will be removed. Your child will be encouraged to start many of their regular daily activities.



Going home



What to expect

- When your child is discharged from the hospital, you will be taught what activities are okay for your child to do, how to care for the incision(s), and how to give medicines your child may need.
- We typically ask that children stay home from school or daycare for two to four weeks after surgery. Talk with your provider about when your child can return to school or daycare.
- Immediately after discharge, your child will need regular follow-up visits with a cardiologist. Eventually, your child will need to visit the cardiologist less frequently, every 6 to 12 months.
- Your child may need to take antibiotics before going to the dentist for teeth cleaning or other dental procedures to prevent serious heart infections. Ask your cardiologist if this is necessary.

Caring for the incision

When your child goes home, it is likely that their surgical incision will no longer have to be covered by bandages and can be left open to the air. Any remaining stitches will be removed during the follow-up appointment.

You will need to clean the incision daily with soap and water. Your child can bathe in waist-deep water or take a shower. However, do not completely submerge the incision in water (such as in a deep bath or pool). If showering, do not stand facing the water and do not spray water directly on the incision.

Do not expose the incision directly to the sun. Sunburns or tans will make the scar easier to see. We will let you know when it is okay to use scar creams, lotions, or powders on the incision.

Diet

- Most children may resume a regular diet.
- Appetite may not return to normal for several days after going home. Your child should be encouraged to drink plenty of fluids and increase their intake of regular food as tolerated.

Activity

Activity limitations are based on the type of incision as well as your child's age and expected healing process. Here is some information about what you can expect. **Every patient is different and your child's cardiologist and surgical team will provide more detailed information at the time of discharge.**

Infants/Toddlers

- Most infants/toddlers do not require strict restrictions from their usual activities.
- Use infant/car seats when traveling in the car.
- Start tummy time **six weeks** after surgery for up to five minutes at a time as tolerated. You can do tummy time up to four times a day.
- Allow your baby to roll onto their belly on their own.
- Avoid lifting your baby under their arms or pulling them up using their arms. This allows the sternum to heal properly.

Five years and up

- **For the first six weeks**
 - Have your child walk for exercise and whenever possible (including climbing stairs).
 - No lifting, pulling, or pushing greater than 10 pounds (approximately a gallon of milk).
- **After three months**, resume low-impact activities such as running, dancing, swimming, and biking.
- **After six months**, the bone is fully healed, and your child can return to all activities.

Your cardiologist will instruct you further on what activities your child can resume after surgery. If your child participates in special therapies, including physical therapy or occupational therapy, please obtain permission from your cardiologist before resuming these therapies.

Helpful resources

Getting to Mount Sinai

Mount Sinai Kravis Children's Hospital is located at 1184 Fifth Avenue, between East 98th and 99th Streets



For directions and parking information, please visit <https://www.mountsinai.org/locations/kravis-childrens/visiting-us> or scan the QR code.

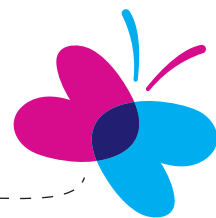
Visitor policy

Mount Sinai welcomes visitors. We promote family-centered care and recognize the important role of visits in the care and well-being of our patients. One parent/guardian is encouraged to spend the night with their child. Your nurse will review these guidelines with you.

Note: The visitor policy may be adjusted to ensure the safety of patients, staff, and visitors. This may include limitations on visiting hours and the number of visitors at bedside.



For the most up-to-date information regarding our visitor policy and visiting hours, scan the QR code or visit our website, [mountsinai.org/locations/kravis-childrens/visiting-us](https://www.mountsinai.org/locations/kravis-childrens/visiting-us).



Support services

We have a variety of additional support resources available to you and your family before and after surgery. Just ask, and we will connect you with the following:

- **Child Life and Creative Arts Therapy:** The staff can help support your child and siblings throughout the hospitalization with medical play, toys, music, art, and pet therapy.
- **Social Work:** Social workers can offer you and your family supportive counseling, community referrals, and assistance with all non-medical concerns.
- **Spiritual Care:** The spiritual care team can provide support to members of all different faiths and are available for prayer, rituals, baptisms, and support.
- **Books or Other Materials:** We have a wide range of books, brochures, and videos. Your social worker or child life specialist can make specific recommendations for you and your child.

Nonprofit organizations

CHD Coalition is a volunteer-based nonprofit organization devoted to improving the quality of life for children and adults affected by congenital heart defect (CHD), the most common birth defect worldwide. <https://chdcoalition.org/>

The Children's Heart Foundation was founded in 1996 and is the country's leading organization solely dedicated to funding congenital heart defect (CHD) research. Their mission is to advance the diagnosis, treatment, and prevention of congenital heart defects by funding the most promising research. <https://www.childrensheartfoundation.org/>

Important contact information

Life Threatening Emergency

Call 911 immediately

Pediatric Cardiology Hotline

24 hours/day, seven days/week

1-844-PEDS-NYC (1-844-733-7692)

Pediatric Cardiac Surgery Office

Weekdays 9 am-5 pm

Phone: 212-241-8213

Fax: 212-241-9618



