

Welcome to our fetal family



We will be with you every step of the way

We cannot imagine how scary it is to hear that your baby has a problem. We want you to know that you are not alone on this journey. Your child will receive care from one of the best pediatric teams in the country. From admission through discharge and beyond, the team at Children's Healthcare of Atlanta will be with you every step of the way—celebrating the good days and supporting you during the tough days.

Children's offers access to more than 1,900 pediatric physicians representing more than 60 pediatric specialties and programs and is ranked among the top children's hospitals in the country by U.S. News & World Report.

With approximately 1,000 neonatal admissions annually, our Egleston and Scottish Rite NICUs provide comprehensive care for critically ill newborns and premature infants in a specialized environment. The NICUs at Children's combine advanced technology and specially trained healthcare professionals to care for our tiniest patients in a specialized environment.

We can't wait to show you what an amazing team of people awaits you. No matter how short or long your child's stay, we will answer your questions, address your concerns and help to ease your mind with a focus on family-centered pediatric care.

Dedicated to All BetterSM

Your child's care team



Small babies need a big team

Cardiac surgeon: A doctor who does surgery on the heart.

Cardiologist: A doctor who takes care of the heart.

Case manager: Someone who helps coordinate your child's care. A case manager will help you find resources to help care for your child in the hospital and at home.

Chaplain: Someone who takes care of your spiritual needs. A chaplain can work with your religious leader to give you spiritual support. They can also do services such as anointments, baptisms, communion or others.

Child life specialist: Someone with special training to teach you ways to help your baby in the hospital. They can also help support siblings.

Genetics counselor: Someone with special training to teach you about how genes can affect your child's health. They can also talk with you about future family planning.

Lactation consultant: Someone who helps with breastfeeding and pumping.

Neonatologist: A doctor who takes care of babies during their hospital stay.

Neurologist: A doctor who takes care of the nervous system (this includes the brain, spine and nerves).

Neurosurgeon: A doctor who does surgery on the brain, spine or nerves.

Nurse practitioner: A nurse with a master's degree. They work with the doctor to care for your child.

Obstetrician: A doctor who takes care of pregnant women. They also care for women during labor and delivery.

Otolaryngologist (ENT): A doctor with special training to care for the ear, nose and throat. They help care for your child's airway.

Pediatric surgeon: A doctor with special training who does general surgery (such as surgery on the chest or belly).

Perinatologist: A specialized obstetrician who cares for high-risk pregnant women. They can help during labor and delivery. They are also called a maternal fetal medicine (MFM) doctor.

Plastic surgeon: A doctor who has special training to do surgery to fix face or body defects due to a birth disorder, an illness, a trauma or a tumor.

Radiologist: A doctor who reads the pictures from X-rays, MRIs, ultrasounds and CT scans.

Social worker: Someone who can give you support and counseling. They can give you information about resources (including financial resources) in the hospital and at home.

Sonographer: Someone who has special training to take ultrasound pictures of your baby.

Welcome to the NICU



Welcome to the Neonatal Intensive Care Unit (NICU) at Children's Healthcare of Atlanta at Scottish Rite. The NICU is a special place where doctors, nurses, nurse practitioners, respiratory therapists and other staff care for very sick newborn babies.

During your baby's stay in the NICU, you may hear alarms and see equipment that confuse you. The NICU team can explain your baby's care to you and answer your questions. Our goal is to help you learn about your baby's care. We will do that in these ways:

- Your baby's doctor will talk to you about the care your baby needs and answer your questions.
- The NICU team will help you learn about your baby's illness. They will also teach you to care for your baby at home.
- Please feel free to ask questions. We want you to feel good about the care your baby receives.

When you visit, here are a few suggestions for things you can do to help your baby:

- Talk softly to and touch your baby. Your nurse will teach you about the tubes and wires your baby needs, so you will feel more comfortable touching and holding your baby.
- Bring comfort objects from home to place at your baby's bedside, such as family photos, stuffed animals or blankets. Please label all items with your baby's name. For your baby's safety, we follow SIDS guidelines. Please check with your nurse before placing items in the crib.
- Bring special music or stories on tape to play for your baby. The NICU child life specialist can help you create a CD of your voice to play for your baby when you cannot visit.
- Help with your baby's care if their condition permits. You may be able to bathe, feed or change your baby.
- Keep track of your baby's care by using the section titled "Parent Notes."

Parent wrist bands

Each parent will receive an orange parent wrist band that you will wear on your wrist during your child's hospitalization. The band indicates that you are the parent and legal guardian, and that you can provide medical consent for your child. You will receive a 25 percent discount in the cafeteria when you show your wrist band. You can get a wrist band from Registration on the first floor or from your unit secretary.

Food services

The hospital cafeteria is located on the ground floor and is open during the following hours:

- Breakfast: 6:30 a.m. to 9:30 a.m.
- Lunch: 11 a.m. to 2:30 p.m.
- Dinner: 3:30 p.m. to 8:30 p.m.
- Late Night: 11 p.m. to 2 a.m.

Meal room service is free for all patients. Parent trays are \$6 each and are limited to two trays for each meal (breakfast, lunch and dinner). To use room service:

- Review the room service menus to decide what you and your child would like to eat.
- Call 5-5324 from a hospital phone (or 404-785-5324 from an outside line) to place the order.
- If there is no answer, leave a message with your order and room number.
- Food services offers additional menu options due to length of stay, restricted diets and personal choices.

Room service is available from 7 a.m. until 8 p.m. every day. Please place orders for breakfast trays between 7 a.m. and 11 a.m. and lunch and dinner trays between 11 a.m. and 8 p.m. Meals are delivered to your room within 45 minutes. The kitchen can also take orders in advance for a set delivery time.

Mothers who are breastfeeding and/or pumping may receive free room service meal trays for breakfast, lunch and dinner, or may receive discounted meals purchased in the cafeteria. Please let your nurse know if you are breastfeeding your baby. The NICU staff can provide juices, sodas, popsicles, ice cream, cereal, some baby foods and crackers for patients and breastfeeding/pumping mothers. Please ask your child's nurse for these items.

Places to relax

While your child is in the hospital, there are several locations throughout the hospital where parents and visitors can relax. There are sitting areas on the first floor, including the main lobby and the coffee shop. There are also three gardens on the first floor - the Frog Pond, Kristen's Garden and the Lou Glenn Garden - as well as the Koi Pond Garden on the sub-basement level and Hope and Will's Backyard. These are great places to relax and get a bit of fresh air.

The Max Brown Family Resource Library

Patients and families are invited to use the free services and materials at the Max Brown Family Resource Library, located on the first floor. There are books in English and Spanish, including health, educational and reference materials; children's books; and videos and DVDs. There are toys and puzzles. There are computers for parents to use with Internet access, CarePages and medical database resources. The librarian is an excellent resource for medical information if you need more detail or have questions about your child's diagnosis. He or she will be happy to assist you with your research needs. You can reach the library at ext. 5-2192. Library hours are posted on the front door.

Parent sleep rooms

A limited number of sleep rooms are available in the Family Amenities area on the first floor. Towels and bed linens are provided; however, pillows must be requested from the NICU secretary.

Each parent sleep room is secure and private and has a telephone, night stand, lamp and mini safe. The Guest Services Liaison (GSL) will have you pick a four-digit number (of your choosing), which will be programmed into the key pad on your door so that only you can unlock your room, which will keep your personal items safe.

To sign up for a parent sleep room "lottery," see the front desk in the main lobby or call 25 from any hospital phone.

- You may sign up for a room each day before 4 p.m. Only one person is allowed per sleep room, and only one sleep room is allowed per patient. Children under the age of 18 are not allowed in the sleep rooms.
- Once you sign up, you will receive a ticket with a number. Rooms will be assigned each day at 5 p.m. for that day only at the front lobby information desk. If more families sign up than we have sleep rooms, we do a lottery drawing, which means that sleep rooms are not always guaranteed.
- Sleep rooms are available daily from 5 p.m. until 9 a.m. the following morning. All belongings must be removed at that time and put in an assigned locker or in your car. Children's Healthcare of Atlanta is not responsible for items left unattended in sleep rooms.
- Food and drinks are not permitted in the sleep room area. Smoking is not permitted anywhere in the hospital.
- Parents who are staying at the Ronald McDonald House are not allowed to sign up for a sleep room.

The Ronald McDonald House

5420 Peachtree Dunwoody Road
Atlanta, GA 30342
404-847-0760

- **Purpose:** To provide temporary lodging for families of hospitalized children in the NICU. You are not allowed to stay at the Ronald McDonald House (RMH) if you are able to stay with your child.
- **Eligibility:** You must be an immediate family member or guardian of the hospitalized child and *live at least 50 miles away*. You must be referred by a social worker if you have not previously stayed at RMH.
- **Services:** One private room is provided to each patient's family. Each room has two double beds, which can sleep up to four people. Each room has a private bathroom with a shower/tub. Dinner is provided each evening, and breakfast and lunch items are often available for self-service.
- **Fees:** Each family is asked to donate \$25 per night toward the cost of their room and services. If unable to do so, the amount requested may be reduced or waived.
- **How to Apply:** New guests must have a referral from a hospital social worker. Availability is based on a first-come, first-served basis.
- **Check-In Times:** Families can check in during the following office hours:
 - Monday through Friday, 9 a.m. to 8:30 p.m.
 - Saturday and Sunday: 10 a.m. to 1 p.m. and 7 p.m. to 9 p.m.
- **Directions:** From the hospital parking garage, go left on Meridian Mark Road, and then left on the Glenridge Connector. At the first traffic light, turn right onto Peachtree Dunwoody Road. RMH is immediately on the right.
- **Transportation:** You may drive your own vehicle (free parking at the house) or walk (0.3 miles from the hospital, or about five minutes). Our hospital security officers can also provide one round-trip ride each day. Call the security office at 404-785-2150 to schedule a ride.

Local hotels

There are several area hotels that offer discounted hospital rates to families. Talk with your baby's social worker for more information. You can also pick up a copy of the booklet "Patient and Family Guide to Services" for more information about nearby lodging, dining and shopping. See an Ambassador or your nurse for a copy of this booklet.

Lactation program for breast pumping

There are lactation rooms for mothers who are pumping breast milk located in the NICU.

The lactation rooms have a hospital-grade breast pump, which are the strongest and most durable breast pumps available. These pumps are designed and approved by the FDA to be safe for multiple users because they have barriers that prevents cross-contamination. We give each mom her own collection kit, which she can wash and re-use throughout her child's hospitalization. We also give you a sheet of *white labels* that have your baby's name and medical record information.

- To pump, bring your breast pump kit, breast milk storage containers called "Snappies," basin for washing your pump kit parts and white patient information labels to the lactation room. Zip-top bags (to place the

Snappies in when finished) and *pink labels* are provided in the lactation rooms. Place a white label *and* pink label on each Snappy of breast milk that you pump. Write your baby's name, the date and time collected on each pink label, and take the milk to your nurse.

- Freshly pumped milk is good for up to four hours at room temperature and up to four days in the refrigerator. If the milk won't be used in that time frame, your nurse will freeze it for later use.
- Be sure to wash your pump kit in warm, soapy water after each use.

Mothers who are breastfeeding or pumping are eligible for the Breastfeeding Meal Program, which means that the hospital pays up to \$6 for each of your three meals each day in the cafeteria (totaling \$18 in meal assistance per day). Once your nurse refers you to the program, your child's name will be on the lactation diet list that the cafeteria cashiers receive each morning. Inform the cashier that you are a breast pumping mom, and \$6 will be deducted from your total. If you go over \$6, you will be expected to pay the difference. If your total is less than \$6, feel free to add something else, as we cannot give you change.

We have a lactation specialist available should you have any questions or need help with breastfeeding and pumping. Ask your nurse to contact the lactation specialist.

Parking at Scottish Rite



Parking

The Children's Healthcare of Atlanta parking garage is a paying lot for ALL visitors. You should pay the \$1 to \$4 daily rate if you plan to visit only one time.

Those who plan to visit more than once should purchase the 5 Exit Pass for \$5. By doing so, your ticket will allow you to exit the garage a total of five times (essentially paying \$1 per exit, regardless of how long your car sits in the garage). The next time you re-enter the parking garage, you will insert your ticket at the automated machine. The arm gate will rise and your ticket will now show that you have 4 Exits remaining. You will insert this same ticket each time you re-enter and exit the garage. On the fifth exit, the machine will not return your ticket, as you will have used up the 5 Exit Pass. The next time to enter the garage, you will need to push the button to receive a new ticket. Then repeat all steps as listed above. The 5 Exit Pass is valid for 12 months.

HOW TO USE AN AUTOMATED MACHINE TO PAY FOR A 5 EXIT PASS

The order of these instructions must be followed or the customer will not get a 5 Exit Pass.

1. Insert parking ticket in the slot labeled "Insert Parking Ticket."
2. The green LED display panel will indicate the total cost of the parking fee.
3. **PRESS THE FLASHING BLUE BUTTON LOCATED AT THE BOTTOM OF THE MACHINE IN THE CENTER.**
4. The green LED display panel will display "**5 Exit Pass \$5.00.**" This indicates your parking ticket has been converted to a "5 Exit Pass."
5. Insert method of payment: CASH on the left, CREDIT/DEBIT on the right. The machine accepts up to \$20 bills. No checks or change allowed.
6. The parking ticket will be returned to you and this becomes your 5 Exit Pass.
7. Your receipt will dispense at the receipt dispenser and indicate "5 Exit Pass" at the bottom.

Suggested prenatal checklist



A few things you can do before your child arrives

- Learn about your child's condition.
 - Finding out that your child has a special condition before they are born gives you the chance to make the most informed decisions for your child and your family's future.
- Find a pediatrician familiar with fetal anomalies.
 - Need a recommendation? Ask us!
 - Your fetal medicine doctor or nurse practitioner would be happy to help.
- Find out where your child's specialist's office is located.
 - Your child will need frequent follow-up visits with their doctor.
- Pack a bag to take with you to the hospital.
 - **Be sure to include your paperwork from your prenatal visit that lists your child's diagnosis.**
 - You can also include blankets, family photos and/or drawings from older siblings to decorate your child's bed space.
 - Your baby will not be able to wear clothing while in the NICU.
- Take a tour of the hospital where you will be delivering.
 - Ask your high-risk doctor if you can meet one of the neonatologists at your delivering hospital if your child might spend a few days in the neonatal intensive care unit (NICU).
 - The neonatologist can give you a good idea of what you can expect after delivery and how your child will get to Children's Healthcare of Atlanta.
- Take a tour of the Children's hospital campus where your baby will be.
 - During the fetal family tour, you can meet a surgeon to discuss your child's potential surgical needs.
 - You will also have a chance to see the NICU where your child will spend time recovering after surgery.
- Obtain a car seat.
 - Your child will need to pass a special angle tolerance test before they can go home, and the seat must be brought to discharge class.
- For breastfeeding moms, order a breast pump for home use.
 - Many private insurance companies will cover this cost, and so will Medicaid.

Common terms



Abdominal wall defects: When a baby is born with organs that stick out through an opening in the belly.

Amniocentesis: A test used to diagnose defects in the second trimester of pregnancy. Doctors use a needle to get a sample of amniotic fluid (the liquid that surrounds an unborn baby).

Anomaly: Something that is different than normal.

Artery: A blood vessel that takes blood with oxygen away from the heart to the body.

Atresia: When there is not a normal opening.

Cardiac anomalies: When the structure of the heart is different than normal.

Chromosome: A threadlike structure found in human cells that carries genetic information.

Chromosome abnormalities: A missing, extra or irregular part of DNA.

Craniofacial anomalies: When a part of the face or head is different than normal (such as a cleft lip or palate).

Cyst: A fluid-filled bag found in the body.

Echocardiogram (echo): A test done with sound waves that shows a picture of the heart.

Heterotaxy: When many organs are on the opposite side of the body than normal.

Hypoplasia When tissue or an organ is not fully developed (or did not fully grow).

Intravenous (IV): A small needle or plastic catheter (tube) that is put into a vein in the hand, foot, arm or umbilicus (belly button). Doctors use an IV to give fluid and medicine.

Lesion: A problem.

Magnetic resonance imaging (MRI): A test that uses a large magnet, radio waves and a computer to take pictures of the inside of the body. It does not expose you or your baby to radiation. It lets the doctor see the entire baby and placenta in detail.

Neonatal Intensive Care Unit (NICU): A special care area for babies who need close monitoring.

Two-vessel cord: An umbilical cord that has only two blood vessels. The umbilical cord usually has three blood vessels (two arteries and one vein).

Ultrasound: A test that uses sound waves to show pictures of the inside of the body. Doctors use ultrasound to see a picture of your baby in the uterus.

Umbilical arterial catheter (UAC): A small catheter (tube) that is put in the umbilical artery to check blood pressure. Doctors can also get blood for lab tests from the UAC.

Umbilical artery (UA): A blood vessel that takes blood without oxygen from the baby back to the placenta. Most babies have two umbilical arteries.

Umbilical cord: The tube that connects the placenta and the baby. The umbilical arteries and umbilical vein are inside the umbilical cord.

Umbilical venous catheter (UVC): An IV that is put in the umbilical vein. Doctors use the UVC to give fluid and medicine.

Vein: A blood vessel that takes blood without oxygen from the body back to the heart.

NICU glossary



Alveoli: Tiny air sacs in the lungs.

Anemia: Not enough red blood cells. Anemia is also called a low hematocrit (HCT).

Apnea: To stop breathing for more than 20 seconds.

Arterial blood gas (ABG): Blood work that comes from an artery. An ABG shows the oxygen, carbon dioxide and acid levels in the blood.

Aspiration: When your child breathes fluid into his airway and lungs.

Bedside rounds (Rounds): When the doctors, nurses and other staff get together each day to talk about each baby's care.

Bililights: Special lights that are like sunshine. These lights can be put over or under a baby to help get rid of high levels of bilirubin.

Bilirubin (bili): A chemical in the blood that is made when red blood cells break down. The body gets rid of bilirubin through the liver.

Blood gas: A test used to check the oxygen, carbon dioxide and acid levels in the blood. Blood gas may also be called an ABG, a CBG or a VBG.

Blood transfusion (transfusion): To give blood or blood products through a vein.

Bradycardia (bradys): When the heart rate is slower than normal.

Bronchiolitis: Swelling of the lower airways of the lungs that may cause breathing problems.

Bronchopulmonary dysplasia (BPD): A long-term lung disease that may cause breathing problems.

Capillary blood gas (CBG): A pinprick to the heel to check a blood gas.

Central venous line (CVL): A central venous line is a special type of IV (intravenous) line used to give fluids, blood products, medicines and nutrition. The end of the CVL lies near the heart in one of the body's large veins. It is a more stable IV that can be used for a longer period of time.

Chemstrip (C/S): A plastic strip that uses a drop of blood to check blood sugar levels.

Chest physiotherapy (CPT): A treatment to loosen mucus and thick fluids in the lungs. It uses gravity and vibration to help move mucus out of the lungs and cause coughing. This will not hurt your child.

Chest tube (CT): A chest tube is a sterile, hollow tube placed into the chest in the space around the lung. A doctor puts the chest tube in to drain air, blood or fluid trapped around the lungs.

Chronic lung disease (CLD): A long-term lung disease that may cause breathing problems.

Computerized Tomography (CT scan): A CT scan is a set of pictures that shows the inside of the body. CT scans use x-rays that rotate around the body to create 3D pictures of your child's body.

Continuous positive airway pressure (CPAP/Aladdin): A small amount of pressure and air put through the nose to keep the lungs open.

Cranial ultrasound (CUS): A test done with sound waves that shows a picture of the brain.

Cyanosis: When there is not enough oxygen in the blood and the skin, lips and nails turn blue.

Echocardiogram (echo): A test that takes pictures of the heart using sound waves.

Electrocardiogram (ECG/EKG): A test that shows the electrical activity (rhythm) of the heart.

Electroencephalogram (EEG): A test that shows the electrical signals of the brain.

Endotracheal tube (ETT): A breathing tube placed in the mouth or nose that goes into the windpipe (trachea).

Gastroesophageal reflux disease (GERD/GE reflux/reflux): When stomach fluids wash back into the esophagus. The esophagus is the "feeding tube" that carries food from the mouth to the stomach.

Gastrostomy tube (GT): A tube that is placed into the stomach. The tube is used to give your child feedings or medicine.

Gavage feeds (NG/OG tube): When a feeding is given through an NG or OG tube.

Glucose: A type of sugar that the body uses for energy.

Heel stick: A pinprick to the baby's heel to get blood for tests.

Hematocrit (HCT): A test that checks the number of red blood cells in the blood.

Hyperalimentation (HAL/HAF/hyperal): A special fluid that gives your child nutrition through an IV. Your child may get HAL when he is not able to eat.

Hyperbilirubinemia (jaundice/hyperbili): Too much bilirubin in the blood. This causes the skin to look yellow.

Hyperglycemia: Too much glucose in the blood.

Hypoglycemia: Not enough glucose in the blood.

Hypoplastic lungs: Lungs that are too small and did not grow normally. Often, this causes breathing problems.

Intralipids (IL): A special fluid that gives your child fat and calories through an IV. Your child may get IL when he is not able to eat.

Intramuscular (IM): An injection (shot) of medicine given into the muscle. IM shots are usually given in the thigh.

Intravenous (IV): A small, short, plastic tube placed in a vein. IVs are used to give medicine or fluids.

Intraventricular hemorrhage (IVH): Bleeding inside the brain.

Intubation: When a special breathing tube is put into the mouth or nose. Then, the tube goes into the trachea (windpipe).

Jaundice (hyperbili): When your child's skin (or the white parts of his eyes) looks yellow. Jaundice is caused by too much bilirubin in the blood.

KUB: An x-ray that looks at the kidneys, ureters and bladder.

Lactation consultant: A person with special training to help with breastfeeding.

Lumbar puncture (LP): A test to check the fluid around the brain and spinal cord. The fluid is checked for blood or infection. It is also called a spinal tap.

Magnetic resonance imaging (MRI): A test that uses a large magnet, radio waves and a computer to take pictures of the inside of your child's body.

Meconium: A baby's first bowel movement. It looks dark green or brown and black. It is very thick and sticky.

Meconium aspiration (MAS): When a baby has meconium before he is born and then breathes it in with his first breath after birth.

Nasal cannula (NC): A special tube that gives your child oxygen through his nose.

Nasogastric tube (NG/NGT): A special tube put into the nose that goes down into the stomach. An NG tube is used to give feedings and medicine. It can also drain fluid out of the stomach.

Necrotizing enterocolitis (NEC): A serious infection when part or all of the bowel is damaged or dies.

Neonatal Intensive Care Unit (NICU): A special nursery for very sick or premature babies.

Nothing by mouth (NPO): When your child is not allowed to eat or drink anything by mouth.

Orogastric tube (OG/OGT): A special tube put into the mouth that goes down into the stomach. An OG tube is used to give feedings and medicine. It can also drain fluid out of the stomach.

Oxyhood (hood): A special box used to give oxygen. The hood covers your child's head.

Pericardial effusion: Fluid in the space around the heart.

Peripheral arterial line (PAL): A small IV tube placed in an artery in the body that goes away from the heart. A PAL can be placed in the wrists, feet or scalp. These are used to check blood pressure and get blood for tests.

Peripherally inserted central catheter (PICC): A special type of IV line used to give fluids, medicines and nutrition. The line is placed in a large vein, usually in the arm above the bend at the elbow. It can also be put in other places. The end of the line is near the heart in one of the body's large veins. A PICC is a more stable IV that can be used for a longer period of time.

Pleural effusion: Fluid in the space between the chest wall and the lung.

Pneumonia: Infection in the lungs.

Pneumothorax (pneumo): Air that is trapped in the space between the chest wall and the lung.

PO: Medicines or feedings that are given by mouth.

PRN: Medicines or treatments that are given as needed.

QD: Medicines or treatments that are given once a day.

QID: Medicines or treatments that are given four times a day.

Renal ultrasound (RUS): An ultrasound test of the kidneys and bladder.

Residual: Milk or formula that is not digested. It is left in the stomach between feedings. Residuals are a sign of how well your child is tolerating his feedings.

Respiratory distress syndrome (RDS): When your child's lungs cannot fully expand because they do not have enough surfactant.

Respiratory syncytial virus (RSV): An infection of the lower airways of the lungs that can cause pneumonia or bronchiolitis.

Retinopathy of prematurity (ROP): A disorder that may cause vision problems or blindness. It mostly affects premature babies. It is caused by abnormal blood vessels in the eye.

Sepsis: An infection in the blood.

Septic work-up: A group of tests that check for infection.

Suctioning: Suctioning is used to remove mucus from your child's airway. It involves placing a small catheter in the nose, mouth and back of the throat to pull mucus out and keep the airway clear. It can also be used to drain extra fluid from the stomach.

Surfactant: A substance found in the lungs that helps keep them open.

Tachycardia: A fast heart rate.

TID: Medicines or treatments that are given three times a day.

Total parenteral nutrition (TPN): Nutrition given through an IV. This includes HAL and IL.

Umbilical artery catheter (UAC): An IV placed in an artery in the umbilical cord. It can be used to check blood pressure and to get blood for tests.

Umbilical vein catheter (UVC): An IV placed in a vein in the umbilical cord. It can be used to give fluids and medicines.

Venous blood gas (VBG): When blood from a vein is used to check a blood gas.

Vital signs (VS): When your child's nurse checks his temperature, heart rate, breathing rate and blood pressure.

Wean: When your child needs less help to breathe. For example, your child may wean from a breathing tube to a nasal cannula.

X-ray: A picture of the inside of the body made with special rays. An x-ray can show bones, tissues or parts of organs. X-ray pictures do not hurt.

When selecting a pediatrician



Questions to consider when choosing your child's pediatrician

- Do you have experience taking care of and coordinating care for children with complex fetal anomalies?
- Does your medical staff have experience with complex fetal anomaly patients?
- Do you feel comfortable caring for my child knowing they have this condition?
- If we have questions, are you available by phone and/or email?
- What is your typical response time to questions left via phone message and/or email?
- Will you accommodate special appointment times to reduce my child's exposure to illness as needed?
- Do you know my child's specialists?
- How will you communicate with my child's specialists?
- Do we as parents need to be involved in the communication process between you and the specialists?
For example, transport/deliver records.

When selecting a surgeon



Questions to ask your child's surgeon

- Why are you and your program qualified to perform my child's operation? How many times have you performed a similar procedure in the past year?
- What is the expected survival rate for this type of procedure in this center? How do your results compare with results nationally?
- What are the most common complications from this procedure? Will there be a need for additional procedures in the next year? Five years?
- Will my child have any long-term limitations? Will they grow and progress according to normal growth projections?
- How are family members involved in the decision-making process? How should I expect to be communicated with before, during and after the procedure?

Helpful resources



Connecting with your support team

- Case Manager—Katie Carssow, MPH, RN
 - Available Monday through Friday, 8 a.m. to 5 p.m.
 - E mail: katie.carssow@choa.org
 - Office: 404-785-3916
 - Mobile: 678-429-5754
- Child Life Specialists—Kalli Lamkin, M.S., C.C.L.S., or Stephanie Dill, M.S., C.C.L.S.
 - Available Monday through Friday, 9 a.m. to 5:30 p.m.
 - Email: kalli.lamkin@choa.org
 - Email: stephanie.dill@choa.org
 - For more information, visit choa.org/childlife or ask your nurse to connect you
- Social Workers (Egleston NICU)—Sabrina Torrez and Mariah Corcoran
 - Available Monday through Friday, 9 a.m. to 5 p.m.
 - Email: sabrina.torrez2@choa.org
 - Email: mariah.corcoran@choa.org
- Social Workers (Scottish Rite NICU)—Erika Alexander and Jodi-Ann Masilo
 - Available Monday through Friday, 9 a.m. to 5 p.m.
 - Email: erika.alexander@choa.org
 - Email: jodi-ann.masilo@choa.org
- Chaplain— Egleston
 - Available 24 hours a day, 7 days a week
 - Office: 404-785-1086
- Chaplain— Scottish Rite
 - Available 24 hours a day, 7 days a week
 - Office: 404-785-2160
- Genetics Counselor
 - Ask your doctor if a genetics counselor would be a good addition to your care team
- Lactation Specialist (Egleston)—Claire Eden, I.B.C.L.C.
 - Available Monday through Friday, 8 a.m. to 4 p.m.
 - Email: claire.eden@choa.org
 - Office: 404-785-0392
 - For more information, email Claire directly or ask your nurse to connect you
- Lactation Specialist (Scottish Rite)—Nichole Koons, I.B.C.L.C.
 - Available Monday through Friday, 8 a.m. to 4 p.m.
 - Email: nichole.koons@choa.org
 - Office: 404-785-2765
 - For more information, email Nichole directly or ask your nurse to connect you

Do you have questions about how a team member could help you and your child?

- See the document titled “Your child’s care team” in this binder.

Recommended websites



Sources for helpful information

Educational Resources

- **Children's Healthcare of Atlanta**
 - **Center for Craniofacial Disorders**
choa.org/craniofacial
 - **Neurosciences**
choa.org/neuro
 - **General & Thoracic surgery**
choa.org/generalsurgery
 - **Otolaryngology (ENT)**
choa.org/ent
 - **Neonatal Intensive Care Unit (NICU)**
choa.org/nicu
- **The Fetal Medicine Foundation**
fetalmedicine.org
- **Congenital Abnormalities**
healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Congenital-Abnormalities.aspx

Support Resources

- **Fetal Health Foundation**
fetalhealthfoundation.org
- **Birth Defect Research for Children - Parent support services**
birthdefects.org/parent-services
- **Foundation for Faces of Children - Dedicated to improving the lives of children with craniofacial differences**
facesofchildren.org
- **Georgia Down Syndrome Organizations**
globaldownsyndrome.org/georgia-down-syndrome-organizations
- **National Organization for Rare Disorders (NORD)**
rarediseases.org
- **Genetic and Rare Diseases (GARD) Information Center**
rarediseases.info.nih.gov/GARD
- **March of Dimes**
marchofdimes.org

Helping siblings cope



What you can do to help

- Share information with your child according to how much they want to know. Use simple, honest language to let them know that the new baby will need extra help, whether it's surgery and/or medication.
- Let them know it's not their fault and it's not contagious. Kids have great imaginations and can worry a lot.
- Communicate with your child's school or daycare so they can be supportive.
- Help children express feelings or concerns through art and/or play.
- Help your child learn how to talk to others about the baby if they want.
- Let siblings decide how much they want to be involved in preparing for the baby. Also allow them time to just be a kid!

Resources for you

Books

- "What About Me? When Brothers and Sisters Get Sick" (Peterkin, 1992)
- "My Brother Needs An Operation" (Jaworski, 1998)
- "A Place to Grow" (Bloom, 2002)
- "The Way I Feel" (Cain, 2000)
- "Magnificent Marvelous Me!" (artwithheart.org)
- "I Know I Made It Happen – A gentle book about feelings" (Blackburn, 1990)
- "The Invisible String" (Karst, 2000)

Other Resources

- Website with kid-friendly information: kidshealth.org
- Talk to a Child Life Specialist or a counselor for additional ideas.

Mommy love squares



Did you know that your baby can recognize your smell?

- Babies first learn about smells in their mother's womb.
- Each mother's amniotic fluid has a special smell depending on her diet and environment. This same smell is on her skin and in her breast milk.
- Even very young preemies know their own mother's scent!

Your baby can find comfort from your scent while you're away from the NICU.

- Wear a little love square (provided by your nurse) close to your heart so it picks up your scent.
- Put it in the bed close to your baby's face. Your mommy smell will stay with your baby for a long time.
- The square you pick up from the bed will smell like your baby. You can sniff it to help you let down when you're pumping breast milk.
- Change the square daily so your baby will always have a renewed scent square to enjoy.



This image shows a full page of white paper with horizontal grey ruling lines. The lines are evenly spaced and run across the width of the page, typical of notebook or legal stationery. There are no margins, text, or other markings on the page.

Children's Healthcare of Atlanta nondiscrimination statement



Children's Healthcare of Atlanta complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability or sex. Children's Healthcare of Atlanta does not exclude people or treat them differently because of race, color, national origin, age, disability or sex.

Children's Healthcare of Atlanta:

Provides free language services to people whose primary language is not English, such as:

- Qualified interpreters
- Information written in other languages

Provides free aids and services to help people with disabilities to communicate effectively with us, such as:

- Qualified sign language interpreters
- Written information in other formats (large print, audio, accessible electronic formats and more)

If you need these services, contact a registration staff member or call **404-785-KIDS (5437)**.

If you believe that Children's Healthcare of Atlanta has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability or sex, you can file a grievance with a patient representative at:

- Egleston hospital: **404-785-6163**
- Hughes Spalding hospital: **404-785-9788**
- Scottish Rite hospital: **404-785-5194**
- Children's Surgery Center at Meridian Mark: **404-785-5194**
- Ambulatory Care Network and Marcus Autism Center: **404-785-7188**

If you need help filing a grievance, a patient representative will help you.

Visit choa.org for more information.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services Office for Civil Rights electronically through the Office for Civil Rights complaint portal, available at ocrportal.hhs.gov/ocr/portal/lobby.jsf, or by mail or phone at:

Centralized Case Management Operations
U.S. Department of Health and Human Services
200 Independence Ave. SW
Room 509F, HHH Building
Washington, D.C. 20201
1-800-368-1019
1-800-537-7697 (TDD)

Visit hhs.gov/sites/default/files/ocr/civilrights/complaints/discrimhowtofile.pdf to access complaint forms.



Children's
Healthcare of Atlanta
Dedicated to All Better

Language

Spanish	ATENCIÓN: Si usted habla español, tiene a su disposición servicios gratuitos de interpretación. Comuníquese con alguien del personal de registros o llame al 404-785-5437.
Vietnamese	CHÚ Ý: Nếu quý vị nói tiếng Việt, chúng tôi có dịch vụ trợ giúp ngôn ngữ miễn phí dành cho quý vị. Xin liên lạc với nhân viên phụ trách ghi danh hay gọi số 404-785-5437.
Korean	알림: 한국어를 사용하는 경우, 언어 지원 서비스(통역)를 무료로 이용하실 수 있습니다. 등록 담당자 또는 다음 번호로 404-785-5437 문의하십시오.
Chinese	注意：如果您使用中文，可以免費獲得語言援助服務。請聯絡登記人員或致電 404-785-5437。
Gujarati	સુચના: જો તમે ગુજરાતી બોલતા હો, તો નિ:શુલ્ક ભાષા સહાય સેવાઓ તમારા માટે ઉપલબ્ધ છે. નોંધણી કરનાર સ્ટાફ વ્યક્તિનો સંપર્ક કરો અથવા 404-785-5437 પર ફોન કરો.
French	ATTENTION : si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Veuillez contacter notre personnel chargé de l'enregistrement ou appeler le 404-785-5437.
Amharic	ማሳሰቢያ-አማርኛ ተናጋሪ ከሆኑ፤ ነፃ የሆነ የቋንቋ ዕገዛ አገልግሎቶች ለእርስዎ ተዘጋጅተዋል። ከምዝገባ ሰራተኞች ውስጥ አንዳቸውን ያነጋግሩ ወይም በስልክ ቁጥር 404-785-5437 ይደውሉ።
Hindi	ध्यान दें: यदि आप हिंदी बोलते हैं तो आपके लिए मुफ्त में भाषा सहायता सेवाएं उपलब्ध हैं। पंजीकरण की स्टाफ व्यक्ति से संपर्क करें या 404-785-5437 पर फोन करें।
French Creole	ATANSYON: Si ou pale Kreyòl Ayisyen, gen sèvis asistans ak lang disponib pou ou gratis. Kontakte yon manm pèsònèl nan enskripsyon oswa rele nimewo 404-785-5437.
Russian	ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Обратитесь к сотруднику регистратуры или позвоните по телефону 404-785-5437.
Arabic	ملاحظة: إذا كنت تتحدث أدخل اللغة، فإن خدمات المساعدة اللغوية تتوفر لك مجاناً. إتصل بموظف . 404-785-5437تسجيل أو على الرقم
Portuguese	ATENÇÃO: Se você fala português, serviços de assistência ao idioma estão disponíveis gratuitamente. Entre em contato com o departamento de cadastro, ou ligue para 404-785-5437.
Farsi	توجه: اگر به زبان فارسی صحبت می کنید، تسهیلات زبانی به صورت رایگان در دسترس شما قرار می گیرد. برای کسب اطلاعات بیشتر با یکی از کارکنان بخش ثبت نام تماس بگیرید یا با شماره 404-785-5437 تماس حاصل نمایید.
German	ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Wenden Sie sich an das Anmeldepersonal oder wählen Sie die Rufnummer 404-785-5437.
Japanese	注意事項：日本語での言語サポートを無料で提供しています。レジストレーション・スタッフ、または 404-785-5437 までお問い合わせください。