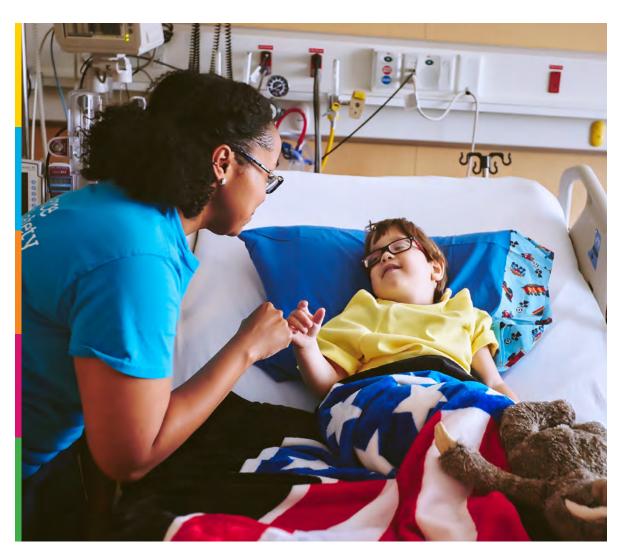
# Your Inpatient Stay A Guide for Patients and Families







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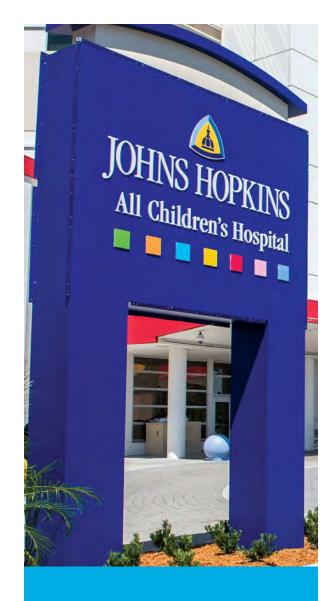
## **WELCOME**

#### A Message from the Family Advisory Council

There are times when the hospital is the only place you and your child can receive the care you need. We hope this guide will help you during your stay by providing you with information about our caregivers, the facilities, routines and policies at Johns Hopkins All Children's Hospital and the many resources that are available to you. On some of these pages we've included advice from parents who have been there—often many times—to guide you through your medical journey and ease your path.

We wish you healing.

The Johns Hopkins All Children's Hospital Family Advisory Council





The Family Advisory Council was established in 2008. It brings together patients, parents and caregivers to look at ways to improve the patient and family experience at our hospital. For more information on council activities and how to become a member, please contact ACHFamilyAdvisoryCouncil@jhmi.edu or visit HopkinsAllChildrens.org/FAC.

# Safety

# PRIVACY AND SOCIAL MEDIA GUIDELINES

Social networks and the Internet have created an endless and instant exchange of information, opinions and images but this comes with a risk. We work hard to respect your family's privacy and ask you to respect the privacy of other patients and families:

- Please don't ask our staff for information about other patients.
- It's OK to take a picture or video of your own child, but do not take pictures or video of any other patients or areas where other patients are seen.
- We understand that bonds can develop with nurses and caregivers, but please don't request that they become social media friends—again, in an effort to protect privacy.
- If you use Facebook, Instagram and other social media, do not write about or post a photo of any patients except your family member.

#### **SOME SAFETY TIPS**

#### Patient Identification

Checking a patient's ID helps us provide the right care to the right patient.

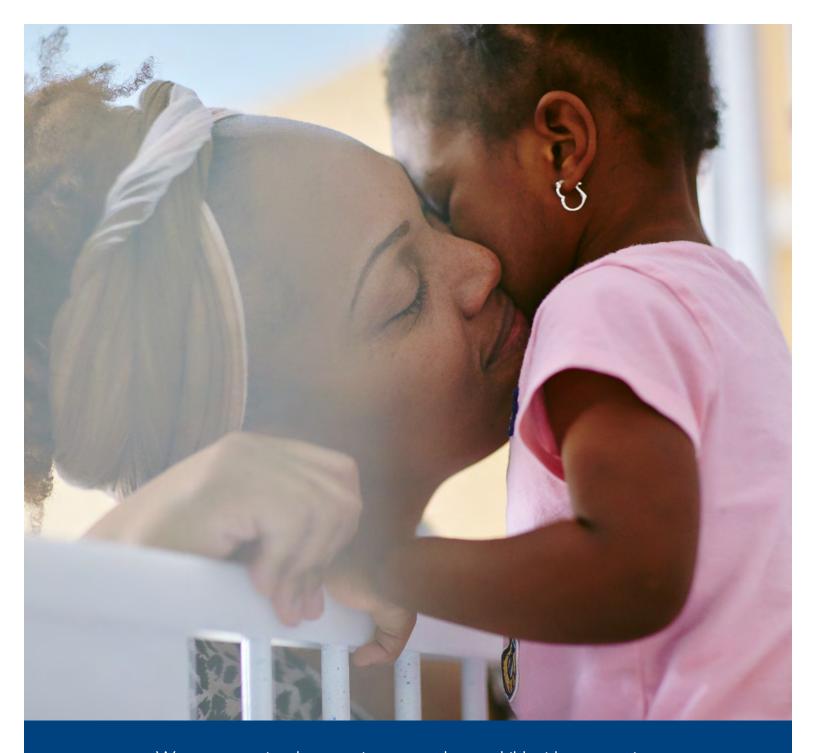
- We will look at your child's armband to check name, date of birth and medical record number.
- It's OK to ask our staff if they have checked your child's armband. Be sure to tell us if the armband falls off.
- Each time we administer medication we will scan the ID band.
- When you or your child are sleeping, we'll make every effort to scan the band quickly without disturbing you.

#### Please Bring Your Child's Home Medications With You

Please bring all of the medications your child takes at home with you to the hospital. This helps us continue those medications during your child's stay and coordinate what your child will need when he or she is ready go home. It's best to bring all of the medications with you so that we can see the labels.

#### MyHealth Patient Portal

Johns Hopkins All Children's Hospital patients and their parents now have electronic access to some of their key health information through MyHealth, an online patient portal through the hospital's website, bringing information to a family's fingertips. The MyHealth personal health record includes: a list of health issues (illnesses and problems rather than a diagnosis), home medications, lab results, discharge documentation, known allergies and immunizations given at Johns Hopkins All Children's. Keeping privacy and confidentiality in mind, Johns Hopkins All Children's has designed its patient portal so that it will not show information about certain health problems, lab results or prescribed medications. And for patients ages 11-18, the health care provider can mark some information "private" so that it is not available for a parent to view, in keeping with Florida privacy laws. Learn more at HopkinsAllChildrens.org/MyHealth.



We are committed to treating you and your child with compassion and respect. We believe that you deserve honesty in our communication about the plan for your child's care and we will demonstrate uncompromising integrity to earn your trust. We will be responsible for including each family as a part of our care team that is committed to safe and innovative care practices. Our goal is to inspire hope for you and your child through our focus on inquiry, collaboration, and teamwork.



#### **EVERYDAY SAFETY:**

- Crib rails must be up at all times. Side rails on beds should be up when your child is sleeping or on medication
- Make sure children do not climb on furniture in patient rooms or in other areas
- IV poles are not safe for children to ride on
- Candles and appliances such as curling irons, coffee pots and fans are not permitted
- Don't leave valuables (purses, laptops, cell phones) unattended

#### **EMERGENCY PROCEDURES**

If there is an emergency in your room, use the call button to get help. If there is an emergency in the hospital, like a fire alarm, STAY IN YOUR ROOM WITH YOUR CHILD. A hospital staff member will tell you if you need to leave. Emergency evacuation maps are located on all floors. USE THE STAIRS during an emergency evacuation. Do not use the elevators.

Call Security for a ride or for a security concern at ext. 73300 or 727-767-3300

#### HAVE A SAFE STAY

We need your help to keep our environment safe. If you have any safety concerns, please talk to your child's nurse or a patient experience navigator. You may also call 1-844-SPEAK2US.

#### HAND HYGIENE—Help Prevent Infections

#### Always clean your hands:

- · Before and after visits
- After contact with body fluids, using the bathroom or changing a diaper
- · After touching equipment or removing gloves, gowns or masks

#### Wash your hands this way to remove germs:

- Use warm water and soap
- Apply the soap and then scrub well for at least 20 seconds to remove germs
- Be sure to scrub between fingers, under and around nails
- · Rinse hands and leave water running
- Dry hands with a clean paper towel
- · Use the paper towel to turn off the water

#### When and how to use alcohol-based hand rub:

- You can use the hand rub if your hands are not visibly dirty (unless the nurse says you always need to use soap and water)
- · Pump some hand rub onto your hands, then rub together
- Be sure to rub between fingers, under and around nails
- · Do not rinse the hand rub off with water

#### MORE ABOUT SAFETY

#### Help us keep your room clean

Just like at home, your hospital room should look and smell clean. Our patient rooms are cleaned daily by our Environmental Services staff, but there are ways that you can help. The places that people touch frequently are most likely to contain germs. These "high-touch surfaces" include: bed rails, bedside tables, IV poles, call bells, door handles, bathroom surfaces and computer keyboards.

#### Don't add clutter

Limit personal items and store them in the cabinet for family items. This makes it easier to clean the room. Use the safe in your room to store valuables like laptops and cell phones. When you have items for the trash, throw them away immediately.

#### Here are more important ways that you can support a safe hospital environment:

- Do not plug personal equipment (laptops, phone chargers, etc.) into red outlets
- Do not prop doors open
- Do not coil restroom pull cords around the handrails—they must hang free for use
- Do not tape over door latches or closures
- · Don't use a room fan without first getting approval from our infection prevention, nursing and safety staff
- Don't use push pins or tacks in your room—use magnetic strips instead
- Create a scrapbook or "treasure box" for cards or letters to reduce clutter

#### Never use a dirty pillow

If your pillow falls on the floor or becomes soiled, ask for a new one. You can tell your nurse or request one through GetWellNetwork.

#### Visitors carry germs

Don't let visitors sit on your bed or touch your equipment—including the keyboard or pillow speaker for GetWellNetwork. Ask visitors to sanitize their hands when entering and leaving your room. This prevents them from bringing germs in or carrying them out.

Friends or family should not visit if they are sick, or if in the last three days they have had: nausea, vomiting, diarrhea, fever (or feeling feverish), cough or a rash.

#### Take slippers & socks off

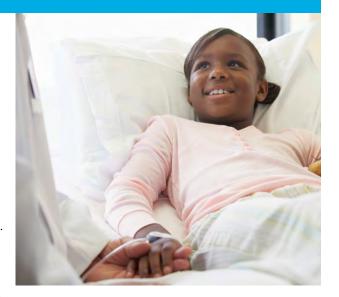
To keep germs from the floor from contaminating the bed, patients should remove slippers, socks or "footies" before putting their feet on or in the bed. (If cold feet are an issue, socks can be worn in bed—but put slippers over the socks when getting out of bed).

#### Help us keep you and your child safe

In our hospital community, we rely on everyone to keep their eyes and ears alert for anything unusual. We have zero tolerance for any kind of abuse or threats. If you see anything out of the ordinary or witness anyone (visitor or staff) abusing or threatening anyone, please tell your nurse or call Security at ext. 73300.

#### Flu shots

In the interest of our patients, Johns Hopkins All Children's Hospital requires employees to get the flu vaccine each year. We encourage parents and family members to do the same—it's an easy step to take and can help protect your child and all of our patients.





## Visit the Child Life Activity Center

(Child Life Auditorium) on the second floor for fun things to do. In your room, you may participate in video bingo or have a pet therapy visit.

## The Basics

#### Family-Centered Care

We are committed to family-centered care and work to do the following:

- · Place the patient and family at the center of care
- Work to keep the family together as a unit during a hospital stay
- Encourage the family's participation in decisions about care
- · Promote the safety of patients, families, visitors and staff
- Create a healing environment through attention to psychosocial, environmental and complementary therapies

#### Family Presence

Parents and guardians aren't visitors. You are a vital part of your child's care team and you can be with your child any time of the day or night. You will receive a special badge so you can have access 24 hours a day. With parental consent, grandparents can be with the patient 24 hours a day.

#### Visiting Policy & Hours

For other family members and friends, visiting hours are usually 7 a.m. to 9 p.m. Some exceptions apply to intensive care units and some patient care units have special rules about visiting--ask your nurse of Health Unit Coordinator. Please remind all visitors to stay home if they have a cold or fever or if they have been exposed to someone with a cold, the flu, or an illness like chicken pox. This protects your child's health and the health of all our patients!

#### **Badges**

Parents, guardians and grandparents (with parental permission) are given special badges. Other visitors must get a new visitor pass each day from the Information Desk on the first floor of the hospital or the Information Desk on the second floor of the Outpatient Care Center.

#### Cafeteria/Dining Room ext. 73019

The Cafeteria serves food from 7 a.m. to 12:30 a.m. It has indoor seating, an outdoor dining area (non-smoking) and sells items to dine in or to go. There are vending machines near the Dining Room exit that are available 24 hours a day.

#### Meals for Patients: Room Service ext. 73663

Patients can order from the Room Service menu between 7 a.m. and 11 p.m. There are many great snacks and meals to choose from, plus ICEE drinks and milkshakes.

# AN IMPORTANT WORD ABOUT OUR PATIENT DIRECTORY

As part of the admitting process, your child's name is listed in the computerized Patient directory. Our phone operators may use this directory to transfer calls to your child's room (NICU rooms do not have phones). Our Information Desk staff use the directory to give your child's room number to visitors who ask for a pass.

Please be aware: If you choose not to have your child's name listed in the Patient directory, our phone operators and Information Desk staff will not be able to tell relatives or friends that your child is a patient here. They will not be able to transfer phone calls to you or send visitors to your child's room or care unit (unless you yourself have talked to that person to give them the room number). Please see the Admitting Department (first floor) if you want to make a change to your decision about being included in the Patient directory.

#### **Guest Trays**

"Guest Tray" meals are available for family members and other guests of patients and are delivered to the patient's room. You can purchase Guest Tray meal tickets in the cafeteria or you can pay using your credit/debit card when you order. Call ext. 73663 to order the Guest Tray meal. Guest Trays are available between 7 a.m. and 11 p.m. daily.

#### Coffee

Coffee is sold in the cafeteria, which is open 7 a.m. to 12:30 a.m. every day. The Outpatient Care Center Café (OCC second floor) sells coffee from 7:30 a.m. to 4 p.m. Late at night, when the cafeteria is closed, coffee is still available—use the back entrance to the cafeteria to access.

#### If Your Child is NPO

"NPO" means no food or beverages. NPO patients may be more comfortable when parents/visitors don't have food or drink in the room.

# YOUR GUIDE TO PATIENT CARE UNITS

5 North: Heart Center & CVICU

(Cardiovascular Intensive Care Unit)

**5 South:** PICU (Pediatric Intensive Care Unit)

6 North: NICU

(Neonatal Intensive Care Unit)—NICU C

6 South: NICU

(Neonatal Intensive Care Unit)—NICU A & B

7 North: Surgery & Neuroscience

7 South: Vincent Lecavalier Pediatric Cancer

& Blood Disorders Center

8 North: Pediatric Medicine

8 South: Pediatric Medicine

#### Gift Shop

The Gift Shop on the first floor has a selection of toys, foil balloons, books, magazines, merchandise with the Johns Hopkins All Children's logo and other items. Proceeds benefit Johns Hopkins All Children's.

#### Retail Pharmacy

The Retail Pharmacy (on the first floor) can fill prescriptions your child will need after leaving the hospital. Ask your child's nurse about this service. The pharmacy also sells non-prescription medications like Tylenol and Motrin. The pharmacy is open 8 a.m. – 8 p.m. on weekdays, and closed weekends; call ext. 78933 or 727-767-8933 for information.

#### **Parking**

The Family & Visitor Parking Garage is connected to the Outpatient Care Center and the Hospital by an overhead walkway. The address for the garage is 651 5th Street South. Valet parking is available at the main entrance of the hospital from 5:30 a.m. to 9 p.m. M–F and 8 a.m. to 9 p.m. on weekends for a small fee.

#### After-Hours Entrance to the Hospital

The main lobby of the hospital closes at 9 p.m. After 9 p.m., parents can enter the hospital through the Family & Visitor Parking garage. You can enter the Outpatient Care Center from the second floor of the garage and then continue to the hospital. You will need to display your parent badge before the entry door from the garage to the Outpatient Care Center will open.

#### Ronald McDonald House

Ronald McDonald House Charities of Tampa Bay provides a "home-away-from-home" for inpatient and outpatient families that live a distance from the hospital. This includes a private room with bathroom for overnight guests. Three Ronald McDonald Houses (East, West and Central) serve Johns Hopkins All Children's Hospital. A Day Use program is also available that offers snacks, a relaxation area and laundry service from 10 a.m. to 4 p.m. for inpatient family members staying bedside. Look for information on the Ronald McDonald House on your unit's information board or visitor station or call 727-767-7694 to request a room. www.rmhctampabay.com



#### **Phones**

If you're calling another area of the Hospital from your room, you'll dial a 5-digit extension. Our main phone number: 727-898-7451 or toll free: 1-800-456-4543. Most cell phones should work from anywhere in the building.

#### Computers & WiFi

Wireless Internet access is available throughout the hospital. Our service set identifier (SSID) is allkids (use lowercase letters). Encryption is not available. Computers for families to use are available in some of the Family Lounges, the Family Resource Center (second floor of the Outpatient Care Center) and in Ronald McDonald House Central (first floor of the Outpatient Care Center). Bedside computers are for staff only.

#### U.S. Mail

There is a mailbox in front of the hospital. If friends and relatives want to send mail to your child it should be addressed: Patient's Name & Room Number, Johns Hopkins All Children's Hospital, 501 Sixth Avenue South, St. Petersburg, FL 33701.

#### ATM/Banking

An ATM is located on the second floor of the Outpatient Care Center near the Information Desk and on the first floor of the hospital inside the main cafeteria.

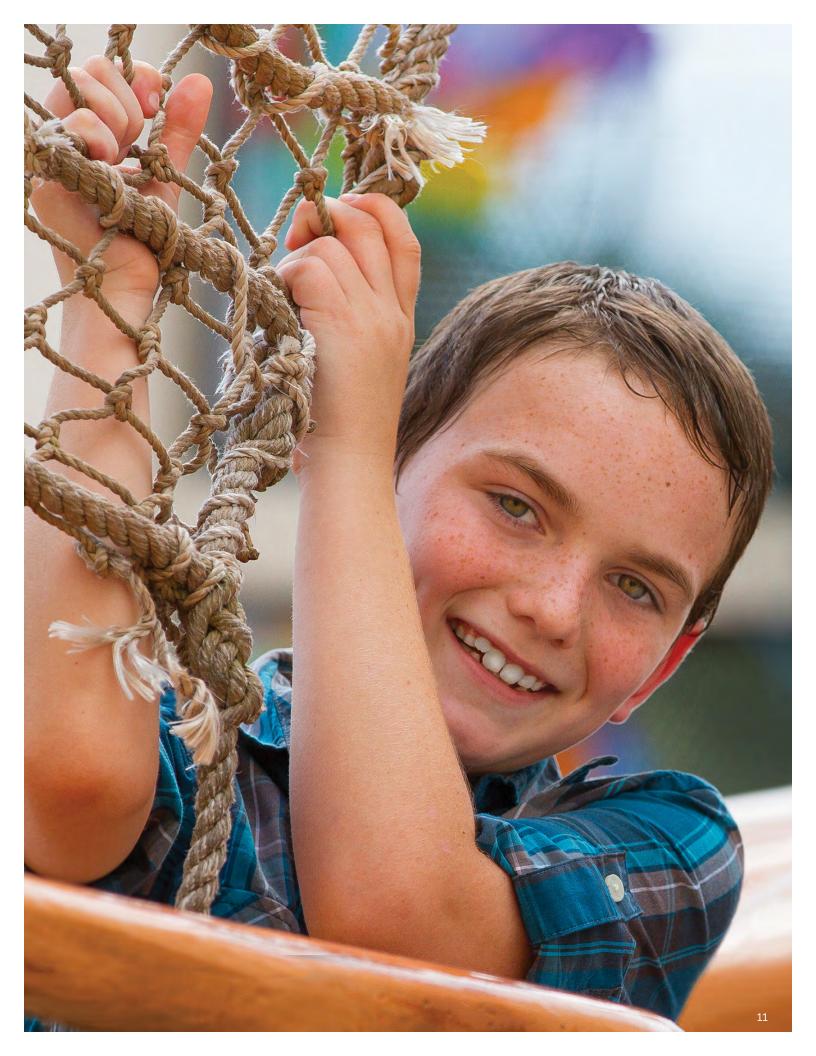
#### Smoke-Free Campus

Johns Hopkins All Children's is a smoke-free campus. Smoking is prohibited on all hospital property including the main hospital building and all outer buildings, parking lots and garages.

#### No Fragrances, Flowers or Latex Balloons

Some patients and staff have allergies to perfumes, colognes and scented lotions. Please refrain from wearing fragrances when you are on hospital property.

- · Flowers can cause respiratory problems or carry infections, therefore they are not allowed on patient floors.
- · Latex balloons are a choking hazard and are not allowed.
- Foil balloons, new stuffed animals and toys are good alternatives as gifts for patients and can be found in the hospital's gift shop.



# Your Room and Other Special Places

#### Children's Activity Center

The Children's Activity Center (Children's Auditorium) is on the second floor of the hospital near the bridge to the Outpatient Care Center. Activities are held Monday through Friday with special programs held weekly that include video bingo, movie nights and other special performances. Check the weekly schedule on Channel 18. Your child's health care team must give the OK to visit this area.

#### Rooftop Terrace

There is a Rooftop Terrace on the second floor. It's a nice place to sit and enjoy the outdoors. There is a small pirate ship play area for patients and siblings. (Your child's health care team needs to give the OK to visit the Terrace.)

#### Family Resource Center Library, ext. 73880 or 727-767-3880

The Family Resource Center (FRC) Library is a health information library for our inpatient and outpatient families located on the second floor of the Outpatient Care Center. Family members can use the library's collection of books, magazines, videos, computers and online resources to learn about their child's health condition. A professional medical librarian can assist in finding relevant health information and resources. Computer workstations, a printer/copier/fax machine, and universal cell phone chargers are available to use while visiting the library. Comfortable seating areas are provided for relaxing or reading as well as a media room for watching family-friendly videos. For kids of all ages, the library has four monthly programs: Arts 4 You, Paws to Read (a literacy program for children to read aloud to gentle "listening dogs"), Story Time and Trivia Thursday. The FRC Library is open Monday through Friday, 9 a.m. to 5:30 p.m.

#### **Family Lounges**

Each Patient Care Unit has a Family Lounge. Ask where to find the Family Lounge for your area. It's a good place to visit with family members or take a break from the bedside.

#### Chapel & Reflection Garden

The chapel on the first floor provides a welcoming environment for people of all faiths. The chapel is open 24 hours a day. An outdoor Reflection Garden is located next to the chapel.

#### TV & GETWELLNETWORK

- The patient's TV is connected to the GetWellNetwork, a patient entertainment and educational system.
- It has more than 60 games, cable TV, on-demand movies for kids and the Internet.
- Internet access is standard, but parents can set controls. (If you choose parental controls there is a toggle switch to turn them on and off.)
- You can use the GetWellNetwork to make some requests (an extra blanket, for instance), rate your experience at Johns Hopkins All Children's, nominate an employee for the Daisy Award (for nurses).
- The GetWellNetwork also provides you with education about asthma, diabetes and other pediatric health issues.

#### **PLAYROOMS**

There are several playrooms to meet our patients' needs:

#### 8th Floor

This playroom (south of the elevator) is open to all patients (with medical clearance) and siblings. It has special features for young children, but all ages are welcome.

#### 7th Floor

This playroom (south of the elevator) is open to all patients with medical clearance and siblings. It has a special focus on older children and teens, but all ages are welcome.

#### Sensory Playroom—5 North

The Sensory Playroom is reserved for CVICU patients with limited mobility.

#### PICU Playroom—5 South

For our pediatric intensive care unit patients and families

#### Hematology-Oncology Playroom—7 South

This playroom in the hematology-oncology unit is limited to 7 South patients.

## Your Health Care Team



As a teaching hospital, Johns Hopkins All Children's uses a team approach to provide comprehensive care. Your Health Care Team may include doctors, nurses, respiratory therapists, pharmacists, phlebotomists (staff members who draw blood samples) and other professionals. Families are an important part of the team!

#### A LEARNER'S ENVIRONMENT

At Johns Hopkins All Children's, we are a teaching hospital committed to training the next generation of physicians and pediatric specialists. And at Johns Hopkins All Children's, we are always teaching and learning new, innovative approaches in medicine and health care, keeping us at the leading edge of pediatrics as we provide patient-centered care. We have two residency programs running simultaneously at the hospital, the Johns Hopkins All Children's Hospital residency and one from the USF Health Morsani College of Medicine. We also have fellows doing work at the hospital in a specific pediatric field.

#### MORE ABOUT DOCTORS

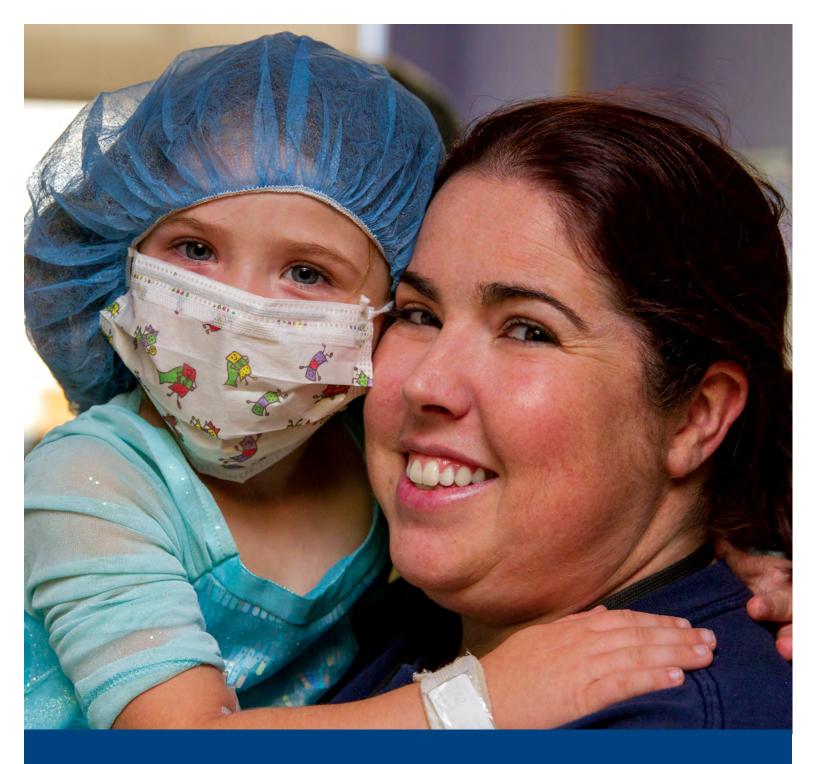
When developing your child's plan of care, you may request the hospital's treating physician to consult with your primary care provider or specialist provider.

The Attending Doctor is the physician in charge of your child's care or who performs your child's surgery. The attending physician may change according to your child's condition or special needs. The attending doctor may be a pediatric subspecialist (a pediatrician who has completed years of advanced training in a particular area of child health).

A Hospitalist is a pediatrician who specializes in taking care of hospitalized patients. A hospitalist may be your child's attending physician, or the hospitalist may work with several subspecialists to coordinate your child's inpatient care and discharge plan.

A Resident Physician (or resident) is a medical doctor who has graduated medical school and is completing advanced training in pediatric care. Residents are very involved in patient care at teaching hospitals like Johns Hopkins All Children's. An attending physician always supervises their work. Other people who may assist your child's doctors:

- A Fellow is a physician who has completed a residency and is now doing advanced training in one particular area of pediatric care. An attending physician always supervises their work.
- A Medical Student is a future doctor who learns by participating in the health care team and is supervised by an attending physician.
- A Physician Assistant (PA) has advanced clinical training and works closely with your child's physician. They can perform some of the same tasks that doctors do.



We are proud to be a U.S. News & World Report Best Children's Hospital.

If you have had a great experience with one of our employees, please feel free to share it with us. We'd love to hear from you.

### MORE ABOUT NURSES & THE CARE TEAM

You and your child will interact the most with nurses during your stay. There are different kinds of nurses who have different roles, and all of them are dedicated to your child's needs. Please ask them any questions you have about your child's care.

Registered Nurse (RN): Your child's daily care will be directed by a registered nurse. The nurse is the key contact person between you, your child and the other members of the health care team. Nurses work in "shifts." Most of the time your child will have two or three nurses during a 24-hour period.

Patient Care Technician (PCT): Patient care technicians may check vital signs (temperature, blood pressure & more), ask about pain, and help with patient care.

Advanced Practice Registered Nurses (APRN or NNP) and Clinical Nurse Specialists: These nurses have graduate level education and certification. They often have an active role in a patient's care. Advanced Practice Registered Nurses may perform some of the same functions as physicians or physician assistants.

Charge Nurse: During each shift, the charge nurse is the acting supervisor and is the "go to" person on the unit for other nurses.

Department Director: Each nursing unit has a Department Director who oversees all nursing care.



#### **ACUTE CARE REHAB TEAM**

Our Acute Care Rehabilitation (Rehab) Team works with patients on speech and communication, motor skills, cognitive problems after injuries, and activities of daily living. The team helps families plan for the discharge home and can make referrals to other Johns Hopkins All Children's Outpatient centers close to home.

#### **IV TEAM**

An IV (intravenous needle) may be part of your child's care. An IV may be used to give medicines or fluids. Sometimes the IV is started in a treatment room to make the process easier for the child and the nurse. The nurse inserting the IV will choose the best vein. In infants and babies, choices include the hand, arm, foot, scalp and neck. If possible, the IV nurse will avoid using the feet in children who are able to stand and walk. Even though IVs are checked often, problems can still occur. Tell your child's nurse right away if you see or feel any redness, swelling, pain, wetness or rash near the IV site, or if the alarm sounds on the IV pump.

#### PAIN TEAM

At Johns Hopkins All Children's Hospital, our goal is to help children be as comfortable as possible while they heal. Nurses will assess your child's pain every four hours, or more often if needed. There are many pain assessment tools to help us measure a child's pain. We will use the assessment that works best for your child's pain, developmental age and medical condition. Ask your nurse which pain assessment tool they are using.

Talk to your child's doctor or nurse if you have concerns. The attending doctor orders pain medicines and therapies, and may choose to consult the Pain Management Team. The nurse specialists on the team may suggest additional medicines and/or techniques like guided imagery, breathing techniques, music and other complementary therapies. Let the nurse, doctor or another Care Team member know if you are interested in complementary therapies like aromatherapy, massage, self-hypnosis, therapeutic touch and other healing therapies.

#### SKIN CARE TEAM

Our nurses monitor your child's skin for changes like rashes or wounds. Sometimes illnesses, medicines or changes in activity can cause skin problems that may be difficult to heal. Your child's doctor or nurse may consult the Skin Care Team. Talk to your child's doctor, nurse or other health care provider if you have questions about skin care.

# Advice For Families From Families

#### **QUESTIONS ABOUT EATING**

If your child doesn't seem to have an appetite, you may not feel comfortable encouraging them to eat. The Room Service menu has kid-friendly choices that can be more appealing than a traditional meal. Patients can order snacks or meals from the Room Service menu throughout the day and evening, so they can eat when they're hungry instead of on a regular schedule. Things like milkshakes and ICEEs, pizza, tacos, spaghetti and mac-and-cheese are available. Encourage your child to try something. If that works, your child may be able to eat a little more the next time.

#### **QUICK TIPS**

- If a care team member you don't know comes into your child's room, ask for an introduction.
- Be honest. Tell the Care Team everything they need to know about your child—even if it's something that makes you a little uncomfortable to talk about.
- Let kids speak for themselves when possible. We try hard to take care of our child's needs—but kids should be able to answer questions directly—and able to ask them, too.
- Don't be embarrassed or afraid to ask for a simpler explanation of your child's condition. If you hear medical words or abbreviations you don't understand, ask for an explanation.
- When you are worried or sleep-deprived it can be hard to understand or remember what a caregiver tells you. Write down information you'll want to remember.
- Tell the team if your family has any special religious, cultural, home care and/or financial needs that will affect the treatment plan and your child's care after you return home.
- If something "just doesn't feel right," please speak up. You are an expert about your child, and your concerns are important.

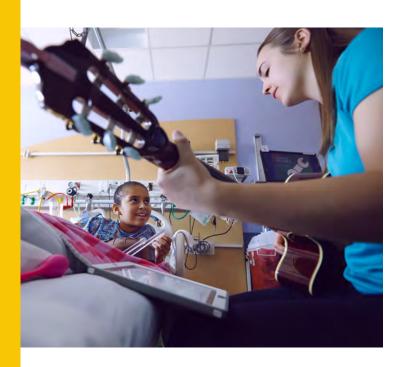
#### TAKE CARE OF "YOU"

Having a child in the hospital can be very stressful. Taking care of yourself will help you cope with stress. Try to get enough rest and have healthy meals. Taking a little time away from your child's bedside can help you "regroup." You may find that after a short break you're able to be more relaxed and reassuring with your child. If you need to have conversations—in person or by phone—that may be stressful for your child, it's best to find a place away from your child's room. If you have other children here with you at the hospital, they may appreciate some time with you away from the bedside, too. This can make it easier for you to focus just on them for a few minutes.

#### **INSURANCE ADVICE**

You may wind up talking to several people at your health insurance company or other offices. Keep a notebook and try to write down their names, titles and phone numbers and the date/time of the call. Use the pages at the back of this book or get a small notebook to keep with you. If your child will have an extended hospital stay, organizing a three-ring binder that contains medical and insurance information you need can be very helpful. Don't be afraid to ask questions!

# Support for Patients and Families



### Patient & Family Care Coordination: Child Life, Social Work, Case Management

Our Division of Patient & Family Care Coordination helps in many ways. Not every family will need these services, but many do—and we are happy to be of assistance. Each Patient Care Unit has a Social Worker, Case Manager and Child Life Specialist. The administrative office for Patient & Family Care Coordination is located on the first floor of the hospital.

#### Integrated Care Management, ext. 74147 or 727-767-4147

The department includes social workers and nurse case managers who are here to support you through your stay and to help you prepare for discharge from the hospital.

#### Child Life Department, ext. 74323 or 727-767-4323

Child Life Specialists understand the special needs and concerns of hospitalized patients. They can help children to:

- Understand why they are in the hospital and cope with fears and worries
- Use medical play to get ready for procedures
- · Express feelings and questions
- Cope with pain, discomfort and stress
- Enjoy activities like Video Bingo, pet therapy, and activities in the playrooms or the Children's Auditorium
- Help celebrate a birthday that occurs during your hospital stay

#### Music Therapy, ext. 78513 or 727-767-8513

A board-certified Music Therapist is a member of the health care team who uses music to help with relaxation, pain management and coping.

#### Patient Academic Services, ext. 74130 or 727-767-4130

The Patient Academic Services Coordinator can help patients with school support, homework, school absence concerns, homebound school plans (if the doctor says your child will need to be out of school for more than three to four weeks), and special needs when the patient returns to school.



### The Family Resource Center Library

on the Outpatient Care Center second floor has books, magazines, computers and health information resources—plus monthly programs like Arts 4 You, Paws to Read, Story Time and Trivia Thursday.

#### **HELPFUL PHONE NUMBERS**

- From a Hospital phone, dial the 5-digit extension listed here
- From outside the hospital, dial the 7-digit number (plus the area code if you're calling from outside Pinellas County)
- Toll-free from outside Pinellas County, dial
   1-800-456-4543 and ask for the extension you need

Security & Transport: ext. 73300

Safety Hotline: ext. 78894 Retail Pharmacy: ext. 78933

Cafeteria Hours & Daily Menu: ext. 73019

Interpreter Requests: ext. 74147

Main Hospital Operator: 727-898-7451

In case of an emergency in the Hospital or Outpatient Care Center, dial 73111 from a hospital phone or 727-767-3111 from a cell phone. *Please do not call 911 from either of these buildings*.

In any other building on our campus, please call 911 in case of an emergency.

#### Patient Experience Navigators, ext. 72110 or 727-767-2110

Patient Experience Navigators are available to be your advocate. Their role is to help you, our patient family, with:

- Communicating concerns or requests
- Contacting hospital departments and services on your behalf
- Discussing any other special concerns or needs you have
- Providing extra support during your hospital stay

#### Spiritual Care, ext. 74258 or 727-767-4258

Our Spiritual Care Team can provide spiritual support while honoring your family's religious traditions. If you would like, we can encourage a religious leader of your choice to visit you at the hospital. Our chaplains are on campus daily from 7 a.m. to 7 p.m. and also are on call for emergencies. Our chapel on the first floor is welcoming to people of all faiths and is open 24 hours a day. There is a Reflection Garden next to the chapel. Talking with a chaplain can be especially helpful in emergencies, at a turning point when it may be time to reconsider treatment options, or with bereavement issues. They also help families explore medical ethics issues with our Advisory Committee on Human Values & Ethics or the Institutional Review Board.

#### Interpreter Services, ext. 74147 or 727-767-4147

We can provide language or sign interpreter services to you if needed, at no charge to you. Interpreter services may be provided by phone. We also can provide TDD phones. To meet your needs, it helps us to be able to plan in advance. Please call ext. 74147 or 727-767-4147 from outside the hospital, to let us know if someone in your family needs an interpreter.

#### Support for Breastfeeding Mothers

Specialists are available to assist nursing mothers through our BEST (Breastfeeding, Education and Support Program, ext. 78686 or 727-767-8686) and our Mother's Milk Depot (ext. 72929 or 727-767-2929).

#### FINANCIAL QUESTIONS & MEDICAL RECORDS

Our financial counselors are available to answer questions about insurance issues and hospital charges. Please call them at ext. 74163, 78874 or 78016.

#### Getting Medical Records & Copies of Radiology Studies

Please talk to the doctor or nurse if you would like to discuss your child's medical record or protected health information during a hospital stay. You can visit the Health Information (Medical Records Department) on the first floor of the Outpatient Care Center to request medical records or you can print out. You can also print out a request form on our website, www.HopkinsAllChildrens.org. The phone number for our Health Information Management department is ext. 74281, or 727-767-4281. You can get a CD with copies of radiology studies (x-ray, CT, MRI) on the day of discharge. Go to the Radiology Department on the Hospital's first floor for this request.

#### MyHealth Patient Portal

You can see some of your child's health information online by using our MyHealth patient portal. See page 3 for more information.

#### Financial Assistance Policy Information

The Johns Hopkins All Children's Hospital Financial Assistance Policy applies to patients who have no health insurance or limited health insurance coverage. Financial Assistance is available to patients and families who are not eligible for Florida Medical Assistance (Medicaid) through the Department of Children and Family Services, or any other governmental program, including Medicare. Patients and families must provide all necessary information for processing the request for Financial Assistance.

#### **Application Process**

Patients and their families are responsible for starting and completing the Financial Assistance application in a timely manner and providing any information needed to complete the application. You may apply for Financial Assistance before services are rendered, throughout the treatment process, and at any time during the billing and collection process. Please contact our dedicated Financial Assistance line at 727-767-3475 for an application or go to our website: HopkinsAllChildrens.org/financialassistance.

#### Eligibility Criteria

Families will be asked to apply for a determination from Florida Medical Assistance (Medicaid) through the Department of Children and Family services and apply all required information needed to complete the application. Apply at: *myflorida.com/accessflorida*. To apply for financial assistance, you must be a citizen of the United States or a permanent legal resident. Financial Assistance is based on family total household income.

#### Notification

We will attempt to contact all applicants by phone and also provide written notification of whether their request was approved, denied or requires more information. Any incomplete or unsigned applications cannot be processed for approval. We will attempt to notify you by phone and in writing at the last known address available.

#### **Appeal Process**

If your request for Financial Assistance was denied, you may appeal this decision by contacting Johns Hopkins All Children's Hospital at 727-767-3475 and request reconsideration. Please allow 30 days for the appeal process to be completed.

#### PATIENT RIGHTS AND RESPONSIBILITIES

Johns Hopkins All Children's Hospital

To promote patient safety, we encourage you to speak openly with your health care team, be well informed, and take part in care decisions and treatment choices. Join us as active members of your health care team by reviewing the rights and responsibilities listed below for patients and patient representatives.

#### You or your designee have the right to:

#### RESPECTFUL AND SAFE CARE

- 1 Be given considerate, respectful and compassionate care.
- 2 Have a family member/friend and your doctor notified when you are admitted to the hospital.
- 3 Be given care in a safe environment, free from abuse and neglect (verbal, mental, physical or sexual).
- 4 Have a medical screening exam and be provided stabilizing treatment for emergency medical conditions and labor.
- 5 Be free from restraints and seclusion unless needed for safety.
- 6 Know the names and jobs of the people who care for you.
- 7 Know when students, residents or other trainees are involved in your care.
- 8 Have your culture and personal values, beliefs and wishes respected.
- 9 Have access to spiritual services.
- 10 Have conversations with the Ethics Service about issues related to your care.
- 11 Be treated without discrimination based on race, color, national origin, age, gender, sexual orientation, gender identity or expression, physical or mental disability, religion, ethnicity, language or ability to pay.
- 12 Be given a list of protective and advocacy services, when needed. These services help certain patients (e.g., children, elderly, disabled) exercise their rights and protect them from abuse and neglect.
- 13 Ask for an estimate of hospital charges before care is provided.

### EFFECTIVE COMMUNICATION AND PARTICIPATION IN YOUR CARE

- 14 Get information in a way you can understand.

  This includes sign language and foreign language interpreters and vision, speech and hearing aids provided free of charge.
- 15 Get information from your doctor/provider about:
  - · your diagnosis
  - your test results
  - outcomes of care
  - · unanticipated outcomes of care
- 16 Be involved in your plan of care and discharge plan or request a discharge plan evaluation at any time.
- 17 Involve your family in decisions about care.
- 18 Ask questions and get a timely response to your questions or requests.

- 19 Have your pain managed.
- 20 Refuse care.
- 21 Have someone with you for emotional support, unless that person interferes with your or others' rights, safety or health.
- 22 Ask for a chaperone to be with you during exams, tests or procedures.
- 23 Choose your support person and visitors and change your mind about who may visit.
- 24 Select someone to make health care decisions for you if at some point you are unable to make those decisions (and have all patient rights apply to that person).

#### **END OF LIFE DECISIONS**

- 25 Create or change an advance directive (also known as a living will or durable power of attorney for health care).
- 26 Have your organ donation wishes known and honored, if possible.

#### INFORMED CONSENT

- 27 Give permission (informed consent) before any nonemergency care is provided, including:
  - · risks and benefits of your treatment
  - · alternatives to that treatment
  - · risks and benefits of those alternatives
- 28 Agree or refuse to be part of a research study without affecting your care.
- 29 Agree or refuse to allow pictures for purposes other than your care.

#### PRIVACY AND CONFIDENTIALITY

- 30 Have privacy and confidential treatment and communication about your care.
- 31 Be given a copy of the HIPAA Notice of Privacy Practices.





#### **COMPLAINTS AND GRIEVANCES**

- 32 Complain and have your complaint reviewed without affecting your care. If you have a problem or complaint, you may talk to your doctor, nurse manager or a department manager.
- 33 You may contact the risk manager at 727-767-8959, call toll free 1-800-456-4543, ext. 78959 or email achRiskManagement@jhmi.edu
- 34 If your issue is not resolved to your satisfaction, other external groups you may contact include:
  - Hospital's Quality Improvement Organization (QIO) for coverage decisions or to appeal a premature discharge:

**KEPRO** 

Organization for Beneficiary Family Centered Care (BFCC-QIO) 5201 West Kennedy Blvd., Suite 900 Tampa, FL 33069 1-844-455-8708

• State Agency:

Agency for HealthCare Administration (AHCA) Complaint Administrative Unit 2727 Mahan Drive, Mail Stop #49 Tallahassee, FL 32308 Toll free: 1-888-419-3456 CAU@ahca.myflorida.com

• Accreditation Agency:

The Joint Commission Office of Quality and Patient Safety One Renaissance Blvd. Oakbrook Terrace, IL 60181 1-800-994-6610 patientsafetyreport@jointcommission.org

 To address discrimination concerns, you may also file a civil rights complaint with the U.S. Department of Health and Human Services:

Office for Civil Rights 200 Independence Ave., SW Room 509F, HHH Building Washington, DC 20201 1-800-368-1019, 1-800-537-7697 (TDD) OCRMail@hhs.gov Complaint forms are available at: www.hhs.gov/ocr/office/file/index.html

#### You have the responsibility to:

- 1 Provide accurate and complete information about your health, address, telephone number, date of birth, insurance carrier and employer.
- 2 Call if you cannot keep your appointment.
- 3 Be respectful of your hospital team, from the doctors, nurses and technicians to the people who deliver your meals and the cleaning crews.
- 4 Be considerate in language and conduct of other people and property, including being mindful of noise levels, privacy and number of visitors.
- 5 Be in control of your behavior if feeling angry.
- 6 Give us a copy of your advance directive.
- 7 Ask questions if there is anything you do not understand.
- 8 Report unexpected changes in your health.
- 9 Follow hospital rules.
- 10 Take responsibility for the consequences of refusing care or not following instructions.
- 11 Leave valuables at home.
- 12 Keep all information about hospital staff or other patients private.
- 13 Do not take pictures, videos or recordings without permission from hospital staff.
- 14 Pay your bills or work with us to find funding to meet your financial obligations.

# Our Vision, Mission and Values

#### Vision

Creating healthy tomorrows... for one child, for all children.

#### Mission

- To provide leadership in child health through treatment, education, advocacy and research.
- Treatment: Deliver quality services with compassion and commitment to family-centered care.
- Education: Provide educational programs for our patients, families and employees and health care professionals.
- Advocacy: Provide leadership in promoting the well-being of children.
- Research: Develop, support and participate in clinical, basic and translational research.

#### **Values**

- · Honesty and integrity
- · Inspiration and hope
- Collaboration and teamwork
- Inquiry and innovation
- · Compassion and respect
- · Responsibility and safety



#### Value Statement

"There is only one child in all the world and the child's name is all children."

—Carl Sandburg

We trust each other to do the right thing for patients, families and each other. We inquire and inspire. We embrace change. We create knowledge and train future pediatric leaders. We strive to be the best.

Learn more about our culture at HopkinsAllChildrens.org/Culture

#### LIMITED ENGLISH PROFICIENCY NOTICE

Johns Hopkins health care providers and all employees of Johns Hopkins Medicine comply with applicable Federal civil rights laws and do not discriminate against, exclude, or treat people differently on the basis of race, color, ethnicity, national origin, age, language, physical or mental disability, religion, sex, sexual orientation, and gender identity or expression. Organizations that follow this Notice (collectively "Johns Hopkins Medicine Entities") include all Johns Hopkins health care providers providing health care to the public at their delivery sites and employees of Johns Hopkins Medicine, including those listed in this Notice.

Johns Hopkins Medicine Entities:

- Provide free aids and services to 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, other formats);
- Provide access to approved Language Services, free of charge, for all patients and Family/Friends who have Language Services needs (e.g., Limited Vision, Speech Disability, Deaf/Hard of Hearing or Limited English Proficiency) when having Medical Discussions regarding the patient, patient's condition, and treatment planning or management.

If you need these services, you or your representative may inform a member of your treatment team, such as a nurse, advance practice practitioner, or physician.

If you or your representative believe that the Johns Hopkins Entity from which you are receiving medical services has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, or sex, you or your representative may contact the Patient Relations office to initiate a formal complaint or grievance.

If you need help with submitting your grievance, you may obtain assistance from the Patient Relations Office at your Johns Hopkins Medicine Entity at the corresponding phone number below:

Johns Hopkins All Children's Hospital, Inc. All Children's Health System, Inc. 501 Sixth Avenue South St. Petersburg, FL 33701 727-767-8959 1-800-456-4543, ext. 78959 achRiskManagement@jhmi.edu

Agency for HealthCare Administration (AHCA)
Complaint Administrative Unit
2727 Mahan Drive, Mail Stop #49
Tallahassee, FL 32308
1-888-419-3456
Access the online Licensed Health Care Facility Complaint
Form at https://apps.ahca.myflorida.com/hcfc/

The Joint Commission Office of Quality and Patient Safety
One Renaissance Boulevard
Oakbrook Terrace, IL 60181
Online at jointcommission.org using the Report a Patient Safety Event link in the Action Center on the home page patientsafetyreport@jointcommission.org

If your complaint is not resolved to your satisfaction, other external groups/agencies you may contact include: To address discrimination concerns, 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 <a href="https://ocrportal.hhs.gov/ocr/portal/lobby.jsf">https://ocrportal.hhs.gov/ocr/portal/lobby.jsf</a>, or by mail or phone at:

#### U.S. Department of Health and Human Services

200 Independence Avenue, SW Room 509F, HHH Building Washington, D.C. 20201 1-800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at http://www.hhs.gov/ocr/office/file/index.html

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 727-767-7147. ATANSYON: Si w pale KreyòlAyisyen, gen sèvisèdpoulangkidisponib gratis pouou. Rele 727-767-7147.

