

# Welcome to OHSU Doernbecher Children's Hospital.

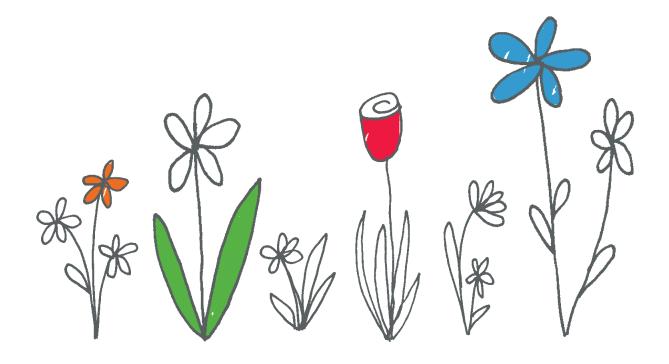
At Doernbecher, we know that moms, dads and caregivers know more about their child than anyone else. That's why we put families at the center of what we do. We also recognize that children are not just small adults. We've designed a hospital with their special needs in mind, so they can feel safe and comfortable. We are dedicated to providing you and your child with the best care available.



Campus Phones	
To dial out	9 + (area code) + (7-digit number)
To dial on campus	Dial the last 5 digits of the number

Important phone numbers (dial last 5 digits from room phone)	
Hospital operator	503-494-8311
Admitting	503-418-5313
Billing	503-494-8760
9th floor information desk in OHSU Hospital	503-418-1818
Child development and rehabilitation center (CDRC)	503-494-8095
Discharge planning / social work / care managers	503-494-2273
Gift shop	503-494-5761
Parking	503-494-8283
Patient relations	503-494-7959
Pharmacy (Doernbecher)	1-866-770-2666
Privacy practices information	503-494-0219
Public Safety / lost and found	503-494-7744

Addresses	
OHSU Doernbecher Children's Hospital	700 S.W. Campus Drive Portland, OR 97239
Doernbecher pediatric emergency room	3181 S.W. Sam Jackson Park Road Portland, OR 97239-3098
NICU	3181 S.W. Sam Jackson Park Road Portland, OR 97239-3098
Flower and gift deliveries for Doernbecher	3181 S.W. Sam Jackson Park Road Portland, OR 97239-3098



# **Language Services**

OHSU Doernbecher Children's Hospital provides free language services to patients, family members, personal representatives and caregivers. Please let your care team know if you would like to have an interpreter.

# **Special Needs**

Talk with your nurse if you have any special needs requirements, such as closed-captioned television, sign language interpretation, volume-controlled telephones, free TTY phone number and Telecommunications Devices for the Deaf (TDD). OHSU supports the use of service animals. There are some areas where service animals are not allowed, such as in the ICU and cancer units.

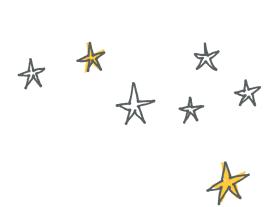






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### **About**

OHSU Doernbecher is recognized as one of America's leading children's hospitals. We have more pediatric specialists than anywhere else in Oregon, with more than 1,000 doctors, nurses and staff all specially trained in pediatric care and dedicated exclusively to your child's needs. We are proud to be one of the first five hospitals in the country to become verified as both a Level 1 Children's Trauma Center and a Level 1 site for Children's Surgery as designated by the American College of Surgeons.

As part of Oregon's only academic health center, Doernbecher is the only place in the state where breakthrough pediatric research quickly translates into new treatments and access to life-changing care. At the same time, we recognize that kids must be kids, and that smiles are an important part of helping your child get better. That's why everything about Doernbecher is designed just for kids and families. Together we'll work as a team for the benefit of your child.







# Staying With Your Child in the Hospital

### Spending the night

If you are a parent or primary caregiver, we encourage you to spend the night at Doernbecher with your child. This can make your child feel more comfortable. Each patient room is private and has space for one or two parents to sleep. In the NICU, parents may not spend the night.

### Siblings

Your child's brothers and sisters may not spend the night, so please make plans for your other children. If you are a mother who is also nursing a baby, the baby may stay with you in your child's room. Please bring a safe place for your nursing baby to sleep such as a travel crib. Siblings must be healthy when they visit. If a sibling has cold or flu symptoms, please ask them to visit another time. An adult must accompany visitors under 18 at all times.

### Safe sleep

We will provide a bed for your child according to age and developmental level. For safety reasons, please do not share a sleeping surface with your child.



### Lodging

There are many off-site hotel lodging options available near OHSU Doernbecher, and some offer OHSU patients a discounted rate. Ask for the most up-to-date rate when making reservations. Visit **www.ohsu.edu/lodging** or pick up a hotel list from any of the hospital concierge desks. For information about the Ronald McDonald House, visit **www.ohsudoernbecher.com/ronaldmcdonald**.

### Parking/valet

Patients and visitors to Doernbecher may park for free in the lot directly in front of the main entrance, in marked spaces in the lower lot and on the lower floors of the parking garage to the west of Doernbecher.

If you cannot find parking, please see the attendant at the main entrance for a permit and directions or call **503-494-8283**. Also, Doernbecher offers free valet parking at the main entrance of the Doernbecher hospital building.





### **Services**

We provide a variety of resources to make you and your child comfortable during your stay at OHSU Doernbecher, including services that may be helpful to your visiting family and friends.

### Concierge services

503-418-1818

OHSU's concierge staff are here to make your stay more comfortable and to provide information to your visitors. The concierge can assist with hospital information, directions and locations for dining and lodging.

### Oregon Fresh room service

503-494-1111

Once your child settles into a room, a room service associate from OHSU's Food and Nutrition Department will meet with you to talk about meals. Our nutritional program allows your child to choose what he or she wants to eat (based on diet orders) from a restaurant-style menu and to order when hungry. Place orders over the phone and delivery is within 60 minutes. This service is available 6:30 a.m.–8:30 p.m.

### **Play areas**

An outdoor play structure is located outside of the Doernbecher lobby level, behind Starbucks. Use the doors just past Starbucks and look for the play structure on the right. Patients and their families can also enjoy the outdoor courtyard on the 9th floor.

**Pharmacy** 888-279-9211

The OHSU Doernbecher Children's Hospital Pharmacy is on the 7th floor in the Outpatients Clinics area. The pharmacy is open Monday – Friday, 9 a.m. – 5:30 p.m. www.ohsuhealth.com/pharmacy.

**Lactation** 503-418-4500

Doernbecher's lactation consultants help mothers and babies who are having problems with breastfeeding. A team of nurses who are Board Certified Lactation Consultants work with patients during hospital stays or for follow-up. Ask a staff member where the nearest lactation rooms are located.

### **Spiritual care**

A team of chaplains serve Doernbecher patients and families for spiritual guidance, prayer, emotional support and comfort. We provide counseling to anyone who asks. You do not need to be a member of any particular faith. Chaplains are available Monday – Friday, 9 a.m. – 5 p.m., and on an emergency basis on weekends and evenings.

### **Meditation room**

Doernbecher has a peaceful meditation room on the 10th floor for patients and families.



### Family lounges

Family lounges are available near your child's room. Each lounge has a refrigerator, microwave and seating area.

### Laundry

A washer and dryer are located on the 9th floor of Doernbecher for your convenience. Free soap is available.

### **Bathing**

Showers are located in your child's room. Also, there are shower facilities in the Pediatric Intensive Care Unit at the entrance to the unit across from the family waiting room for PICU families.

### Computers and internet access

We offer patients and visitors free wireless internet access in patient rooms and in common areas, as well as the Family Resource Center. The computers on wheels are for medical personnel only and not for use by patients and their families.

### **Family Resource Center**

503-418-5390

The Family Resource Center is located in the Doernbecher lobby. The center has health information, computers with internet access, fax and copy machines. The center is open Monday–Friday, 8 a.m.–4 p.m.

### Language services

We provide free language services to patients, family members, personal representatives and caregivers. Please let your care team know if you would like to have an interpreter.

### **Volunteer services**

Doernbecher has many volunteers who play games, read and enjoy activities with children who are in the hospital and hold and comfort babies. If you would like a volunteer to visit, please ask a staff member.

### Where to go for exercise

Ask your care team about walking trails and exercise options while staying at the hospital, including:

- VA sky-bridge between OHSU and the VA hospital
- Pedestrian path along Terwilliger Blvd.
- Swimming pool in the Student Center

**Gift shop** 503-494-5761

The gift shop is located in the 9th floor lobby of OHSU Hospital for magazines, toys, balloons, cards, personal toiletries and gifts. Hours are Monday–Friday, 9 a.m.–5:30 p.m.



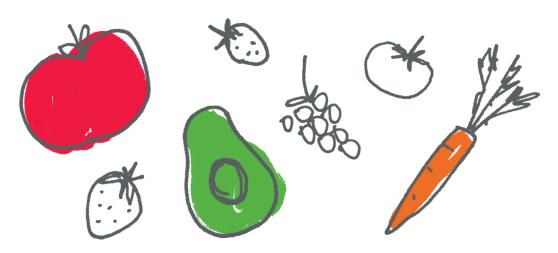


# **Dining Options for Visitors**

Doernbecher visitors can easily cross to OHSU via the 9th floor bridge, which has several cafes and restaurants.

Café	Location	Hours
OHSU Café	OHSU Hospital, 3rd floor	24 hours every day
Plaza Café	Hatfield Research Center, 9th floor	Mon. – Fri., 6:30 a.m. – 2 p.m.
Skybridge Café	OHSU Hospital, 9th floor	Mon Fri., 6:30 a.m 5 p.m.
Starbucks	OHSU Doernbecher	Mon. – Fri., 5 a.m. – 8 p.m.

Vending machines are located throughout Doernbecher. Please check with your nurse or health unit coordinator about the nearest machines, or for a list of local restaurants that deliver to Doernbecher.



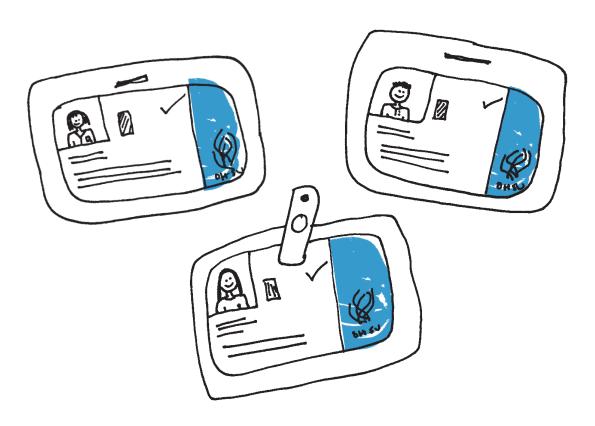
## Your Child's Health Care Team

At OHSU Doernbecher, our teams of health care specialists and providers partner with you to give your child the best care available. There will be many people helping to support you and your child.

All members of your child's health care team will:

- Introduce themselves when they enter your child's room
- Let you know what their role is in your child's care
- Always wear an OHSU badge.

If you are unsure about anyone's role, you can and should ask. As a teaching hospital, sometimes doctors will have several people observing as they visit patients.



Your child's health care team will include some or all of these experts:				
Registered Nurse (R.N.)	A nurse licensed by the Oregon State Board of Nursing. This person is your main supporter and go-to resource for questions and concerns. They are trained to care for you and execute the plan of care.			
Attending Physician	The doctor who is responsible for your child's care plan.  They supervise the other doctors and health care providers on your child's health care team.			
Resident	A licensed doctor who is completing three or four years of training in a specialty. They work with your child's attending physician to care for your child. Residents supervise interns.			
Intern	A licensed doctor in the first year of a residency program.			
Nurse Practitioner (N.P.)	A nurse with advanced training, usually in a specialty, who works with the medical team.			
Certified Nursing Assistant (C.N.A.)	A health care provider who works under the supervision of your child's registered nurse or nurse practitioner to assist you and your child.			
Hospitalist	A physician who cares for patients who stay overnight at the hospital.			

Your child's health care team might also include:				
Nurse Case Manager	A specialty nurse who can help you arrange home care for things like IV medicines, oxygen, wheelchairs and other needs.			
Social Worker	A health care provider who can help you cope with your child's illness and treatment. They can also find resources for your family's needs.			
Child Life Specialist	A specialist who uses play and recreation to help you and your child cope with your child's hospital stay or procedures.			
Dietitian	A specialist in medical nutrition for children with normal or special diet needs.			
Pharmacist	A person who is trained to teach you safe and effective medication use.			
Physical or Occupational Therapist	Licensed therapists who can work with your child after surgery or during a hospital stay to develop the use of muscles and movements for daily activities.			
Respiratory Therapist	A licensed therapist who uses oxygen and other treatments to help your child breathe better after surgery, a hospital stay or illness.			
Speech Pathologist	A licensed health care provider who treats children who have problems communicating, feeding or swallowing.			





# Your Role in Your Child's Care

# Communicating with your team

As a parent or caregiver, you are an important member of your child's health care team. Here are some ways you can be involved and communicate with the health care team.

# Speak up to advocate for your child

As the expert on your child, please share how your child is feeling, raise any concerns and ask questions about your child's care. Your knowledge of the medicines your child takes, their purpose and possible side effects your child may have, is helpful for us. Also, tell us right away if your child has pain or discomfort or if there are any special needs.

### Family spokesperson

We recommend that you designate a trusted relative or friend as your family spokesperson — a person who can help with communications and keep other family and friends informed while you're in the hospital.

### **Child Life Program**

Just about everything about staying in the hospital is stressful, so we have specially trained experts who know how to use play to help your child become more comfortable. Whether it's using puppets or a medical play kit, these experts have tips for helping you and your child have a more successful visit.



### Bedside reporting

When your nurse is about to go off duty and transition your child's care to a new nurse, they will meet at the bedside to talk about care. During a bedside report, the nurses will:

- Introduce your child's new nurse.
- Talk with you about your child's health.
- Check the medicines your child is taking.
- Ask what could have gone better during the last shift.
- Answer any questions you may have.



Please write any questions you may have below.					

### Bedside reporting tips

- Decide which family members or visitors should be present with you during the meeting. We want to protect your child's privacy and will only talk about their health with others when you say it is OK.
- Think about any concerns and questions you have and write them down. This is the perfect time to speak up.
- Let us know if something is confusing. If the nurses use any words or share information that you don't understand, ask them to explain it.

### Patient and family rounding

On most units in the hospital, the care team performs rounds. Rounds are a structured time for doctors, nurses and representatives from other departments to discuss your child's health, results from labs and procedures and next steps. The care team generally gathers in front of your child's room to discuss your child's health and care plan. We encourage you or your family spokesperson to participate in rounds. Your questions and input help the team make the best decisions for your child's care.

Please write any questions you may have below.



### Your child's medications

Be sure your child's care team knows what medicines your child has been taking at home, including prescription medicines, over-the-counter medicines, vitamins, herbal supplements and natural remedies. It may be helpful to keep a list of these with you.

### Allergies and reactions



Tell your child's care team if your child is allergic to medicines, anesthesia, foods, latex (rubber) products or other items.

#### **Medications from home**



While you are in the hospital, DO NOT give your child any medications from home. Your doctor will approve any medications AND the correct dose. Your nurse will administer your child's medications.

### **Hospital medications**





- What is the name of the medication?
- Why does my child need to take it?
- How much should my child take and at what times?
- What are the possible side effects?

### Medication safety tip

When your child's care team brings medicines or intravenous (IV) fluids, make sure the care provider checks your child's ID bracelet to ensure that this medication is intended for your child.

### Pain management

Staff may ask you or your child for their specific pain target goal. This may be done by using pain rating scales and/or the ability to perform certain tasks.

### Keeping your family doctor informed

Even if your child's pediatrician is not an OHSU doctor, they are still part of your child's care team. Your Doernbecher team will communicate with your child's pediatrician or primary care provider regarding treatment, lab results and follow-up care.



# Your Child's Safety

### Hand hygiene

Proper hand hygiene is the single most important way to prevent the spread of infection. It is important for you, the patient and your visitors to practice good hand hygiene while you are in the hospital. Ask everyone who enters the room, including care providers, to wash their hands with soap and water or to clean their hands with hand sanitizer.

### How to practice good hand hygiene

- Wash hands with soap and water for 15 seconds or use the hospital's hand sanitizer.
- Make sure you and your visitors clean your hands often; remind care providers to clean their hands, too.

### Always clean your hands:

- Before eating.
- After using the bathroom.
- After blowing your nose, coughing or sneezing.
- Whenever your hands look dirty.



### Safe sleep

We will provide a bed for your child according to age and developmental level. For safety reasons, please do not share a sleeping surface with your child.

### Signs and symptoms of infection

Some infections appear as redness, pain, swelling or drainage at an IV catheter site or surgery site. Often these symptoms come with a fever. Tell your care team if your child has these symptoms. Tell your care team if your child has diarrhea three or more times in 24 hours, especially if he or she is taking an antibiotic.

### Patient identification

Your child's care team may ask you your child's name and birth date each time they interact with you. This is for your child's safety to ensure the right treatment for the right patient. Additionally, we will check your child's wristband before giving medications, treatments or tests.

### Call, don't fall







## Reporting safety concerns or injuries

If you have a safety concern, call your child's nurse immediately. If the concern is not resolved to your satisfaction, please ask to speak with the unit manager. You can also notify Patient Relations at **503-494-7959**.

# Rapid Response Safety Team

If you notice a sudden change in your child's condition or behavior, ask your nurse to check in right away. If you do not feel the nurse or doctor is responding to your concerns, call **503-494-7777** to reach the Family Initiated Rapid Response Safety Team. The operator will ask for your name, and the response team will be called immediately.

## Electrical equipment and devices

Check with your child's nurse before using any electronic devices or electrical equipment, including games, computers, hair dryers, shaving razors or medical equipment, such as nursing pumps or sleep apnea devices that you would like to use during yourstay. Heat-producing devices (such as heating pads and space heaters) are strictly prohibited in the hospital.

## No weapons at OHSU

The possession or use of weapons anywhere on OHSU property is prohibited.

# **Your Visitors**

Parents and primary caregivers are welcome 24 hours a day. Phone calls to patient rooms are allowed 10 a.m. – 9 p.m.

Visiting a Doe	rnbecher Patient
Flowers	Flowers may be sent to all units EXCEPT Doernbecher and OHSU's intensive care or cancer units, in order to control infections.
Tobacco- free campus	OHSU and Doernbecher are tobacco-free, indoors and outdoors. If you or your child's visitors smoke, we provide free nicotine lozenges to help manage cravings at the OHSU Hospital Information Desk, 9th floor lobby. We recognize that nicotine is a powerful addiction. If you use tobacco, OHSU is committed to support you in quitting or in managing your cravings by providing medication during your child's stay with us.
Siblings	Your child's brothers and sisters may not spend the night, so please make plans for your other children. If you are a mother who is also nursing a baby, the baby may stay with you in your child's room. Please bring a safe place for your nursing baby to sleep such as a travel crib. Siblings must be healthy when they visit. If a sibling has cold or flu symptoms, please ask them to visit another time.  Adults must accompany visitors under 18 at all times.



Lodging	There are many off-site hotel lodging options available near OHSU Doernbecher, and some offer OHSU patients a discounted rate. Visit www.ohsu.edu/lodging or pick up a hotel list from any of the hospital concierge desks. For information about the Ronald McDonald House, visit www.ohsudoernbecher.com/ronaldmcdonald.
Parking/ valet	Doernbecher offers free valet parking at the main entrance of the Doernbecher hospital building. Patients and visitors to Doernbecher may park for free in the lot directly in front of the main entrance, in marked spaces in the lower lot and on the lower floors of the parking garage to the west of Doernbecher.
Belongings	Please be sure that you and your visitors keep cell phones, computers and belongings where you need them. Some units may have special rules about what may not be brought onto the unit for infection control or safety reasons. Please check with your child's nurse.
Pet policy	Official therapy dogs are arranged by Volunteer Services.  Personal service animals are permitted to accompany and assist their handlers while the handlers are at OHSU. No other animals other than personal service animals or official therapy dogs are allowed in patient care and/or common areas.  Disruptive or poorly groomed animals may be excluded from OHSU.
Flu season	Flu season typically runs from mid-October to February.  There may be visitation restrictions during those times. Please ask your nurse what policies are in place during this time.



# Tips for visitors

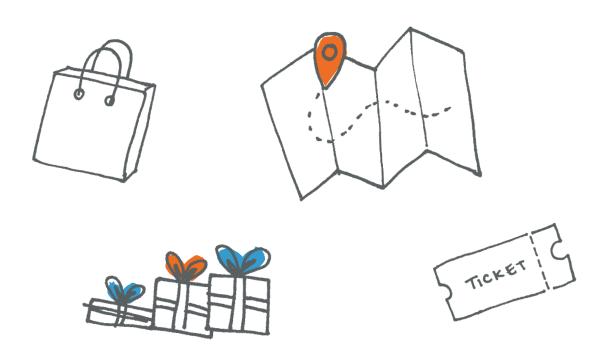
Friends and family can play a vital role in a patient's recovery. Here are some tips for a successful visit:

- Stay home if you are not feeling well. A phone call is much better than a contagious illness.
- Make sure visitors under 18 are accompanied by an adult.
- Keep voices low. Rest promotes healing and recovery.
- Avoid touching any tubes, dressings or medical equipment.

# Questions? Need directions?

Our hospital concierge staff is here to help. Contact us at **503-418-1818** or visit any of our concierge desk locations and we can assist you with:

- Providing hospital information.
- Directions to get around campus.
- Getting tram passes for patients and their families.
- Advice about where to dine, shop or find a hotel.

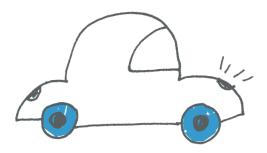


# When Your Child Goes Home

When your child's health care team determines he or she is ready, they will authorize your child to go home from the hospital. Please be patient; it takes time to coordinate all the things that need to happen for discharge. You may hear early in the day that you are going home, but it still may be several hours before your child is released. You can use this time to pack personal belongings.

Before you leave, your nurse will go over instructions for your child's care at home. If your child will need additional services or follow-up appointments after leaving Doernbecher, we will also give you that information. Please ask any questions you have.

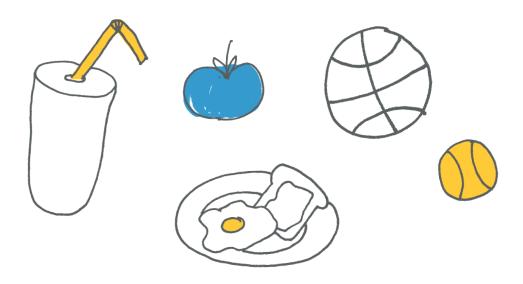
Please write any questions you may have below.	
•	
	_







How to take care of your child	
How do I take care of any wounds, cuts or incisions?	
What foods or drinks should I avoid giving my child? For how long?	
Are there any activities my child should not do, like running or climbing stairs? For how long?	
What exercises are good for my child?	
What do I need to do to make our home safer?	



# What medicine(s) does my child need to take when they leave the hospital? Does my child take the same medicines that they took before they went into the hospital?

For each medication:	
What is the name of this medicine? Is this the generic or brand name?	
Why do does my child take this medicine?	
When and how do should I give this medicine to my child?	

How much do I give?	
What does this medicine look like?	
What are potential side effects of this medicine? What problems do I need to look out for?	
Will this medicine interfere with other medicines, foods, vitamins, or other herbal supplements my child takes?	
Where and how do I get this medicine?	
What medicines can I give my child for pain? Upset stomach? Headaches? Allergies?	

Assistance you may need after you	get home
When we get home, what kind of help or care will my child need?	
Will my child need home nursing care? For how long? Who pays for it?	
Will my child need physical or occupational therapy for help with exercises or relearning how to do things? For how long? Who pays for it?	
Will my child need help eating, bathing or going to the bathroom? For how long?	
Will my child need any equipment, such as a wheelchair or oxygen? Where do I get it? Who pays for it? How do I use it?	

What problems to watch for wher	you get home
What problems do I need to watch for when we get home? If my child has problems, how do I know when I should call?	
Who do I call if I have questions or my child has problems when we get home?	

Follow-up care	
What appointments does my child need after we leave the hospital? Can the hospital help me make these appointments?	
Are we waiting on results of any tests? When should we get the results?	
Are there tests my child needs after we leave the hospital?	



## Assistance at Home

Your pediatric nurse case manager can help you arrange for your child's health care at home, including home health care, medical transportation and home medical equipment. You can also call Care Management at **503-494-2273**.

## Online Medical Records

If you and your child already have a MyChart account, you can securely access your child's OHSU medical record. MyChart gives you easy online access. You can log on to connect with your OHSU Doernbecher health care team, request an appointment, check lab results, pay your bill or view your medical records. If you would like to sign your child up for MyChart, you will receive more information at discharge.

## We Value Your Feedback

Our goal is to provide you with outstanding service and high-quality medical care. You may receive a survey asking about the care you received at OHSU. This is your opportunity to tell us what we did well, and where we could use some improvement. We hope that you will take a few moments to provide us your feedback. Thank you for choosing OHSU. We look forward to partnering with you in your health care.





# **Your Rights**

# Patient privacy

Your child's medical information is confidential. Under the federal Health Insurance Portability Accountability Act, or HIPAA, legal guardians (or your child if they are over 15) have the right to:

- Inspect and receive a copy of your child's medical information.
- Request changes to incorrect information about your child.
- Request a restriction on how we use or share your child's information.
- $\bullet$  File a complaint about our privacy practices.

You can find OHSU's Notice of Privacy Practices in Appendix A of this guide.

## Your rights and responsibilities

Your child's health care is our priority. At OHSU Doernbecher, we provide patient-and family-centered care. That means:

- We care about your child as a unique individual.
- We attend to your child's physical, emotional and spiritual needs.
- We acknowledge that we are guests in your family's lives.
- We earn your trust and become your partner.

As an OHSU Doernbecher patient, you and your child have several rights, including the right to respect, privacy and dignity. You and your visitors also have responsibilities, such as the responsibility to be considerate and respectful of others. You can find a full list of your rights and responsibilities in Appendix B of this guide.

## Inclusive patient care and communication

OHSU Doernbecher complies with applicable state and federal civil rights laws and does not discriminate, exclude people or treat them differently on the basis of race, color, national origin, age, disability or sex. For more information, please see Appendix C.

## Tissue sample donation

Tissue donations help researchers develop new and better medical treatments. They can come from common medical procedures and include materials from the body such as skin, blood and other bodily fluids. You have the choice to allow OHSU to use your child's excess tissue samples for medical research. For more information, go to www.ohsu.edu/biolibrary/patient. You can decline tissue donation by electronically signing or filling out the form in Appendix D and returning it to the admitting desk.

Notes			

# **Appendices**

#### appendix a

#### **Notice of Privacy Practices**

This notice describes how medical information about you may be used and disclosed and how you can get access to this information. Please review it carefully.

#### A. Purpose of this notice.

Oregon Health & Science University ("OHSU") is committed to preserving the privacy of your health information. In fact, we are required by law to do so for any health information created or received by us. OHSU is required to provide this Notice of Privacy Practices ("Notice") to you. The Notice tells you how we can and cannot use and disclose the health information that you have given to us or that we have learned about you when you were a patient in our system. It also tells you about your rights and our legal duties concerning your health information.

OHSU is required to abide by this Notice and any future changes to the Notice that we are required or authorized by law to make at all OHSU locations, including the schools of Dentistry, Medicine, Nursing, and Science & Engineering; OHSU Hospital, and Doernbecher Children's Hospital; numerous primary care and specialty clinics; multiple research institutes and centers; and several community service and outreach programs. This Notice applies to the practices of:

- All OHSU employees, volunteers, students, residents and service providers, including clinicians, who have access to health information.
- Any health care professional authorized to enter information into your OHSU health record.
- Any non-OHSU clinicians who might otherwise have access to your health information created or kept by OHSU, as a result of, for example, their call coverage for OHSU clinicians.

For the rest of this Notice, "OHSU," "we" and "us" will refer to all services, service areas, and workers of OHSU. When we use the words "your

health information," we mean any information that you have given us about you and your health, as well as information that we have received while we have taken care of you (including health information provided to OHSU by those outside of OHSU).

We will have a copy of the current Notice with an effective date in clinical locations and on our website at www.ohsu.edu/xd/about/services/integrity/ips/npp.cfm.

# B. Uses and disclosures of health information for treatment, payment and health care operations at OHSU.

- 1. Treatment, Payment and Health Care Operations. The following section describes different ways that we use and disclose health information for treatment, payment and health care operations. For each of those categories, we explain what we mean and give one or more examples. Not every use or disclosure will be noted and there may be incidental disclosures that are a byproduct of the listed uses and disclosures. The ways we use and disclose health information will fall within one of the categories.
- For Treatment. We may use your health information to provide you with medical or dental treatment or services. We may disclose your health information to staff physicians, staff dentists, postgraduate fellows, midwives or nurse practitioners, and other personnel involved in your health care. We may also disclose your health information to students and resident physicians who, as a part of their OHSU educational programs (and while supervised by physicians or dentists), are involved in your care. Treatment includes (a) activities performed by nurses, office staff, hospital staff, technicians and other types of health care professionals providing care to you or coordinating or managing your care with third parties, (b) consultations with and between OHSU providers and other health care providers, and (c) activities of non-OHSU providers or other providers covering an OHSU practice by telephone or serving as the on-call provider.

For example, a physician or dentist treating you for an infection may need to know if you have other health problems that could complicate your treatment. That provider may use your medical history to decide what

treatment is best for you. They may also tell another provider about your condition so that he or she can decide the best treatment for you.

b. For Payment. We may use and disclose your health information so that we may bill and collect payment from you, an insurance company, or someone else for health care services you receive from OHSU. We may also tell your health plan about a treatment you are going to receive to obtain prior approval, or to determine whether your plan will pay for the treatment.

For example, we may need to give your health plan information about surgery you received at OHSU so your health plan will pay us or reimburse you for the surgery.

c. For Health Care Operations. We may use and disclose your health information in order to run the necessary administrative, educational, quality assurance and business functions at OHSU.

For example, we may use your health information to evaluate the performance of our staff in caring for you. We may also use health information about patients to help us decide what additional services we should offer, how we can improve efficiency, or whether certain treatments are effective. Or we may give health information to doctors, nurses, technicians, or health profession students for review, analysis and other teaching and learning purposes.

Fundraising Activities. As a part of OHSU's healthcare operations, we may use and disclose a limited amount of your health information internally, or to the OHSU Foundation and Doernbecher Children's Hospital Foundation (collectively, "Foundations") to allow them to contact you to raise money for OHSU. The health information released for these fundraising purposes can include your name, address, other contact information, gender, age, date of birth, dates on which you received service, health insurance status, the outcome of your treatment at OHSU and your treating physician's name and department at OHSU. Any fundraising communications you receive from OHSU or its Foundations will include information on how you can elect not to receive any further fundraising communications from OHSU.

- Uses and Disclosures You Can Limit.
- a. Hospital Directory. Unless you notify us that you object, we may include certain information about you in the hospital directory in order to respond to inquiries from friends, family, clergy and others who inquire about you when you are a patient in the hospital. Specifically, your name, location in the hospital and your general condition (e.g., good, fair, serious, critical) may be released to people who ask for you by name. In addition, your religious affiliation may be given to a member of the clergy, such as a priest or rabbi, even if they don't ask for you by name.
- b. Family and Friends. Unless you notify us that you object, we may provide your health information to individuals, such as family and friends, who are involved in your care or who help pay for your care.

We may do this if you tell us we can do so, or if you know we are sharing your health information with these people and you don't stop us from doing so. There may also be circumstances when we can assume, based on our professional judgment, that you would not object. For example, we may assume you agree to our disclosure of your information to your spouse if your spouse comes with you into the exam room during treatment.

Also, if you are not able to approve or object to disclosures, we may make disclosures to a particular individual (such as a family member or friend), that we feel are in your best interest and that relate to that person's involvement in your care. For example, we may tell someone who comes with you to the emergency room that you suffered a heart attack and provide updates on your condition. We may also make similar professional judgments about your best interests that allow another person to pick up such things as filled prescriptions, medical supplies and X-rays.

# C. Other permitted uses and disclosures of health care information.

We may use or disclose your health information without your permission in the following circumstances, subject to all applicable legal requirements and limitations:

- 1. Required By Law. As required by federal, state, or local law.
- 2. Public Health Activities. For public health reasons in order to prevent or control disease, injury or disability; or to report births, deaths, suspected abuse or neglect, non-accidental physical injuries, reactions to medications, school immunizations under certain circumstances or problems with products.
- 3. Victims of Abuse, Neglect or Domestic Violence.

  To a government authority authorized by law to receive reports of abuse, neglect or domestic violence when we reasonably believe you are the victim of abuse, neglect or domestic violence and other criteria are met.
- 4. Health Oversight Activities. To a health oversight agency for audits, investigations, inspections, licensing purposes, or as necessary for certain government agencies to monitor the health care system, government programs, and compliance with civil rights laws.
- 5. Lawsuits and Disputes. In response to a subpoena, discovery request or a court or administrative order, if certain criteria are met.
- 6. Law Enforcement. To a law enforcement official for law enforcement purposes as required by law; in response to a court order, subpoena, warrant, summons or similar process; for identification and location purposes if requested; to respond to a request for information on an actual or suspected crime victim; to report a crime in an emergency; to report a crime on OHSU premises; or to report a death if the death is suspected to be the result of criminal conduct.
- 7. Coroners, Medical Examiners and Funeral Directors. To a coroner or medical examiner, (as necessary, for example, to identify a deceased person or determine the cause of death) or to a funeral director, as necessary to allow him/her to carry out his/her activities.
- 8. Organ and Tissue Donation. To organizations that handle organ procurement or organ, eye or tissue transplantation, or to an organ donation bank, as necessary to facilitate a donation and transplantation.
- 9. Research. For research purposes under certain limited circumstances. Research projects are subject to

- a special approval process. Therefore, we will not use or disclose your health information for research purposes until the particular research project, for which your health information may be used or disclosed, has been approved through this special approval process.
- 10. Serious Threat to Health or Safety; Disaster Relief. To appropriate individual(s)/organization(s) when necessary (i) to prevent a serious threat to your health and safety or that of the public or another person, or (ii) to notify your family members or persons responsible for you in a disaster relief effort.
- 11. Military. To appropriate domestic or foreign military authority to assure proper execution of a military mission, if required criteria are met.
- 12. National Security; Intelligence Activities; Protective Service. To federal officials for intelligence, counterintelligence, and other national security activities authorized by law, including activities related to the protection of the President, other authorized persons or foreign heads of state, or related to the conduct of special investigations.
- 13. Inmates. To a correctional institution (if you are an inmate) or a law enforcement official (if you are in that person's custody) as necessary (a) to provide you with health care; (b) to protect your or others' health and safety; or (c) for the safety and security of the correctional institution.
- 14. Workers' Compensation. As necessary to comply with laws relating to workers' compensation or similar work-related injury program.

#### D. When written authorization is required.

Other than for those purposes identified above in Sections B and C, we will not use or disclose your health information for any purpose unless you give us your specific written authorization to do so. Special circumstances that require an authorization include most uses and disclosures of your psychotherapy notes, certain disclosures of your test results for the human immunodeficiency virus or HIV, uses and disclosures of your health information for marketing purposes that encourage you to purchase a product or service, and for sale of your health information with

some exceptions. If you give us authorization, you can withdraw this written authorization at any time. To withdraw your authorization, deliver or fax a written revocation to OHSU Health Information Management, Mail Code OP17A, 3181 S.W. Sam Jackson Park Road, Portland, OR 97239; fax: (503) 494-6970. If you revoke your authorization, we will no longer use or disclose your health information as allowed by your written authorization, except to the extent that we have already relied on your authorization.

#### E. Your rights regarding your health information.

You have certain rights regarding your health information which we list below. In each of these cases, if you want to exercise your rights, you must do so in writing by completing a form that you can obtain from the OHSU Information Privacy and Security Office, Mail Code ITG09, 3181 S.W. Sam Jackson Park Road, Portland, OR 97239, or on the Web at www.ohsu.edu/xd/about/services/integrity/policies/ips-policies-hipaaforms.cfm#results. In some cases, we may charge you for the costs of providing materials to you. You can get information about how to exercise your rights and about any costs that we may charge for materials by contacting the OHSU Information Privacy and Security Office at 503-494-0219.

- 1. Right to Inspect and Copy. With some exceptions, you have the right to inspect and get a copy of the health information that we use to make decisions about your care. For the portion of your health record maintained in our electronic health record, you may request we provide that information to or for you in an electronic format. If you make such a request, we are required to provide that information for you electronically (unless we deny your request for other reasons). We may deny your request to inspect and/or copy in certain limited circumstances, and if we do this, you may ask that the denial be reviewed.
- 2. Right to Amend. You have the right to amend your health information maintained by or for OHSU, or used by OHSU to make decisions about you. We will require that you provide a reason for the request, and we may deny your request for an amendment if the request is not properly submitted, or if it asks us to amend information that (a) we did not create (unless the

- source of the information is no longer available to make the amendment); (b) is not part of the health information that we keep; (c) is of a type that you would not be permitted to inspect and copy; or (d) is already accurate and complete.
- 3. Right to an Accounting of Disclosures. You have the right to request a list and description of certain disclosures by OHSU of your health information.
- Right to Request Restrictions. You have the right to request a restriction or limitation on the health information we use or disclose about you (a) for treatment, payment, or health care operations, (b) to someone who is involved in your care or the payment for it, such as a family member or friend, or (c) to a health plan for payment or health care operations purposes when the item or service for which OHSU has been paid out of pocket in full by you or someone on your behalf (other than the health plan). For example, you could ask that we not use or disclose information about a surgery you had, a laboratory test ordered or a medical device prescribed for your care. Except for the request noted in 4(c) above, we are not required to agree to your request. Any time OHSU agrees to such a restriction, it must be in writing and signed by the OHSU Privacy Officer or his or her designee.
- 5. Right to Request Confidential Communications. You have the right to request that we communicate with you about health matters in a certain way or at a certain place. OHSU will accommodate reasonable requests. For example, you can ask that we only contact you at work or by mail.
- 6. Right to a Paper Copy of This Notice. You have the right to a paper copy of this Notice, whether or not you may have previously agreed to receive the Notice electronically.
- 7. Right to be Notified of a Breach. You have the right to be notified if there is a breach a compromise to the security or privacy of your health information due to your health information being unsecured.

  OHSU is required to notify you within 60 days of discovery of a breach.

#### F. Revisions to this notice.

We have the right to change this Notice and to make the revised or changed Notice effective for health information we already have about you, as well as any information we receive in the future. Except when required by law, a material change to any term of the Notice may not be implemented prior to the effective date of the Notice in which the material change is reflected. OHSU will post the revised Notice at OHSU clinical locations and on its website and provide you a copy of the revised notice upon your request.

#### G. Questions or complaints.

If you have any questions about this Notice, please contact OHSU (503) 494-8311. If you believe your privacy rights have been violated, you may file a complaint with OHSU or with the Secretary of the Department of Health and Human Services. To file a complaint with OHSU, contact OHSU at 503-494-8311. You will not be penalized for filing a complaint. This Notice tells you how we may use and share health information about you. If you would like a copy of this Notice, please ask your health care provider.

#### appendix b

December 22, 2016

#### Patient Rights, Responsibilities and Safety

"OHSU is committed to an inclusive culture that is safe and creates a respectful and healthy environment for all."

—Joseph E. Robertson, Jr., M.D., M.B.A.

OHSU President (2005-2018)

OHSU is committed to being a safe, respectful and welcoming place for people of all ages, cultures, abilities, ethnicities, genders, national origins, races, colors, religions, sexual orientations and ideas. All are welcome. OHSU will not discriminate against you.

For this same reason, OHSU will not honor patient requests to refuse involvement of specific healthcare or service personnel in their care based on race, ethnicity or creed. We are committed to providing care to all of our patients and to protecting our employees from bias or bigotry.

#### As an OHSU patient you have a right to:

- Care that is delivered in a way that is free from abuse, discrimination or harassment based on age, race, color, ethnicity, national origin, culture, language, sex, sexual orientation, gender identity and expression, physical or mental disability, religion, socioeconomic status, marital status, military or reserve status, or any other status protected by law.
- Individualized care that takes into account your comfort and dignity.
- Assistance with communication, including free language services.
- Privacy, confidentiality of your personal health information and dignity.
- Know the names of people who are helping or caring for you.
- Have a chaperone present during your examination.
- Tell us who you would like to help you make decisions about your care.
- Ask questions and receive answers in a way that meets your needs and helps you understand.
- Be involved in developing and implementing your care plan and the plans for your care after you leave the hospital.
- Receive information about your health condition and the results of the care we provided you.
- Informed consent: the right to understand and agree to the care plan your provider recommends.
- Informed refusal: the right to refuse care and receive information about the risks and benefits of refusing the care your provider recommends.
- Prepare an Advance Directive, which will tell
  your health care providers or family members
  in advance about the care you do or do not want
  to receive. You also have the right to have those
  decisions respected.
- Refuse to be part of a research project.
- Feel safe and free from any form of abuse or neglect.
   You also have the right to ask for protection or help through an advocate during your visit.
- Access to pastoral and other spiritual services.
- Request and receive relief from pain, as agreed upon by your provider.
- Be free from restraint, unless it is necessary to keep you safe.

- Understand a decision to transfer you to another facility.
- · Review and ask questions about your bill.
- Tell us about your concerns or complaints, and to receive a response, without affecting the quality or delivery of care.
- Tell us who plays a significant role in your life, and who you would like to visit you or your child in the hospital. This may include loved ones not legally related to you, such as a non-registered domestic partner, different-sex or same-sex significant other, foster parents, same-sex parents, step-parents, and others.
- Have family, friends and physicians promptly notified upon admission to the hospital.
- Opt out of being included in the directory for emergency room and admitted patients by notifying Patient Access Services at 503-494-8927. Unless you notify us that you object, we may include certain information about you in the hospital directory in order to respond to inquiries from friends, family, clergy and others who inquire about you when you are either admitted to the hospital or being seen in our emergency room. Specifically, your name, location in the hospital and your general condition (e.g., good, fair, serious, critical) may be released to people who ask for you by name. In addition, your religious affiliation may be given to a member of the clergy, such as a priest or rabbi with official OHSU Volunteer status, even if they don't ask for you by name.

If we are not doing what you expect, we hope you will tell us.

# As an OHSU patient you, and your family and visitors, have a responsibility to:

- Be considerate and respectful of people who are helping or caring for you. They are chosen for their skill and ability, and would never be reassigned for reasons of race, ethnicity or other characteristics unrelated to their professional or service role.
- Refrain from using discriminatory, profane, derogatory or threatening language or behavior.

- Be thoughtful of other patients and visitors in order to maintain a healing environment.
- Provide accurate, honest and complete information about your medical history, including information about medicines and drugs you have used, previous illnesses, injuries or medical care, and information about your current health conditions.
- Take part in your health care decisions unless you give that responsibility to a friend or family member.
- Ask questions and tell us when you do not understand a treatment or decision we are considering.
- Tell us about unexpected changes in your condition and things about your care you think might be risks.
- Follow instructions once you and your provider have agreed on your care.
- Accept what happens if you do not follow the care plan or treatment your providers recommend.
- Let the staff know if you must leave a care area (hospital or clinic), and when you expect to return.
- · Follow the hospital's policies.
- Carefully review the OHSU Notice of Privacy
   Practices, which explains how we may use or share
   your health information. The NPP also explains
   how you may have access to this information.
- · Cancel appointments you are not able to keep.
- Share your compliments and concerns, and provide suggestions that will help us provide you the best care possible.
- Meet your financial obligations.

#### Patient safety

When you are a patient at OHSU, you have a right to receive safe medical care. Being involved in your care is one important way to be certain you are safe. This means:

- Ask questions: Ask questions until you understand your illness, treatments, necessary surgeries or procedures, the medicine you will take, and how to care for yourself at home.
- Double check: Help our staff provide safe care and a safe care environment. It's OK to ask if they remembered to:

- Confirm they are providing care to the correct patient.
- Wash their hands.
- Mark the site for your surgery or procedure.
- Do everything they could to protect you from falling.

Please talk with your care givers or our patient advocates if you have concerns about the safety of your care. When we know about your concerns, we can help make the necessary changes.

#### Concerns and suggestions

Please talk with us if you have concerns. Tell us your complaints and suggest ways we can improve. We will not force you to do something, discriminate against you, interrupt the services we are providing or punish you in some way just because you complain. If you are concerned or upset about your visit, we would like you to talk with the manager of the service before you leave. He or she often can solve the problem or clear up a misunderstanding.

OHSU is committed to the prompt resolution of complaints and grievances. If you still have a concern after talking with the manager or wish to file a grievance, please contact OHSU Patient Relations department by phone, mail, fax or e-mail.

OHSU Patient Relations
OHSU Hospital
Mail code UHS-3
3181 S.W. Sam Jackson Park Rd.
Portland, OR 97239-3098
503-494-7959, Fax: 503-494-3495
E-mail: advocate@ohsu.edu

Additional information is available online at: www.ohsu.edu/advocate

If we still have not addressed your concern, the following resources are also available to assist you. Oregon Health Authority Health Care Regulation and Quality Improvement 800 N.E. Oregon St., Ste. 465 Portland, OR 97232

971-673-0540, Fax: 971-673-0556 E-mail: mailbox.hclc@state.or.us

State Quality Improvement Org. Acumentra Health 2020 S.W. 4th Ave., Ste. 520 Portland, OR 97201 503-279-0100. Fax: 503-279-0190

DNV-GL Healthcare
400 Techne Center Drive, Suite 100
Milford, OH 45150
Phone: 866-496-9647, Fax: 513-947-1250
www.dnvglhealthcare.com/patient-complaint-report

U.S. Department of Health and Human Services
Office for Civil Rights
200 Independence Ave. S.W., Room 509F
HHH Building
Washington, D.C. 20201
800-868-1019, 800-537-7697 (TDD)
ocrportal.hhs.gov/ocr/portal/lobby.isf

#### Patient feedback survey

You may receive a Patient Feedback Survey in the mail. Please complete and return it to us so we can learn about your experience at OHSU. We would like to hear about what may have been a concern or what you were particularly pleased with during your visit to OHSU. You may also provide positive feedback about the care you received at OHSU to the organizations listed in the "Concerns and suggestions" section.

#### Notice of privacy practices

OHSU protects the privacy of its patients'
personal health information. If you would like
a copy of the OHSU Notice of Privacy Practices, please
ask for a copy at your next visit or call 503-494-0219.

#### appendix c

#### Inclusive patient care and communication

#### OHSU is committed to providing inclusive patient care

OHSU complies with applicable state and federal civil rights laws and does not discriminate, exclude people or treat them differently on the basis of:

Race

• Age

Color

- · Disability; or
- National origin
- Sex.

# We are happy to help you with communication aids and language access

OHSU provides free auxiliary 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 and other formats)

OHSU also provides free language services to people whose primary language is not English, such as:

- · Qualified interpreters
- Information written in other languages

If you need these services, contact your care provider's office. They will make the language services arrangements for you. OHSU offers free language services in over 120 languages.

#### We are here to help you with your concerns

If you believe that OHSU 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 in writing to the Patient Advocate at the Patient Relations Office, 3181 SW Sam Jackson Park Road, Mail Code: UHS-3, Portland OR 97239, Phone: 503-494-7959, Fax: 503-494-3495, Email: advocate@ohsu.edu. You can file a grievance in person or by mail, fax or email. If you

need help filing a grievance, the Patient Advocate is available to help you.

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 https://ocrportal.hhs.gov/ocr/portal/lobby.jsf, 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, 1-800-868-1019, 800-537-7697 (TDD). Complaint forms are available at www.hhs.gov/ocr/office/file/index.html.

#### Language services notification:

#### Translations for most-spoken languages in Oregon

Language assistance services (in person, live over the phone or live video) are available to you free of charge upon request. Please let your provider's office staff know that you need language services for your visit.

#### **English**

If you speak [insert language], language assistance services, free of charge, are available to you. Call your care provider's office and they are happy to make the language services arrangements for you.

#### Español (Spanish)

Si usted habla español, contamos con servicios de asistencia de idiomas, sin costo, disponibles para usted. Si necesita estos servicios, comuníquese al consultorio de su proveedor de atención médica. Ellos gustosamente coordinarán los servicios de idiomas para usted.

#### Tiếng Việt (Vietnamese)

Nếu bạn nói tiếng Việt, dịch vụ hỗ trợ ngôn ngữ, miễn phí, có sẫn dành cho bạn. Nếu bạn cần những dịch vụ này, hãy liên lạc văn phòng của bác sĩ chăm sóc của bạn. Họ sẽ sẵn sàng thu xếp các dịch vụ ngôn ngữ cho bạn.

#### 中文 (Chinese-Simplified)

如果您说中文,可为您提供免费的语言援助服务。如果您需要这些服务,请联系您保健提供者的办公室。他们将乐意为您安排语言服务。

#### Русский (Russian)

Если вы говорите на русском языке, вам могут предоставить бесплатные услуги переводчика. Если вам требуются такие услуги, обратитесь в офис своего поставщика медицинских услуг. Сотрудники с радостью предоставят вам переводчика!

#### 한국어 (Korean)

한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 이 서비스가 필요하시면 귀하의 의료 제공자 사무실에 연락하십시오. 귀하를 위해 기꺼이 언어 서비스를 준비해드릴 것입니다.

#### Українська (Ukrainian)

Якщо ви розмовляєте українською мовою, послуги мовної допомоги доступні для вас безкоштовно. Якщо вам потрібні ці послуги, зв'яжіться з офісом вашого постачальника послуг. Вони будуть раді надати вам послуги мовної допомоги.

#### 日本語 (Japanese)

あなたの母語が日本語であれば、言語サポートサービスを無料 にてご用意しています。サービスをご希望の場合には、あなたの ケアプロバイダー事務所までご連絡ください。喜んで言語サポートサービスの手配をいたします。

#### (ARABIC) العربية

إذا كنت تتحدث العربية، فإن خدمات المساعدة اللغوية متاحة لك مجانًا. إذا كنت تحتاج إلى هذه الخدمات، فاتصل عكتب مقدم الرعاية الخاص بك. سيكون الموظفون هناك سعداء بإجراء الترتيبات المتعلقة بالخدمات اللغوية . من أجلك

#### Română (Romanian)

Dacă vorbiți română, puteți beneficia de asistență lingvistică gratuită. Dacă aveți nevoie de astfel de servicii, luați legătura cu biroul furnizorului dvs. de servicii medicale. Reprezentanții acestuia vă vor ajuta cu plăcere să beneficiați de asistență lingvistică.

#### មន-ខមរ័រ (Mon-Khmer Cambodian)

បុរសិនបើលាកអុនកនិយាយកាសា មន-ខុមរៃ, ភាសាខុមរៃ នាះសវៅជំ នួយផុនកែភាសាមានផុតល់ជូនលាកអុនកជាយឥតគិតចូល។ៃ បុរសិនបើ លាកអុនកត្សវការសវៅទាំងនេះ សូមទំនាក់ទំនងទាកាន់ការិយាល័យអុ នកផុតល់ការថទំាំរបស់លាកអុនក។ ពួកគពេញចិត្តកុនុងការៀបចំស វាផុនកែភាសាផុសងេៗសម្គាប់លាកអុនក។

#### Oroomiffa (Oromo)

Afaan Kuush (Oromoo), dubbattu yoo ta'e, tajaajilliwwan deeggarsa afaanii, kaffaltii irraa bilisa ta'an, isiniif ni jiraatu. Tajaalilawwan kanneen ni barbaaddu yoo ta'e, wajjira dhiyeessaa deeggarsa keessanii qunnamaa. Isaan gammachuudhaan tajaajilawwan afaanii isiniif mijeessu.

#### Deutsch (German)

Wenn Sie Deutsch sprechen, stehen für Sie kostenlos Sprachassistenzdienste zur Verfügung. Wenn Sie diese Dienste in Anspruch nehmen möchten, wenden Sie sich bitte an das Büro Ihres Leistungserbringers. Dort wird man die Sprachassistenzdienste gerne für Sie arrangieren.

#### (FARSI) فارسى

اگر به زبان فارسی صحبت می کنید، سرویس کمک زبانی به صورت رایگان در دسترس شما خواهد بود. اگر به این سرویس ها نیاز دارید، با دفتر ارائه دهنده خدمات تماس بگیرید. آنها حتماً مقدمات لازم را برای دسترسی به .سرویس های زبانی در اختیارتان قرار می دهند

#### Français (French)

Si vous parlez français, des services d'aide linguistique gratuits sont à votre disposition. Si vous nécessitez ces services, contactez le cabinet de votre prestataire de soins. Ils se feront un plaisir d'organiser ces services linguistiques pour vous.

#### ไทย (Thai)

หากท่านพูดภาษาไทย จะมีบริการความช่วยเหลือทางด้านภาษา โดยไม่มีค่าใช้จ่าย หากท่านต้องการใช้บริการดังกล่าว โปรดติดต่อ สำนักงานผู้ให้บริการดูแล ซึ่งพร้อมที่จะจัดหาบริการทางด้านภาษา ให้แก่ท่าน

#### appendix d

Notice Of Your Right To Decline Future
Sample Research, Including Anonymous Or
Coded Genetic Research

OHSU collects, stores, and distributes human biological samples (such as tissue, blood, or body fluids) and associated health information, including genetic information, for use in future research projects. Gathering and storing many human biological samples and associated health information together can help future researchers by having more

samples available, having samples ready to go, and avoiding the need to re-collect samples and information from participants. Research with the stored samples and information can help us understand more about how the human body works, develop new tests to diagnose diseases, find new ways to treat and prevent diseases, or develop new products, such as drugs.

#### Donation of unused samples

"You," "your" or "I" refers either to you or to the person for whom you are making healthcare decisions. If you consent to a treatment or procedure as part of your healthcare at OHSU, there may be biological samples collected to help diagnose a condition or as part of the treatment. All biological samples will first be used for this purpose. There may or may not be biological samples left over after the treatment or procedure. If there are extra biological samples, you can authorize OHSU to store those extra biological samples and any associated health information indefinitely for use in future research.

By allowing the storage of your biological samples, you are also permitting the use of your biological samples for research, and use of your biological samples and health information for anonymous and coded genetic research. The samples will be used by OHSU, as well as public or private entities with which OHSU collaborates. This may include for-profit companies that conduct research, including research to develop products such as drugs and diagnostic tests. These biological samples and health information may be used to make a discovery that could be profitable to OHSU or another company. You will not be financially compensated if this happens. However, you will have no responsibility or liability for any use made of your biological samples or health information.

#### Privacy & confidentiality

The health information that we gather about you for research is personal and will be used and disclosed by OHSU in compliance with the law.

Your health information may be shared with others outside of OHSU for research purposes. Research records may be reviewed and/or copied by government oversight agencies or others authorized by law. Whenever possible, biological samples and information will be maintained in a form that is either anonymous or coded. In anonymous research, personal information that could be used to identify you, like your name or medical record number, cannot be linked to your biological samples or health information. In coded research, personal information that could be used to identify you is kept separate from your biological sample or health information so it would be very difficult for someone to connect it back to you. Both methods protect your identity. Unless there is a scientific need for them to be identifiable (for example, labeled with your name or medical record number), researchers will be given only the anonymous or coded biological samples or health information. The main reason identifiable information might be needed for research is to link information from different sources, such as linking information from your healthcare record with your biological sample.

#### About research at OHSU and genetic research rights

The federal government has laws to ensure that research conducted at institutions like OHSU is safe and ethical. Consistent with these laws, OHSU has an Institutional Review Board that reviews research before it begins to make sure those requirements are met. Research at OHSU using biological samples or your health information mayinvolve genetic research. The State of Oregon has laws to protect the genetic privacy of individuals. These laws give you the right to refuse to have your biological samples or health information used for genetic research. In addition, you can also choose to not allow use of your extra biological samples for any research. The choice is yours. Your decision will not affect the care you receive from your health care provider or OHSU, or your health insurance coverage, and there will be no penalty or loss of any benefits to which you are otherwise entitled.

#### How to participate

If you agree to allow your biological samples to be stored and used for research, and your biological samples and health information to be used for anonymous and coded genetic research, you do not have to do anything else. We will consider this to be your decision to donate your biological samples to OHSU and to allow future research using your biological samples and allow anonymous or coded genetic research using your biological samples and health information without further notice to you.

#### If you don't want to participate

If you do not want to have your biological samples stored and used for future research, or your biological samples and health information used for anonymous and coded genetic research, you must tell OHSU by completing this form and:

 Giving it to your OHSU health care provider; or Mailing it to:
 Health Information Services
 3181 SW Sam Jackson Park Rd.
 Mail Code OP-17A
 Portland, OR 97239-3098

If you decide not to participate, your decision becomes effective on the date OHSU receives this form.

No matter what you decide now, you can always change your mind later. If you change your mind, complete this form and mail it to the above address at any time. If you change your mind, that decision will apply only to biological samples and health information collected after OHSU receives this completed form.

If you have questions or want more information about anything in this notice, please read our educational brochure "Why Sample Donations Matter: What You Need to Know," call the OHSU Research Integrity Office at 503-494-7887 or visit us online at www.ohsu.edu/xd/research/about/integrity.

sample	s or health information for research, as follows:
0	I do not want my extra biological samples stored and used for future research.
0	I do not want my biological samples and health information to be used for anonymous or coded genetic research.

By checking the box and signing below, I am not allowing or I am limiting the use of my biological



OHSU accepts most major health plans.
OHSU is an equal opportunity, affirmative action institution

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