



Name:

# Patient Registration Form

<b>Patient Demographics:</b>			
<b>Gender:</b> <i>Male Female</i>	<b>Date of Birth:</b>	<b>Race:</b>	<b>Hispanic:</b> <i>Yes No</i>
<b>Marital Status:</b> ( <u>circle one</u> ) <i>Single Married Divorced Separated Widowed Other</i>			
<b>Patient Contact Information:</b>			
Address 1:			
Address 2:			
City:	State:	ZIP:	
Patient's Home Phone:		Patient's Mobile Phone:	
Patient's E-Mail:			
<b>Employment:</b> ( <u>circle one</u> ) <i>Child/Student Employed Disabled Part-time Retired Unemployed Homemaker</i>			
Patient's Employer: ( <u>if applicable</u> )		Patient's Employer Phone:	
<b>Guarantor (Person Responsible for Payment): Please Provide All Information</b>			
<input type="checkbox"/> Patient will be the Guarantor ( <u>if checked, skip to the next section</u> )			
Guarantor Name:		Guarantor Phone:	
Relationship: ( <u>circle one</u> ) <i>Parent Spouse Partner Other (describe):</i>			
Guarantor Date of Birth:		Guarantor Gender: <i>Male Female</i>	
Guarantor Address 1:			
Guarantor Address 2:			
Guarantor City:	State:	ZIP:	
<b>Primary Care Doctor:</b>			
Name:			
Address 1:			
Address 2:			
Address 3:			
City:	State:	ZIP:	
Office Phone:		Other Phone:	
<b>Family Information</b>			
Father's Name:	Phone:	Lives with patient? ( <u>circle one</u> ) <i>Yes No</i>	
Mother's Name:	Phone:	Lives with patient? ( <u>circle one</u> ) <i>Yes No</i>	
Spouse/Partner's Name:	Phone:	Lives with patient? ( <u>circle one</u> ) <i>Yes No</i>	

## Patient Registration Form (continued)

Work Contact Information		
<b>Father's Work</b> (if applicable)		
<b>Company Name:</b>	<b>Work Phone:</b>	
<b>Mother's Work</b> (if applicable)		
<b>Company Name:</b>	<b>Work Phone:</b>	
<b>Spouse/Partner's Work</b> (if applicable)		
<b>Company Name:</b>	<b>Work Phone:</b>	
Emergency Contacts		
<b>Name:</b>	<b>Relationship:</b>	<b>Phone:</b>
<b>Name:</b>	<b>Relationship:</b>	<b>Phone:</b>
<b>Name:</b>	<b>Relationship:</b>	<b>Phone:</b>

I, \_\_\_\_\_, (print name of person completing form) certify that the information provided here is accurate to the best of my knowledge.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

**Mountain States Regional Hemophilia and Thrombosis Center  
University of Colorado at Denver and Health Sciences Center  
CONSENT FOR TREATMENT**

1. **CONSENT FOR TREATMENT.** I voluntarily consent to outpatient care and treatment performed by my physician and all other health care providers at the Mountain States Regional Hemophilia and Thrombosis Center (MSRHTC). I also consent to routine services, diagnostic procedures, medical treatment, and other services as deemed necessary by the health care providers treating me. I understand that the practice of medicine is not an exact science and that diagnosis and treatment may cause injury or even death. I understand that I have a right to consent or to refuse to consent to any proposed treatment and to discuss it with my health care provider.
2. **RESEARCH.** I understand that if I am participating in a research protocol and have signed the Colorado Multiple Institutional Review Board (COMIRB) consent form, I am exempt from paragraphs 2 and 3 of this Consent for Treatment with respect to the services specifically described in that research protocol. I understand that all provisions of this Consent for Treatment shall apply to those tests and services not included within the research protocol. I understand that my medical information may be released to agencies and individuals identified in the COMIRB Subject Consent Form.
3. **AUTHORIZATION FOR RELEASE OF INFORMATION.** I authorize MSRHTC, University Physicians Incorporated (UPI), University of Colorado Hospital (UCH), and The Children's Hospital (TCH) to utilize protected health information contained in my medical record as necessary for treatment, payment, or health care operations. I further authorize the release and discharge of such protected health information to my insurance company or other health coverage plan as necessary for claims payment, medical management and quality review activities conducted by such company or plan, or its designees. This authorization includes the release of an Acquired Immunodeficiency Syndrome (AIDS) diagnosis or a positive Human Immunodeficiency Virus (HIV) antibody test result, alcohol and/or drug abuse information, genetic testing, congenital disorders, and mental health information. I understand this authorization for release of information can be revoked by me in writing at any time but only with respect to the proposed treatment and not with respect to care and treatment that has already been rendered to me.
4. **MEDICARE, MEDICAID, OR COLORADO INDIGENT CARE PROGRAM.** I authorize any holder of medical or other information about me to release to the Social Security Administration, the Department of Health and Human Services, the Colorado Department of Social Services and their intermediaries, carriers or agents any information needed for this or a related claim. I request that payment of authorized benefits be made on my behalf.
5. **WAIVER OF RESPONSIBILITY FOR PERSONAL VALUABLES.** I understand that MSRHTC does not assume any responsibility for the loss or damage to my personal property.
6. **PAYMENT AGREEMENT AND ASSIGNMENT.** I agree to be responsible for my co-payments, deductibles or other charges for medical services not covered or paid by insurance or other third party payers, except as prohibited by any agreement between my insurance company and MSRHTC or by state or federal law. I authorize MSRHTC, UPI, UCH or TCH to file any claims for payment of any portion of the patient bills and assign all rights and benefits to UPI as appropriate. I further agree, subject to state or federal law, to pay all costs, attorney fees, expenses and interest in the event UPI has to take action to collect same because of my failure to pay in full all incurred charges.
7. **PHOTOGRAPHY.** I further authorize the MSRHTC to take photographs/videos of \_\_\_\_\_ for the purpose of identification within Center records, scientific and medical purposes and for use in medical and scientific publications and presentations. I understand that I will not receive financial compensation for their use. I also understand that I may, at any time, make a written request to exclude use of said images.  Agree  Disagree

**By signing, I indicate that I have read and understand the terms of this Agreement.  
I agree to the terms stated above and am signing this Consent for Treatment voluntarily.  
The consent for outpatient treatment shall be effective for one (1) year.**

\_\_\_\_\_  
**PATIENT NAME**

\_\_\_\_\_  
**PATIENT SIGNATURE**

\_\_\_\_\_  
**DATE**

(OR Parent/Guardian/Other Authorized Person  
if Patient is A Minor, Mentally Incompetent, or  
Physically Unable to Sign this Form)

\_\_\_\_\_  
**RELATIONSHIP TO PATIENT**

If Signatory is not the Patient, Print Name and  
Relationship of Person Authorized to Sign for  
Patient

\_\_\_\_\_  
**Reason Patient is Unable to Sign**

**University of Colorado Hospital  
University of Colorado Health Sciences Center  
University Physicians, Incorporated**

**ACKNOWLEDGMENT OF RECEIPT OF JOINT NOTICE  
OF PRIVACY PRACTICES**

By signing this document, I acknowledge that I have received a copy of the joint Notice of Privacy Practices for University of Colorado Hospital, University of Colorado Health Sciences Center and University Physicians, Incorporated.

\_\_\_\_\_  
Name (Sign)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name (Print)

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For Internal Use Only

Reason Acknowledgment was not obtained: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

\_\_\_\_\_  
Name (Sign)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name (Print)

## Authorization to Refer Information to the Hemophilia Society of Colorado (HSC)

The Hemophilia Treatment Center (HTC) provides medical services, while the Hemophilia Society of Colorado (HSC) provides other support services to persons with bleeding disorders. Such services include education, community activities, financial assistance, scholarship opportunities and support groups to help members deal with the new responsibilities of caring for a child with Hemophilia.

With your consent, the Hemophilia Treatment Center will release your contact information as indicated below to the HSC. The HSC will then send you an information package and membership application for your review. There is no obligation to join.

If you'd like to receive an information package from the HSC, please sign below authorizing the Hemophilia Treatment Center to release your information to the HSC. The information you provide will be released to HSC only and will not be used for any other purpose.

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I \_\_\_\_\_ (**print full name**), hereby authorize the Hemophilia Treatment Center to release the following information to the HSC. I wish to receive an informational package from the HSC.

- Address: \_\_\_\_\_
- Phone
  - Home: \_\_\_\_\_
  - Work: \_\_\_\_\_
- Name of person with bleeding disorder: \_\_\_\_\_

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Signature

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Date

**OR**

I \_\_\_\_\_ (**print full name**), do not wish to release any information regarding my child or myself to the HSC. I do not wish to receive an information package from the HSC.

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Signature

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Date

**University of Colorado Hospital  
University of Colorado Health Sciences Center  
University Physicians, Incorporated**

**NOTICE OF PRIVACY PRACTICES  
Effective: April 14, 2003**

**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.**

This notice tells you how we may use and disclose protected health information about you. Protected health information means any health information about you that identifies you or that could be used to identify you. In this notice, we call all of that protected health information, “medical information.”

This notice also tells you about your rights and our duties with respect to medical information about you. In addition, it will tell you how to complain to us if you believe we have violated your privacy rights.

**Who Will Follow This Notice**

This notice describes University of Colorado Hospital, University of Colorado Health Sciences Center and University Physicians, Incorporated practices and uses and disclosures of your medical information at our service delivery sites.

University of Colorado Hospital, University of Colorado Health Sciences Center and University Physicians, Incorporated include the campuses located at Ninth and Colorado and at Fitzsimons in addition to all remote clinics and other areas of the State of Colorado served by these organizations.

The following are included as a part of these campuses:

- Any health care professional authorized to enter information into your hospital or clinic chart;
- All departments and units of University of Colorado Hospital, University of Colorado Health Sciences Center and University Physicians, Incorporated;
- Any member of a volunteer group University of Colorado Hospital allows to help you while you are in the hospital;
- All employees, staff and other hospital and clinic personnel;
- All students in certified training programs; and
- All University of Colorado Health Sciences Center physicians.

All of these entities, sites and locations will follow what is said in this notice. In addition, these entities, sites and locations may share medical information with each other for your treatment, payment or our health care operations described in this notice.

**Who Won't Follow This Notice**

The following will not follow this notice. They have their own notice that you should request:

- The University of Colorado Health Sciences Center Graduate Medical Education Housestaff Benefit Plan (a health plan that provides health insurance benefits for our trainees); and
- Any other University of Colorado campus that is required to provide a notice.

## **Our Pledge Regarding Medical Information**

University of Colorado Hospital, University of Colorado Health Sciences Center and University Physicians, Incorporated understands that medical information about you and your health is personal. We are committed to protecting medical information about you. We create a record of the care and services you receive at the hospitals and clinics. We need this record to provide you with quality care and to comply with certain legal requirements. This notice applies to all of the records of your care, whether made by hospital or clinic personnel, research staff, medical students, or your own personal doctor. Your personal doctor, if not an employee of University of Colorado Health Sciences Center or when rendering services at a private practice location, may have different policies or notices regarding the doctor's use and disclosure of your medical information.

This notice will tell you about the ways in which we may use and disclose medical information about you. It will also describe your rights and obligations regarding the use and disclosure of medical information.

We are required by law to:

- Make sure that medical information that identifies you is kept private;
- Give you this notice of our legal duties and privacy practices with respect to medical information about you; and
- Follow the terms of the notice that is currently in effect.

### **How We May Use and Disclose Medical Information About You Without Your Prior Written Agreement**

The following categories describe different ways that we use and disclose your medical information. We will share medical information about you with each other as necessary to carry out treatment, payment, or our health care operations. For each category we will explain what we mean and try to give an example. Not every use or disclosure in a category will be listed. However, all of the ways we are permitted to use and disclose information will fall into one of the categories.

#### • **For Treatment**

We may use medical information about you to provide, coordinate or manage your health care and related services by both us and other health care providers. We may disclose medical information about you to doctors, nurses, hospitals, medical students and other health facilities that become involved in your care. We may consult with other health care providers concerning you and, as part of the consultation, share your medical information with them. Similarly, we may refer you to another health care provider and, as part of the referral, share medical information about you with that provider. *For example*, a doctor treating you for a broken leg may need to know if you have diabetes because diabetes may slow the healing process. In addition, the doctor may need to tell the dietician if you have diabetes so appropriate meals can be arranged. Different departments of the hospital may also share medical information about you in order to coordinate the different things you need, such as prescriptions, lab work and x-rays. We may also disclose medical information about you to people outside the hospital who may be involved in your medical care after you leave the hospital, such as family members and home health nurses that we use to provide services that are part of your care.

#### • **For Payment**

We may use and disclose medical information about you so we can be paid for the services we provide to you. This can include billing you, your insurance company, another payor, or someone else who pays for your care. *For example*, we may need to give your insurance company information about surgery we performed on you or a clinic visit you had so your insurance company will pay us for those services or reimburse you for amounts you have paid. We also may need to provide your insurance company or a government program, such as Medicare or Medicaid, with information about your medical condition and

the health care you need to receive to determine if you are covered by that insurance program and see if the program will pay us for your treatment.

- **For Health Care Operations**

We may use and disclose medical information about you for our own health care operations. These are necessary for us to operate University of Colorado Hospital, University of Colorado Health Sciences Center and University Physicians, Incorporated and make sure that all of our patients receive good care. *For example*, we may use medical information to review your treatment and our services and to evaluate the performance of our staff caring for you. We may also combine medical information about many hospital patients into a report in order to decide what additional services the hospital should offer, what services are not needed, and whether certain new treatments are effective. We may disclose information to doctors, nurses, technicians, medical students, and other hospital personnel for review and learning purposes. We may remove information that identifies you from this set of medical information so others may use it to study health care and health care delivery without learning who you are.

- **How We Will Contact You**

Unless you tell us otherwise in writing, we may contact you by either telephone or by mail at either your home or your office. At either location, we may leave messages for you on the answering machine or voice mail. We will try not to leave messages with specific information about you. If you want to request that we communicate with you in a certain way or at a certain location, let the person registering or treating your know so that you may be given a form to make this request.

- **Appointment Reminders**

We may use and disclose medical information about you to contact you to remind you of an appointment you have with us.

- **Treatment Alternatives**

We may use and disclose medical information to tell you about or recommend possible treatment options or alternatives that may be of interest to you.

- **Health Related Benefits and Services**

We may use and disclose medical information to tell you about health-related benefits or services that may be of interest to you.

- **Fundraising**

We may use information about you to contact you in an effort to raise money for University of Colorado Hospital or University of Colorado Health Sciences Center and its operations. We may disclose this information to a business associate or the University of Colorado (CU) Foundation, an institutionally related foundation, so that it may contact you to raise money for University of Colorado Hospital or University of Colorado Health Sciences Center. We will only release contact information, such as your name, address and phone number and the date you received treatment or services. No medical information will be provided. If you do not want University of Colorado Hospital or the Foundation to contact you for fundraising efforts, you must notify the Office of Development in writing at P.O. Box 6508, Aurora, CO 80045-0508. Information on how to stop receiving fundraising material will be provided on all information sent to you from our organizations or business associates.

- **Hospital Directory**

We may include certain limited information about you in the hospital directory while you are a patient at the hospital. This information may include your name, location in the hospital, your general condition (for example, fair, stable, etc.) and your religious affiliation. The directory information, except for your religious affiliation, may also be released to people who ask for you by name. Your religious affiliation

may be given to a member of the clergy, such as a priest, pastor or rabbi, even if they don't ask for you by name. The directory is used so that your family, friends and clergy can visit you in the hospital and generally know how you are doing. If you do not wish to be listed in the directory or have clergy visit you must notify the person registering you at the hospital or the Admissions Department so that your decision can be entered into the hospital's computer system. The Admissions Department will also need to be notified if you desire to change your decision during your hospital stay.

- **Individuals Involved in Your Care or Payment for Your Care**

We may release medical information about you to a friend, relative, or family member or any other person identified by you as being involved in your medical care. We may also give information to someone who helps pay for your care. We may also tell your family or friends your condition and that you are in the hospital if they ask for you by name. We also may use or disclose medical information about you to notify, or assist in notifying, those persons of your location, general condition, or death. If there is a family member, other relative, or close personal friend that you do not want us to disclose medical information about you to, please tell our staff member who is providing care to you. If you are at University of Colorado Hospital you may tell the House Manager or the Director of the nursing unit you are on.

- **Disaster Relief**

We may use or disclose medical information about you to a public or private entity authorized by law or by its charter to assist in disaster relief efforts. This will be done to coordinate with those entities in notifying family members, other relatives, close personal friends, or other people identified by you of your location, general condition or death.

- **Required by Law**

We may use or disclose medical information about you when we are required to do so by federal, state or local law.

- **Public Health Activities**

We may disclose medical information about you for public health activities and purposes. This includes reporting medical information to a public health authority that is authorized by law to collect or receive the information for purposes of preventing or controlling disease. Or, reporting information to someone that is authorized to receive reports of child abuse and neglect. *For example*, if you have cancer, we may release medical information about you to the State Cancer Registry. If you are injured information may be released to a Trauma Registry. These activities generally include the following:

- To prevent or control disease, injury or disability;
- To report births and deaths;
- To report child abuse or neglect;
- To report reactions to medications or problems with products;
- To notify people of recalls of products they may be using; or,
- To notify a person who may have been exposed to a disease or may be at risk for contracting or spreading a disease or condition.

- **Victims of Abuse, Neglect or Domestic Violence**

We may disclose medical information about you to a government authority authorized by law to receive reports of abuse, neglect, or domestic violence, if we believe you are a victim of abuse, neglect, or domestic violence. This will occur to the extent the disclosure is: (a) required by law; (b) agreed to by you; or, (c) authorized by law and we believe the disclosure is necessary to prevent serious harm to you or to other potential victims, or, if you are incapacitated and certain other conditions are met, a law enforcement officer or other public official if he or she represents that immediate enforcement activity depends on the disclosure.

- **Health Oversight Activities**

We may disclose medical information to a health oversight agency for activities authorized by law. *For example*, the Department of Health may come in and review records to make sure we are providing good care to our patients. These oversight activities include, for example, audits of the care we give, investigations, inspections, licensure or disciplinary actions. These activities are necessary for the government to monitor the health care system, government programs, our compliance with civil rights laws, and to make sure we are complying with various government regulations.

- **Judicial and Administrative Proceedings, Lawsuits and Disputes**

We may disclose medical information about you in the course of any judicial or administrative proceeding in response to an order of the court or administrative tribunal. If you are involved in a lawsuit or a dispute, we may disclose medical information about you in response to a court or administrative order. We also may disclose medical information about you in response to a subpoena, discovery request, or other legal process but only if efforts have been made to tell you about the request or to obtain an order protecting the information from being disclosed.

- **Law Enforcement**

We may release medical information if required to do so by a law enforcement official:

- In response to a court, grand jury or administrative order, a subpoena, a warrant, a summons or similar process;
- To identify or locate a suspect, fugitive, material witness, or missing person;
- About an actual or suspected victim of a crime and that person agrees to the disclosure. If we are unable to obtain that person's agreement, in limited circumstances, the information may still be disclosed;
- About a death we believe may be the result of criminal conduct;
- About criminal conduct at any of our facilities;
- In emergency circumstances to report a crime; the location of the crime or victims; or the identity, description or location of the person who committed the crime; or,
- As required by law.

- **Coroners and Medical Examiners**

We may release medical information to a coroner or medical examiner. This may be necessary, for example, to identify a deceased person or to determine the cause of death.

- **Funeral Directors**

We may disclose medical information about you to funeral directors as necessary for them to carry out their duties.

- **Organ, Eye or Tissue Donation**

If you are an organ donor, we may release medical information to organizations that handle organ procurement or organ, eye or tissue transplantation or to an organ donation bank, as necessary to promote organ or tissue donation and transplantation.

- **Research**

Usually we will get your written permission prior to using or disclosing your medical information for research. Under certain circumstances, we may use or disclose medical information about you for research purposes without your written permission. *For example*, a research project may involve comparing the health and recovery of all patients who received one medication to those who received another, for the same condition. All research projects, however, are subject to a special approval process. This process evaluates the needs of the proposed research project with your needs for privacy of your medical information. We may also disclose medical information about you to a person who is preparing

to conduct research to permit them to prepare for the project, for example to look for patients with specific medical conditions or needs, as long as the medical information they review does not leave our facilities. We will almost always ask for your specific permission if the researcher will have access to your name, address or other information that reveals who you are, or will be involved in your care at the hospital.

- **To Avert A Serious Threat to Health or Safety**

We may use or disclose medical information about you if we believe the use or disclosure is necessary to prevent or lessen a serious or imminent threat to the health or safety of a person or the public. Any disclosure would only be to someone able to help prevent the threat. We also may release information about you if we believe the disclosure is necessary for law enforcement authorities to identify or apprehend an individual who admitted participation in a violent crime or who is an escapee from a correctional institution or from lawful custody.

- **Military and Veterans**

If you are a member of the Armed Forces, we may use and disclose medical information about you for activities deemed necessary by the appropriate military command authorities to assure the proper execution of the military mission. We may also release information about foreign military personnel to the appropriate foreign military authority for the same purposes.

- **National Security and Intelligence**

We may disclose medical information about you to authorized federal officials for the conduct of intelligence, counter-intelligence, and other national security activities authorized by law.

- **Protective Services for the President**

We may disclose medical information about you to authorized federal officials so they may provide protection to the President, other authorized persons or foreign heads of state or conduct special investigations.

- **Inmates and Persons in Custody**

If you are an inmate of a correctional institution or under the custody of a law enforcement official, we may release medical information about you to the correctional institution or law enforcement official having custody of you. This release will be made if it is necessary (1) for the institution to provide you with health care; (2) to protect your health and safety or the health and safety of others; or (3) for the safety and security of the correctional institution.

- **Workers Compensation**

We may disclose medical information about you to the extent necessary to comply with workers' compensation and similar laws that provide benefits for work-related injuries or illness without regard to fault.

- **Food and Drug Administration (FDA)**

We may disclose to the FDA health information relative to adverse events with respect to food, supplements, product and product defects, or post marketing surveillance information to enable product recalls, repairs or replacement.

- **Other Uses and Disclosures**

Other uses and disclosures of medical information not covered by this notice or the laws that apply to us will be made only with your written permission. If you provide us permission to use or disclose medical information about you, you may revoke that permission, in writing, at any time. If you revoke your permission, we will no longer use or disclose medical information about you for the reasons covered by

your written authorization. You understand that we are unable to take back any disclosures we have already made with your permission, and that we are required to retain our records of the care we provided to you.

### **Your Rights With Respect to Medical Information About You**

You have the following rights with respect to medical information that we maintain about you.

- **Right to Request Restrictions**

You have the right to request a restriction or limitation on the medical information we use or disclose about you for treatment, payment or health care operations. You also have the right to request that we restrict the uses or disclosures we make to: (a) a family member, other relative, a close personal friend or any other person identified by you; or, (b) to public or private entities for disaster relief efforts. You also have the right to request a limit on the medical information we disclose about you to someone who is involved in your care or the payment for your care, like a family member or friend. For example, you could ask that we not disclose information about a visit or surgery that you had or ask that we not disclose medical information about you to your brother or sister.

*We are not required to agree to your request.* If we do agree, we will comply with your request unless the information is needed to provide you emergency treatment. Even if we agree to a restriction, either you or we can later terminate the restriction.

To request restrictions, you must make your request in writing to the Privacy Officer at 4200 East Ninth Avenue, A025, Denver, CO 80262, or, if at the hospital, the Director of the department or unit you are receiving services from. In your request, you must tell us (1) what information you want to limit; (2) whether you want to limit our use, disclosure or both; and (3) to whom you want the limits to apply, for example, disclosures to your spouse. A form is available for your use when requesting these restrictions. The person receiving the request will forward it to the appropriate personnel, who will notify you in writing of the outcome of your request. If you are making the request at University of Colorado Health Sciences Center, if your restriction is granted it will only be good for the unit where you made the request.

- **Right to Receive Confidential Communications**

You have the right to request that we communicate medical information about you to you in a certain way or at a certain location. For example, you can ask that we only contact you by mail or at work. We will not require you to tell us why you are asking for the confidential communication.

If you want to request confidential communication, you must do so in writing to the person treating you, the Director of the Department, Clinic or Unit where you are receiving care or to the Privacy Officer. Your request must state how or where you can be contacted. You will be notified if your request can be granted. We will attempt to accommodate all reasonable requests. However, we may, when appropriate, require information from you concerning how payment will be handled. If you are making the request at University of Colorado Health Sciences Center, if your restriction is granted it will only be good for the unit where you made the request.

- **Right to Inspect and Copy**

You have the right to inspect and copy medical information that may be used to make decisions about your care. Usually, this includes medical and billing records, but does not include psychotherapy notes.

To inspect or copy medical information about you at University of Colorado Hospital, you must submit your request in writing to the Director, Health Information Management, 4200 East Ninth Avenue, A025, Denver, CO 80262. For University of Colorado Health Sciences Center and University Physicians,

Incorporated clinics you should contact the Director of the clinic. Your request should state specifically what medical information you want to inspect or copy. If you request a copy of the information, we may charge a fee for the costs of copying and, if you ask that it be mailed to you, the cost of mailing.

We will act on your request within thirty (30) calendar days after we receive your request. If we grant your request, in whole or in part, we will inform you of our acceptance of your request and provide access and copying.

We may deny your request to inspect and copy medical information if the medical information involved is:

- a. Psychotherapy notes;
- b. Information compiled in anticipation of, or use in, a civil, criminal or administrative action or proceeding;
- c. Restricted by the Clinical Laboratory Improvements Amendments of 1988 (CLIA); or
- d. Information that is not part of the record set we use to make decisions about your care and treatment.

If we deny your request, we will inform you of the basis for the denial, how you may have our denial reviewed, and how you may complain. If you request a review of our denial, it will be conducted by a licensed health care professional designated by us who was not directly involved in the denial. We will comply with the outcome of that review.

- **Right to Request Amendments**

You have the right to ask us to amend medical information about you if you feel the information we have about you is incorrect or incomplete. You have this right for so long as the medical information is maintained by us.

To request an amendment of a record held by University of Colorado Hospital, you must submit your request in writing to Director, Health Information Management, 4200 East Ninth Avenue, A025, Denver, CO 80262. For University of Colorado Health Sciences Center and University Physicians, Incorporated clinics you should contact the Director of the clinic. Your request must state the amendment desired and provide a reason in support of that amendment. A form is available for making this request.

We will act on your request within sixty (60) calendar days after we receive your request. If we grant your request, in whole or in part, we will inform you of our acceptance of your request.

If we grant the request, in whole or in part, we will seek your identification of and agreement to share the amendment with relevant other persons. We also will make the appropriate amendment to the medical information by appending or otherwise providing a link to the amendment.

We may deny your request for an amendment if it is not in writing or does not include a reason to support the request. In addition, we may deny your request if you ask us to amend information that:

- Was not created by us, unless the person or entity that created the information is no longer available to make the amendment;
- Is not part of the medical information kept by us;
- Is not part of the information which you would be permitted to inspect and copy; or,
- Is felt to be accurate and complete as originally documented by the person who recorded the information.

If we deny your request, we will inform you of the basis for the denial. You will have the right to submit a statement disagreeing with our denial. We may prepare a rebuttal to that statement. Your request for amendment, our denial of the request, your statement of disagreement, if any, and our rebuttal, if any, will

then be appended to the medical information involved or otherwise linked to it. All of that will then be included with any subsequent disclosure of the information, or, at our election, we may include a summary of any of that information.

If you do not submit a statement of disagreement, you may ask that we include your request for amendment and our denial with any future disclosures of the information. We will include your request for amendment and our denial (or a summary of that information) with any subsequent disclosure of the medical information involved.

You also will have the right to complain about our denial of your request.

- **Right to an Accounting of Disclosures**

You have the right to receive an accounting of disclosures of medical information about you. The accounting may be for up to six (6) years prior to the date on which you request the accounting but will not include any disclosures made before April 14, 2003.

Certain types of disclosures will not be included in the accounting:

- Disclosures to carry out treatment, payment and health care operations;
- Disclosures of your medical information made to you;
- Disclosures for our facility directory;
- Disclosures for national security or intelligence purposes;
- Disclosures to correctional institutions or law enforcement officials;
- Disclosures that you have authorized, in writing; and
- Disclosures made prior to April 14, 2003.

Under certain circumstances your right to an accounting of disclosures may be suspended for disclosures to a health oversight agency or law enforcement official.

To request an accounting of disclosures made by University of Colorado Hospital, you must submit your request in writing to Director, Health Information Management, 4200 East Ninth Avenue, A025, Denver, CO 80262. For University of Colorado Health Sciences Center and University Physicians, Incorporated contact the Privacy Officer at those organizations. Your request must state a time period for the disclosures. It may not be longer than six (6) years from the date we receive your request and may not include dates before April 14, 2003.

Usually, we will act on your request within sixty (60) calendar days after we receive your request. Within that time, we will either provide the accounting of disclosures to you or give you a written statement of when we will provide the accounting and why the delay is necessary.

There is no charge for the first accounting we provide to you in any twelve (12) month period. For additional accountings, we may charge you for the cost of providing the list. If there will be a charge, we will notify you of the cost involved and give you an opportunity to withdraw or modify your request to avoid or reduce the fee.

- **Right to Copy of this Notice**

You have the right to obtain a paper copy of our Notice of Privacy Practices. You may request a copy of our Notice of Privacy Practices at any time. If you ask us to, we will also send you a copy of this notice electronically.

You may obtain a copy of our Notice of Privacy Practices over the Internet at our web site, [www.uch.edu](http://www.uch.edu) or [www.uchsc.edu](http://www.uchsc.edu) or [upi.uchsc.edu](http://upi.uchsc.edu).

To obtain a paper copy of this notice, contact Privacy Officer, 4200 East Ninth Avenue, A025, Denver, CO 80262. Paper copies are also available in all areas where care is provided.

### **Our Right to Change Notice of Privacy Practices**

We reserve the right to change this notice. We reserve the right to make the revised or changed notice effective for medical information we already have about you as well as any information we receive in the future. We will post a copy of the current notice at University of Colorado Hospital, University of Colorado Health Sciences Center and University Physicians, Incorporated facilities. The notice will contain the effective date on the first page. In addition, each time you register at or are admitted to or treated at one of our facilities you may request an updated copy of the current notice in effect. We will also post a current notice on each of our websites.

### **Complaints**

You may complain to us and to the United States Secretary of Health and Human Services if you believe we have violated your privacy rights. These complaints must be in writing and must be filed within 180 days of when you learn of or should have known about the violation. To complain to the Secretary of the Department of Health and Human Services contact: Region VIII, Office for Civil Rights, U.S. Department of Health and Human Services, 1961 Stout Street – Room 1185 FOB, Denver, CO 80294-3538. Fax: (303) 844-2025.

To file a complaint with us, contact Privacy Officer, 4200 East Ninth Avenue, Denver, CO 80262. All complaints should be submitted in writing. To help us investigate your complaint, please include how to contact you.

You will not be retaliated against or penalized for filing a complaint. We will not take any action against you or change our treatment of you in any way.

### **Questions and Information**

If you have any questions or want more information concerning this Notice of Privacy Practices for University of Colorado Hospital, please contact Privacy Officer, 4200 East Ninth Avenue, Denver, CO 80262 or by phone at (303) 372-0499.

For UCHCS contact Privacy Officer, 4200 East Ninth Avenue, Campus Box A095, Denver, CO 80262, or by phone at (303) 724-4722.

For University Physicians, Incorporated contact Privacy Officer, 5350 Leetsdale Drive, Denver, CO 80246, or by phone at (303) 372-2330.

# **National Hemophilia Foundation**

## **Consumer Bill of Rights and Responsibilities for Healthcare Services**

**Approved by NHF Board of Directors  
July 6, 1994**

Good healthcare involves teamwork between the health-care provider and the consumer: This two-part bill should serve as a set of goals for both the provider and consumer in seeking, providing and receiving high quality health care within a setting of honesty and respect. This bill takes into account the importance of both consumer rights and responsibilities.

**ACKNOWLEDGEMENTS:** The National Hemophilia Foundation would like to express its gratitude to the NHF Consumer Bill of Rights Working Group, Co-Chairs Renee Paper, RN, and Chris MacDonald, and the members of their committee; Vickie Strange, Andre Jackson, Emily Czapek, MD, Sharon Barrett, MS, Heather Huszti, PhD and Rich Davis for their work on this project.

**NATIONAL HEMOPHILIA FOUNDATION MISSION/PURPOSE:** The National Hemophilia Foundation is dedicated to the treatment and care of hemophilia, related bleeding disorders and complications of those disorders or their treatments, including HIV infection, as well as to improving the quality of life of all those affected through the promotion and support of research, education and other services.

## Part I: Consumer Bill of Rights

- I. **THE RIGHT TO BE TREATED AT ALL TIMES WITH RESPECT AND COURTESY**...within a setting which provides the highest degree of privacy possible.
- II. **THE RIGHT TO FREEDOM FROM DISCRIMINATION**...because of age, ethnicity, gender, disability, religion, sexual orientation, values and beliefs, marital status, medical condition or any other arbitrary criteria.
- III. **THE RIGHT TO FULL ACCESS TO INFORMATION**...from the health-care provider about current FDA-approved or other proven treatments. Also, any biases or conflicts of interest that the health-care provider may have should be disclosed. Consumers must be advised of the risks and benefits of any proposed treatment considered to be of an experimental nature. If needed, the health-care provider should discuss alternative or complementary treatments and should be allowed to make recommendations.
- IV. **THE RIGHT TO KNOW**...the identities, titles, specialties and affiliations of the care coordinator and all healthcare providers. Also, consumers have the right to know about the health care center's and health-care provider's rules and regulations.
- V. **THE RIGHT TO HAVE INFORMATION SHARED IN A WAY WHICH IS EASY TO UNDERSTAND**...taking into account differences in each consumer's background, culture and preferences.
- VI. **THE RIGHT TO BE INVOLVED IN AND MAKE DECISIONS ABOUT THE PLAN OF CARE**...prior to the start of and during the course of treatment. Consumers must have the right to rethink, question and change the treatment care plan at any time. Also, when possible, request for transfer to another facility or health-care provider or for a second opinion should be promptly honored and carried out.
- VII. **THE RIGHT OF CHOICE AND ACCESS TO ALL NEEDED SERVICES**...including, but not confined to, referral for proper care, second opinions, physical therapy, drug trials, brand choices, home care services, counseling and peer support. Also, the consumer should not be denied, pressured, punished or left unaware of services because they are not available or adequate from the consumer's usual health-care provider or center. Third party payers should not be allowed to make treatment decisions on behalf of their consumers. These decisions must rest with the consumer and health-care provider.
- VIII. **THE RIGHT TO DECLINE TO FOLLOW**...treatment plans, trials, counseling or any other service, as allowed by law, based upon the consumer's judgment of risks and benefits and without pressure or unwanted influence from the health-care provider.
- IX. **THE RIGHT TO NAME AN ADVOCATE**...such as a family member or other person to support the consumer.
- X. **THE RIGHT TO HAVE AN ADVANCE DIRECTIVE**...such as a living will, health care proxy or durable power of attorney for health care, and to have that directive followed within the context of existing law. Also, the consumer has a right to know, in a timely manner, any care center or health-care provider rules or preferences which may stop consumer's directives.
- XI. **THE RIGHT TO INSPECT AND RECEIVE AND EXPLANATION OF HEALTH CARE BILLS OR PROPOSED CHARGES**...regardless of payment source, and to receive needed referrals and/or help with reimbursement problems.
- XII. **THE RIGHT TO VOICE COMPLAINTS AND SUGGEST CHANGES**...and to be informed of the process to do that within the center's/health-care provider's chain of command for problems resolution, without interference, pressure, or reprisal. Also, the consumer has a right to receive a response in a timely manner.
- XIII. **THE RIGHT TO CONFIDENTIALITY AND ACCESS TO**...all treatment records and communications to the consumer's case. Information on getting copies of records should be readily available. Copies of requested records must be furnished and at a fair cost, as allowed by law.
- XIV. **THE RIGHT TO BE FREE FROM ALL TYPES OF CONSTRAINTS**...in all dealings with health-care providers and treatment plans.
- XV. **THE RIGHT TO ADEQUATE PAIN MANAGEMENT**...through the application of approved and alternative treatments.

## Part II: Consumer Bill of Responsibilities

- I. **HEALTH CARE PROVIDERS HAVE THE RIGHT TO BE TREATED AT ALL TIMES WITH RESPECT AND COURTESY.**
- II. **THE CONSUMER IS RESPONSIBLE FOR GIVING CORRECT AND COMPLETE INFORMATION TO THE CURRENT HEALTH CARE PROVIDER...**about his or her health status, and the use of other treatments, medications and health-care providers. If on home care (infusion of concentrate, use of other products, etc.) patient should periodically submit a record of product use and bleeding episodes. Consumers should come prepared to appointments with a list of any questions and concerns, so that health-care providers can have the change to address them.
- III. **THE CONSUMER IS RESPONSIBLE FOR SEEKING THE FACTS AND ASKING QUESTIONS ABOUT THE RISKS, BENEFITS, AND FINANCIAL ASPECTS...**of a recommended procedure or course of treatment if he or she does not fully understand.
- IV. **THE CONSUMER IS RESPONSIBLE FOR FOLLOWING THE AGREED UPON TREATMENT PLAN...**If the consumer is not following the agreed upon treatment plan at any time, including when involved in a clinical trial, he or she need to inform the health-care provider of this.
- V. **THE CONSUMER IS RESPONSIBLE FOR THE RESULTS IF HE OR SHE CHOOSES TO ACT AGAINST MEDICAL ADVICE...**or does not follow instructions of an agreed upon treatment plan. The consumer should feel free to discuss his or her reasons for this choice.
- VI. **THE CONSUMER IS RESPONSIBLE FOR KEEPING SCHEDULED APPOINTMENTS...**or canceling them in a reasonable time frame.
- VII. **THE CONSUMER IS RESPONSIBLE FOR MAKING SURE THAT THE FINANCIAL BURDENS OF HIS OR HER CARE ARE ADEQUATELY ADDRESSED...**by giving correct information about payer sources, promptly submitting reimbursement forms or asking for help prior to receiving health care services.
- VIII. **THE CONSUMER IS RESPONSIBLE FOR FOLLOWING RULES AND REGULATIONS...**of the health-care providers and centers involved in their care.
- IX. **THE CONSUMER IS RESPONSIBLE FOR BEING THOUGHTFUL OF THE RIGHTS, PROPERTY AND CONFIDENTIALITY OF OTHERS.**
- X. **THE CONSUMER IS RESPONSIBLE FOR VOICING COMPLAINTS AND ASKING FOR CHANGE...**in an appropriate and timely way, though the health-care provider's/facility's chain of command.

## **CHOICES AVAILABLE TO PATIENTS AND FAMILIES WITH HEMOPHILIA IN THE MOUNTAIN STATES (REGION VIII)**

The following patient choice policy has been adopted for patients and families served by the Hemophilia Treatment Centers in the Mountain States Region (Region VIII). These include Centers at the University of Colorado at Denver and Health Sciences Center, the University of Arizona Health Sciences Center, Phoenix Children's Hospital, the University of New Mexico Health Sciences Center, the University of Utah Health Sciences Center and Primary Children's Hospital.

### **CLOTTING FACTOR**

As a patient and/or family that receive care at one of the Hemophilia Treatment Centers (HTCs) in Region VIII, you have the right to choose the clotting factor that you feel is safe, effective and affordable. In some cases, your choice of clotting factor concentrates may be limited by your medical insurance or other payer. Hemophilia Treatment Center (HTC) staff is committed to advocate for you when there are unreasonable limits on choice or when HTC staff feel a specific clotting factor is medically indicated. The National Hemophilia Foundation's Medical and Scientific Advisory Council has stated that there is no "best" product that fits the needs of every patient.

HTC staff is also committed to ongoing education of the persons with hemophilia about existing clotting factor products, the introduction of new treatment products, and current and upcoming shortages and discontinuation of products. This information is updated during hemophilia comprehensive clinic visits, by mailings to your home, telephone calls or home visits, or during camps and hemophilia chapter meetings. Together with your physician, you may then make an educated and informed decision regarding the products you wish to use.

**When evaluating an infusion product, we suggest considering the following issues:**

<b>ISSUE</b>	<b>QUESTIONS</b>	<b>QUESTIONS</b>
<b>Method of manufacture</b>	Recombinant technology or plasma derived?	
<b>Purity</b>	Does it contain other proteins	Is animal protein used in manufacturing process?
<b>Viral inactivation methods</b>	Solvent detergent?	Heat Treatment?
<b>Efficacy</b>	Does it work for controlling bleeding	Do recovery studies show predicted factor levels?
<b>Data available from well-conducted studies with this product</b>	Any adverse effects from the product?	Are there special requirements for use and storage?
<b>Cost</b>	Are the benefits of using a newer or more expensive product worth the extra cost?	Are there any proven benefits for using a more costly product?)
<b>Volume of treatment product</b>	How much volume is the product for infusion?	

The HTC staff is always available for consultation regarding product use and choice.

### **HOME CARE**

You and your family are encouraged to select a home delivery company with whom you are comfortable, although this choice may be limited by your third party payment sources. Center staff can provide a list of available home delivery companies and you are strongly urged to compare prices and services. As you know, clotting factor is very expensive and there may be a considerable "mark-up" of prices by different home care companies. This makes the sale of factor very profitable for home care companies and their stockholders. We encourage you to become a knowledgeable consumer of these expensive medications, to know the cost of your clotting factor and to remain aware of your lifetime insurance limits. It is in all of our best interests to keep the cost of clotting factor as low as possible by negotiating prices and services with insurance and home care companies or choosing companies that offer both good service and pricing. Your Hemophilia Treatment Center can be a helpful resource for information regarding home care.

Revised 12/13/04

**You and your family should consider some of the following criteria when selecting a home delivery service or discussing the choice of home delivery service with your insurance company, case manager or Medicaid or Medicare plan. The chosen company should**

- 1. Have 24-hour availability of products and services and emergency access to product.**
- 2. Demonstrate appropriate and adequate knowledge of hemophilia in order to provide optimal services.**
- 3. Provide a full range of services to meet your individual needs including pharmacy, delivery service (including rural delivery) and financial counseling.**
- 4. Provide communication with the HTC about any critical or emergency needs you might have, about any problems with inventory and any changes in your health or insurance status.**
- 5. Keep complete records of your prescriptions, billing and communications.**
- 6. Keep adequate inventory for your short and long-term clotting factor needs.**
- 7. Be fully accredited by the appropriate state and/or federal agencies.**
- 8. Demonstrate willingness to resolve problems brought to their attention.**
- 9. Make you and your family aware of company policy regarding discontinuation of services related to loss of your insurance coverage or your inability to pay for services.**
- 10. Provide you with expected costs of medications and services.**
- 11. Promptly report changes in costs to you.**
- 12. Provide accurate data to both you and the HTC regarding shipment and use of products, supplies and adjunctive therapies.**

### **COMPREHENSIVE CARE**

As a patient/family with a bleeding disorder receiving services from the HTCs in Region VIII, you have the right to receive comprehensive hemophilia care. If requested, you may be given choices regarding different components of comprehensive services and at times you may elect to forego certain components or see additional providers outside of the HTC. Every possible consideration is given to scheduling the visit at a time most convenient to you and your family. Assistance in arrangements for transportation and accommodations for families traveling long distances to the HTC is provided as necessary. The HTC is committed to advocating for insurance authorization for comprehensive clinic visits if your payer denies them.

### **PROVIDERS**

You have the right to choose a primary and secondary provider as dictated by convenience, culture, insurance and practicality. Each HTC provides comprehensive care to patients who have primary physicians in the community as well as those who receive primary care in our institutions. HTC staff is willing to work with and consult with any health care provider involved in your care. However, consultation is an adjunct to and not a substitute for comprehensive care. Communication with your primary care provider regarding comprehensive hemophilia care and HTC recommendations is of the utmost importance to facilitate coordinated and optimal hemophilia management.

### **CONSENT**

As a patient or family receiving care in an HTC in Region VIII, I acknowledge that HTC staff has discussed options and choices available to me or my family concerning clotting factor and hemophilia treatment products, home care vendors, comprehensive hemophilia care and primary and secondary health care providers. My signature acknowledges that my choices are made freely. I understand that I may contact HTC staff at any time to discuss any issues related to these choices and that I can expect HTC staff to advocate for my best interests.

**Patient** \_\_\_\_\_

**Signature of patient, parent, or legal guardian** \_\_\_\_\_

**MSRHC staff member** \_\_\_\_\_

**Date** \_\_\_\_\_

## **GRIEVANCE PROCEDURE AVAILABLE TO PERSONS WITH HEMOPHILIA IN THE MOUNTAIN STATES (REGION VIII)**

The Hemophilia Treatment Centers in Region VIII have adopted the following patient grievance procedure with regard to Hemophilia Treatment Center (HTC) staff. Each institution (University of Colorado Health Sciences Center; University of Arizona Health Sciences Center; University of New Mexico; Primary Children's Hospital & the University of Utah Medical Center; Phoenix Children's Hospital) has formal institutional grievance policies and procedures in effect. For grievances within the institution, the agency grievance procedure should be followed. If that procedure does not address the issue, the following steps should be considered:

1. With any grievance against an individual member of the HTC staff, the patient is encouraged to attempt to discuss the issue with the staff member involved. The HTC social worker that has been providing psychosocial services to the patient will support the patient in this endeavor if requested by the patient or family. If the grievance is against the social worker, step 2 should be taken.
2. If grievance is unresolved by using Step 1, the grievance may then be addressed to the HTC Medical Director for resolution. The Medical Director will be available for a scheduled meeting with the patient/family to discuss the problem and possible solutions. He/she will then intervene on the patient's behalf if so requested.
3. Grievances unresolved at the HTC level may then be referred to either the Regional Coordinator or the Regional Director for mediation. Either one of these individuals will be available to the patient/family to discuss the problem in person or via telephone and discuss possible solutions with the patient and the HTC staff. The Regional Director may render a decision as the final individual in the appeals process.

The Hemophilia Treatment Centers in Region VIII are committed to resolve patient grievances in a manner that is non-discriminatory. Culturally sensitive and language appropriate mediation will be offered regardless of the patient's race, sex, national origin, immigration status, functional ability, beliefs, values, educational or financial status. An interpreter will be provided where language is a barrier to successful resolution of the problem.