PATIENT'S RIGHTS AND RESPONSIBILITIES

Patients shall have the following **RIGHTS** to:

- **Information Disclosure.** You have the right to receive accurate and easily understood information about your health plan, healthcare professionals and healthcare facilities. If you speak another language, have a physical or mental disability, or just don’t understand something, assistance will be provided so you can make informed healthcare decisions.

- **Choice of Providers and Plans.** You have the right to a choice of healthcare providers that is sufficient to provide you with access to appropriate high-quality healthcare.

- **Access to Emergency Services.** If you have severe pain, an injury, or sudden illness that convinces you that your health is in serious jeopardy, you have the right to receive screening and stabilization emergency services whenever and wherever needed, without prior authorization or financial penalty.

- **Participation in Treatment Decisions.** You have the right to know all your treatment options and to participate in decisions about your care. Parents, guardians, family members, or other individuals that you designate can represent you if you cannot make your own decisions.

- **Respect and Non-Discrimination.** You have the right to considerate, respectful and nondiscriminatory care from your doctors, health plan representatives, and other healthcare providers.

- **Confidentiality of Health Information.** You have the right to talk in confidence with healthcare providers and to have your healthcare information protected. You also have the right to review and copy your own medical record and request that your physician amend your record if it is not accurate, relevant, or complete.

- **Complaints and Appeals.** You have the right to a fair, fast and objective review of any complaint you have against your health plan, doctors, hospitals or other healthcare personnel. This includes complaints about waiting times, operating hours, the conduct of healthcare personnel, and the adequacy of facilities. Please see Complaints/Grievances Policy.

- **Request or refuse treatment, to the extent permitted by law.** However, you do not have the right to demand inappropriate or medically unnecessary treatment or services.

**Rights under Insurers:**

- Receive cost-free preventative services. If your plan is subject to these new requirements, you would not have to pay a copay or any deductible to receive preventive health services, such as recommended screenings, vaccinations or counseling.

- Keep your dependent children on your health insurance plan until age 26. Previously, health plans could remove enrolled children, usually at age 19, and sometimes older for full-time students.

- Choose a primary doctor, OB/GYN and pediatrician. You can choose your physician from your health plan’s provider network without needing approval from another doctor.

- Seek emergency care outside your plan’s network without prior approval from your health plan.

Patients shall be **RESPONSIBLE** for:

1. You are expected to provide complete and accurate information, including your full name, address, home telephone number, date of birth, Social Security number, insurance carrier and employer, when it is required.

2. You should provide your doctor with a copy of your advance directive if you have one.

3. You are expected to provide complete and accurate information about your health and medical history, including present condition, past illnesses, hospital stays, medicines, vitamins, herbal products, and any other matters that pertain to your health, including perceived safety risks.

4. You are expected to ask questions when you do not understand information or instructions. If you believe you can’t follow through with your treatment plan, you are responsible for telling your doctor.

5. You are responsible for outcomes if you do not follow the care, treatment and services plan.

6. You are expected to actively participate in your pain management plan and to keep your doctors and nurses informed of the effectiveness of your treatment.

7. Please leave valuables at home and only bring necessary items for your clinic visits.

8. You are expected to treat all CIBD staff, other patients and visitors with courtesy and respect; abide by all CIBD rules and safety regulations; and be mindful of noise levels, privacy of others.

9. You are expected to provide complete and accurate information about your health insurance coverage and to pay your bills in a timely manner.

10. You have the responsibility to keep appointments, be on time, and call CIBD if you cannot keep your appointments.
NOTICE OF PRIVACY PRACTICES

THIS NOTICE DESCRIBES HOW HEALTH INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY

THE PRIVACY OF YOUR HEALTH INFORMATION IS IMPORTANT TO US

This notice will tell 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 for which there is a reasonable basis to believe the information can be used to identify you. In this notice, we call all of that protected health information, “medical information.” This notice also will tell 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.

USES AND DISCLOSURES OF HEALTH INFORMATION

We use and disclose health information about you for treatment, payment, and healthcare operations:

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 and other health facilities who 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, we may conclude you need to receive services from a physician with a particular specialty. When we refer you to that physician, we also will contact that physician’s office and provide medical information about you to them so they have information they need to provide services for you.

For Payment:
We may use and disclose medical information about you so we can be paid for the services we provide to you. This may include billing you, your insurance company, or a third party payor. For example, we may need to give your insurance company information about the health care services we provide to you 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 obtain determination if you are covered by that insurance or program.

For Health Care Operations:
We may use and disclose medical information about you for our own health care operations. This is necessary for us to operate The Center for Comprehensive Care & Diagnosis of Inherited Blood Disorders (CIBD) and to maintain quality health care for our patients. For example, we may use medical information about you to review the services we provide and the performance of our employees in caring for you. We may disclose medical information about you to train our staff, volunteers and students working at CIBD. We also may use the information to study ways to more efficiently manage our organization.

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 workplace. At either location, we may leave messages for you on the answering machine or voice mail. If you want to request that we communicate with you in a certain way or at a certain location, please send your request in writing to the privacy officer listed at the end of this form.

Appointment Reminders:
We may use and disclose medical information about you to contact you to remind you of an appointment you have with us (examples: voice mail messages, postcards, and letters).

Treatment Alternatives:
We may use and disclose medical information about you to contact you about treatment alternatives that may be of interest to you.

Marketing Communications:
We may use and disclose medical information about you to communicate with you about a product or service to encourage you to purchase the product or service. This may be to describe a health-related product or service that is provided by us; for your treatment; for case management or care coordination for you; to direct or recommend alternative treatments, therapies, health care providers, or settings of care. We may communicate to you about products and services in a face-to-face communication by us with you. We also may communicate about products or services in the form of a promotional gift of nominal value.

All other use and disclosure of medical information about you by us to make a communication about a product or service to encourage the purchase or use of a product or service will be done only with your written authorization.

Fundraising:
We may use and disclose medical information about you to contact you to raise funds for CIBD. We may disclose medical information to a business associate of CIBD so that business associate may contact you to raise money for the benefit of CIBD. We will only release
demographic information, such as your name and address, and the dates you received treatment or services from CIBD.

**CIBD Directory:**
We may include your name, your address, your condition described in general terms in our directory while you are a patient of the CIBD. This information may be released to people who ask for you by name.

**Individuals Involved in Your Care:**
We may disclose to a family member, other relative, a close personal friend, or any other person identified by you, medical information about you that is directly relevant to that person’s involvement with your care or payment related to your care. 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.

**Disaster Relief, As Required by Law, Public Health Activities:**
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 a family member, other relative, close personal friend, or other person identified by you of your location, general condition or death. We may use or disclose medical information about you when we are required to do so by law. 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. It also includes reporting for purposes of activities related to the quality, safety or effectiveness of a United States Food and Drug Administration regulated product or activity.

**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 you.

**Health Oversight Activities:**
We may disclose medical information about you to a health oversight agency for activities authorized by law, including audits, investigations, inspections, licensure or disciplinary actions. This may include disclosure of protected health information for Workman’s Compensation Benefits.

**Judicial and Administrative Proceedings:**
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. 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 to be disclosed.

**Disclosures for Law Enforcement Purposes:**
We may disclose medical information about you to a law enforcement official for law enforcement purposes as required by law. This could be in response to the court, grand jury or administrative order, warrant or subpoena.

**Research:**
Under certain circumstances, we may use or disclose medical information about you for research. Before we disclose medical information for research, the research will have been approved through an approval process that evaluates the needs of the research project with your needs for privacy of your medical information. We may, however, disclose medical information about you to a person who is preparing to conduct research to permit them to prepare for the project, but no medical information will leave CIBD during that person’s review of the information.

**National Security:**
We may disclose to military authorities the health information of Armed Forces personnel under certain circumstances. We may disclose to authorize federal health officials health information required for lawful intelligence, counter-intelligence, and other national security activities. We may disclose to correctional institutions or law enforcement officials having lawful custody protected health information of an inmate or patient under certain circumstances.

**Other Uses and Disclosures:**
Other uses and disclosures will be made only with your written authorization. You may revoke such an authorization at any time by notifying Privacy Officer, 2670 N. Main St. Suite 100, Santa Ana, CA 92705 in writing of your desire to revoke it. However, if you revoke such an authorization, it will not have any effect on actions taken by us in reliance on it.
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 that we restrict the uses or disclosures of medical information about you to carry out 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) public or private entities for disaster relief efforts. To request a restriction, you may do so at any time. If you request a restriction, you should do so in writing to the Privacy Officer, 2670 N. Main St., Suite 100, Santa Ana, CA 92705 and tell us: (a) what information you want to limit; (b) whether you want to limit use or disclosure or both; and, (c) to whom you want the limits to apply (for example, disclosures to your spouse).

We are not required to agree to any requested restriction. However, if we do agree, we will follow that restriction unless the information is needed to provide emergency treatment. Even if we agree to a restriction, either you or we can later terminate the restriction.

**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. If you want to request confidential communication, you must do so in writing to the Privacy Officer, 2670 N. Main St. Suite 100, Santa Ana, CA 92705. Your request must state how or where you can be contacted. We will accommodate your request. However, we may, when appropriate, require information from you concerning how payment will be handled. We also may require an alternate address or other method to contact you.

**Right to Inspect and Copy:**
With a few very limited exceptions, such as psychotherapy notes, you have the right to inspect and obtain a copy of medical information about you. To inspect or copy medical information about you, you must submit your request in writing to the Privacy Officer, 2670 N. Main St. Suite 100, Santa Ana, CA 92705. 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 copies. We may deny your request to inspect and copy medical information under certain circumstances. 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 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 Amend:**
You have the right to request that we amend medical information about you. You have this right for as long as the medical information is maintained by us. To request an amendment, you must submit your request in writing to the Privacy Officer, 2670 N. Main St. Suite 100, Santa Ana, CA 92705. Your request must state the amendment desired and provide a reason in support of that amendment. 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 and provide access and copying. If we grant the request, in whole or in part, we will seek your identification 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 to amend medical information about you. We may deny your request if it is not in writing and does not provide a reason in support of the amendment or if we deem the medical information is accurate and complete. You will have the right to submit a statement of disagreement with our denial. 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 not before April 14, 2003.

Certain types of disclosures are not included in such an accounting, such as: disclosures to carry out treatment, payment and health care operations; disclosures of your medical information made to you; disclosures that are incident to another use or disclosure; disclosures that you have authorized; disclosures for our facility directory or to persons involved in your care; disclosures for disaster relief purposes; disclosures for national security or intelligence purposes; disclosures to correctional institutions or law enforcement officials having custody of you; disclosures that are part of a limited data set for purposes of research, public health, or health care operations (a limited data set means that things that would directly identify you have been removed); disclosures made prior to April 14, 2003.

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 obtain a paper copy even though you agreed to receive the notice electronically. You may request a copy of our Notice of Privacy Practices at any time. You may obtain a copy of our Notice of Privacy Practices over the Internet at our web site, www.c3dibd.org.

Our Right to Change Notice of Privacy Practices:
We reserve the right to change this Notice of Privacy Practices. We reserve the right to make the new notice’s provisions effective for all medical information that we maintain, including that created or received by us prior to the effective date of the new notice.

Availability of Notice of Privacy Practices:
A copy of our current Notice of Privacy Practices will be posted in the waiting room of the CIBD office at 2670 N. Main St. Suite 100, Santa Ana, CA 92705. A copy of the current notice also will be posted on our web site, www.cibd-ca.org.

At any time, you may obtain a copy of the current Notice of Privacy Practices by contacting the Privacy Officer, 2670 N. Main St. Suite 100, Santa Ana, CA 92705.

Complaints:
You may complain to us and to the United States Secretary of Health and Human Services if you believe your privacy rights have been violated by us. To file a complaint with us, contact the Privacy Officer, 2670 N. Main St. Ste 150, Santa Ana, CA 92705. All complaints should be submitted in writing. To file a complaint with the United States Secretary of Health and Human Services, send your complaint to him or her in care of: Office for Civil Rights, U.S. Department of Health and Human Services; 200 Independence Avenue SW, Washington, D.C. 20201. You will not be retaliated against for filing a complaint.