

# **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.

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**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.