



THE BLEEDERS' BILL OF RIGHTS

HFA is a national nonprofit patient organization that assists and advocates for the bleeding disorders community.

THE BLEEDERS' BILL OF RIGHTS

This tool is about self-advocacy and empowerment. It is a document for us, the people of the bleeding disorders community, as we face major barriers to healthcare access. Use it to remind yourself of your rights, your choices, and your power. The Bleeders' Bill of Rights identifies the real needs of the bleeding disorders community, in our own language. In this, we recognize our ability, responsibility, and right to have a voice—and our responsibility as a community to raise our collective voice.

Let us be heard. 💧

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MEDICAL CARE

- ◆ You have the right to routine, excellent, and timely care.
- ◆ You have the right to care that does not discriminate, respecting your individual culture, background, preferences, and diversity.
- ◆ You have the right to holistic care for both body and mind/spirit.
- ◆ You have the right to safe therapies and access to a viable patient notification system for product recalls, including immediate notification of a recall or withdrawal of a bleeding disorders product or its ancillary supplies.
- ◆ You have the right to qualified medical professionals.
- ◆ You have the right to be included in decision making regarding your plan of care.
- ◆ You have the right to have your medical information kept private.

INFORMATION

- ◆ You have the right to having all information about your bleeding disorder, treatment, and care explained by a medical professional in an easy-to-understand manner.
- ◆ You have the right to have medical information about your bleeding disorder presented in the language with which you feel most comfortable, including the right to an interpreter.
- ◆ You have the right to real-time information regarding your insurance coverage, including changes in policy or coverage.
- ◆ You have the right to request and receive complete information about your therapy and care options.

SUPPORT AND ADVOCACY

- ◆ You have the right to connect with your local and national communities of individuals and families with bleeding disorders.
- ◆ You have the right to care that is specific to your bleeding disorder.
- ◆ You have the right and the responsibility to question your care.
- ◆ You have the right to request and receive access to a valid, documented complaint system, including proper follow-up, should any of these rights be breached.
- ◆ You have the right and responsibility to be an advocate for yourself and/or your family.