



NATIONAL  
BLEEDING DISORDERS  
FOUNDATION

Innovate | Educate | Advocate

HOW TO BE A SAVVY  
COMMUNITY  
MEMBER

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SPEAKER HEADSHOT PLACEHOLDER

NAME

AFFILIATION

Title


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NBDF DISCLAIMER

The information contained in this presentation is provided for your general information only. NBDF does not give medical advice or engage in the practice of medicine. NBDF under no circumstances recommends particular treatment for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

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Agenda

- Being a savvy consumer where you get your healthcare services and treatment (Hemophilia Treatment Centers (HTCs), Specialty Pharmacy, etc.)
- Wants, Needs, Expectations
- Choosing a Treatment Product Provider
- Understanding the “Rules” of engagement with manufactures and specialty pharmacy
- Final Thoughts

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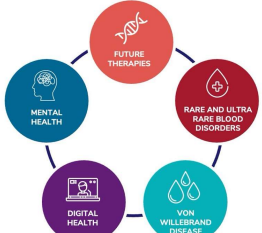
ABOUT NBDF

OUR MISSION

The National Bleeding Disorders Foundation (NBDF) is dedicated to finding cures for inheritable blood and bleeding disorders and to addressing and preventing the complications of these disorders through research, education, and advocacy, enabling people and families to thrive.

NUESTRA MISIÓN

La Fundación Nacional de Trastornos de la Sangre (NBDF, por sus siglas en Inglés) trabaja para encontrar la cura de los trastornos de la sangre y hemorragias hereditarios, así como para tratar y prevenir las complicaciones de estos trastornos a través de la investigación, educación y apoyo, permitiendo que las personas y las familias prosperen.



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What is a “consumer”? How are “community members” also “consumers”?

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## What is a Savvy Consumer?

- Stays Informed
- Makes Educated Decisions
- Sets Boundaries
- Communicates Needs


The first to help you are the ones who know how it feels to fall down.



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## Do you go to a Hemophilia Treatment Center (HTC) for your care?

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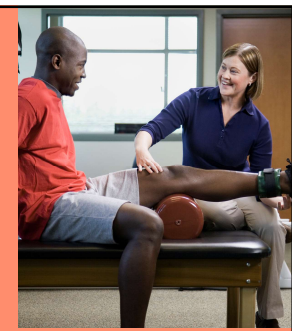
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## What exactly is an HTC?

Specialized health care center that focuses on a **team approach** to patient care for bleeding disorders.

HTC network was **established in 1975**.

Initial grant **funding** for 26 institutions was provided by the **Health Resources and Services Administration (HRSA)**.



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## More About HTCs

Interdisciplinary Teams

Comprehensive



Prevention-focused

Education-focused

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## How much does the likelihood of being hospitalized or dying from bleeding disorder complications decrease when patients were seen at an HTC?

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## 40% reduction



in morbidity and mortality for patients who were seen at an HTC

### Early evaluation of the HTC program indicated that patients who received care at HTCs had:

- fewer hospital visits
- shorter inpatient stays
- lower costs of care
- less unemployment

Source: Jilka, Nave, El, Dahl, B, Alkhatib, A, Coenen, L, Hill, H, Kishner, M, Wilbur, N, and the Hemophilia Surveillance System Project Investigators. Morbidity, among men with hemophilia, reduces with access of medical care. Blood. 2003; 101:427-432.

Source: Jilka, Nave, J, Dahl, B, Briller, G, Hovell, H, Linden, J, and the Hemophilia Surveillance System Project Investigators. Hemophilic factor infusion therapy and hospitalization for bleeding complications among men with hemophilia. Haemophilia. 2005; 11:106-109.

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## Where do you get your bleeding disorder medication from?

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## What is a 340B “Program”?

- The 340B Drug Pricing Program is a federal discount program available to HTC's that receive a HRSA grant.
- Congress established the 340B Program as part of the Veterans Health Care Act of 1992.
- It allows patients to purchase medications from their HTC's who have this program.

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## 340B Program

The 340B Program allows HTC's to purchase bleeding disorder medications for home use at a discount for their patients. This means lower prices for patients and insurers. This can result in increased revenue for the HTC that can help support:

- Research – specific to bleeding disorders
- Services – outreach clinics, educational programs
- Salary Support – nurses, social workers, physical therapists, genetics counselors

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## What is a Specialty Pharmacy?

Provides medications used to treat complex, genetic, rare, and chronic health conditions.

### • Specialty Pharmacy drugs:

- Not available in retail pharmacies and require special storage, handling, delivery and are high cost.
- Require reimbursement assistance & ongoing patient support/education.
- Often injectable or infused medicines but also can include oral meds.
- Require close monitoring of their clinical response in collaboration with a physician.
- Require patient-specific dosing, and medical devices to administer the medicine.

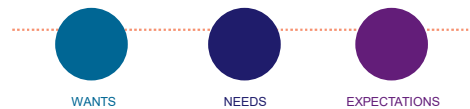
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## What is a Specialty Pharmacy?

- Services may include, but are not limited to:
  - Access to a specially trained pharmacist
  - Assistance verifying insurance & exploring benefit options
  - Assistance in identifying financial assistance options when needed
  - Home delivery of medications & all related ancillary supplies
  - Home nursing services
- **Sometimes referred to as “homecare companies”**

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## Assessing Needs and Wants



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## Assessing Needs and Wants

**NEEDS**

What is something you **need** from your health care provider or pharmacy?

**WANTS**



What is something you **want** from your health care provider or pharmacy?



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## Wants/Needs/Expectations

- What you want/need can be determined by choice, law, and/or standards
- When setting expectations:
  - Clearly communicate
  - Realistic and achievable
  - Know the “cans” and “cannots”
- The Office of the Inspector General (OIG) regulates the behavior of manufacturers and specialty pharmacy providers through “Advisory Opinions”

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## Choosing a Treatment Product Provider





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## Choosing Where You Get Your Treatment From

### Suggested Questions When “Interviewing” A Provider

- Are you a preferred provider under my insurance plan?
- What is your policy on co-pay and deductible costs? Do you have a financial assistance plan?
- What are your hours of operation? Do you have a toll-free customer service line that is available 24 hours a day?
- What is the standard delivery time (24 hours, 48 hours, etc.)?
- What is your policy on emergency orders?
- Do you have an emergency plan in place in the event of a natural disaster or other emergency?



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## Choosing Where You Get Your Treatment From

### Suggested Questions When “Interviewing” A Provider

- Do you have an adequate supply of the product I need on hand and in the dose size I require?
- Are all ancillaries included with my order?
- What is the cost per unit for my clotting factor?
- What additional ancillary services do you provide? Nursing? Physical Therapy?
- What is the cost for these services?
- Will I receive copies of all billing invoices?
- Do you participate in the Patient Notification System for product recalls?

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## Understanding the “Rules” of Engagement

With Manufactures & Specialty Pharmacy



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## MANUFACTURERS

### It's the Law:

- Manufacturers cannot give items or support of any monetary nature directly to patients or potential patients.
- These laws also regulate how industry interacts with doctors, nurses, social workers, etc.
- Regulations are issued at both the federal and state level.
  - In addition, PhRMA (Pharmaceutical Researchers and Manufacturers Association) issues guidelines governing manufacturers as well.

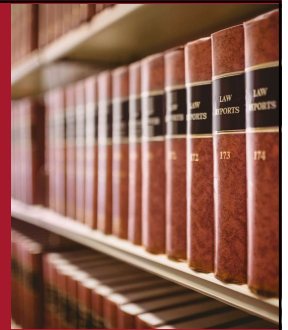


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## SPECIALTY PHARMACIES & MANUFACTURERS

### It's the Law:

- Examples of regulations issued by OIG related to hemophilia specifically:
  - August 30, 2002, the OIG issued a Special Advisory Bulletin on "Offering Gifts and Other Inducements to Beneficiaries".
  - Advisory Opinion No. 02-14, issued September 30, 2002, regarding the provision of certain "free goods" to individuals with hemophilia.



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## WHY DID THE OIG ISSUE THESE ADVISORY OPINIONS?

To give health care providers and suppliers a better general understanding of the provisions of the federal Anti-Beneficiary Inducement Regulation. Safety items mentioned include, among other things, helmets, kneepads, medic alert bracelets, and pagers. (A specialty pharmacy company asked for help!)



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## OIG Q&A

Can a Specialty Pharmacy provide items to you for free?

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## OIG Q&A

What items can a specialty pharmacy provide to patients/caregivers for free?

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## OIG Q&A

Can a Specialty Pharmacy or Manufacturer pay for me or my family to attend regional or national meetings, such as BDC?

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## OIG Q&A

NO! – If the support or gift value is more than \$15 per item or \$75 per year per person, it is illegal under OIG's guidance. The regulation prohibits gifts or payments in order "to induce patients" to select a particular drug, supplier or provider of healthcare items or services.

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## OIG Q&A

**Wait...What about educational dinners?**

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## OIG Q&A

- Can be offered if paired with education.
- Moderate \$\$
- Meals with education are a grey area.
- Don't pick the most expensive place in town and don't expect alcohol.

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## OIG Q&A

**Do I have to sign my name and my personal information when I attend?**

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## OIG Q&A

- No, however, put yourselves in their shoes
- They often are required to collect attendee information
- The purpose of the dinner is to educate and to market their products and services
- They have to track how much they spent per person to be in compliance
- You can do the following:
- You can sign up and expect to get information from the company about their products and services – they will call, email, and snail mail you.
- You can ask the representative how to sign in without sharing your personal information – initials, fake name – all with no contact information. That is perfectly ok. You are NOT REQUIRED to share your information in exchange for a meal.

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## OIG Q&A

**What are the consequences if my specialty pharmacy, manufacturer or I break the law?**

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## OIG Q&A

Fines per violation for the specialty pharmacy providers, supplier or manufacturer. If it is determined that the Anti-Kickback Statute was violated, fines, exclusion from Medicare and Medicaid and, criminal sanctions, including jail sentences could be invoked upon a party giving or receiving prohibited remuneration.

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## OIG Q&A

**Does the Law only apply to those on Medicaid/Medicare?**

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## OIG Q&A

- No, most states apply those “Medicare and Medicaid” anti-kickback laws to private insurance as well.
- **States Anti-Kickback Laws:** Anti-kickback laws make it a criminal offense to knowingly and willingly **offer, pay, solicit or receive** a kickback, bribe or rebate or to induce or reward referrals or items or services reimbursable to a government health care program. **State anti-kickback laws usually apply to all payers;** the federal law <sup>2008</sup> applies only to federal health care program payments. In one state, the state law preempts state Medicaid anti-kickback laws.

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## SO, WHAT SHOULD I DO?

Educate yourself – ask questions, learn about products and services.

Chapters are a great resource.

Industry Representatives are valuable resources

- Know the do's and don'ts
- Communicate your expectations
- Set boundaries

Remember: **YOU** are your best advocate!

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**Thank You to our Community Education Funding Partners**



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**SW0** Based on what I read, it looks like all states now have anti-kickback laws. I'm wondering if this is needed here anyways since we have the bullet point above and it's on the community advocates to know and understand laws that apply to them and where they live. Laws are also changing pretty rapidly across the board so we might want to keep this general.

Sarah Waite-Ardini, 2025-04-29T01:48:58.801


**HH0 0** We can remove this sentence.

Heather Hicks, 2025-04-29T14:09:17.570

**sa0 1** Done thanks.


sarahgwaite@gmail.com, 2025-04-30T18:01:23.022






## Community Voices in Research


National Bleeding Disorders Foundation



A **community-powered registry** that centers research around the lived experience




Electronic surveys: collects information from people affected by an inheritable bleeding disorder and their family members - **CVR transforms the lived experience into evidence**



**Personalized dashboard:**

- Provides personalized resources to empower participants with information
- Offers ways to become active partners in research and their care



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## Community Voices in Research

National Bleeding Disorders Foundation

**Consider enrolling!**


It only takes 5 minutes!



Contact information:  
Matt Hartnett ([mhartnett@bleeding.org](mailto:mhartnett@bleeding.org))



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## Steps for Living

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### Education for All Life Stages

**VISIT THE SITE AND FIND RESOURCES JUST FOR YOU**


Discover information and resources in English and Spanish at NBDF's comprehensive website dedicated to the bleeding disorders community.


Whether you're newly diagnosed or a long-time community member, you'll find valuable information on managing your bleeding disorder no matter your age.


ENGLISH SITE




EN ESPAÑOL







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## What is the THRIVE Campaign?

Nationwide campaign as part of the CDC cooperative agreement


**Goals:**

- Educate individuals with bleeding disorders and their support networks about **six key steps** for leading a healthy life.
- Provide resources to empower community members and their loved ones to thrive in everyday life.






To learn more, check out [bleeding.org/thrive](https://bleeding.org/thrive)




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## THANK YOU

Any questions?

Connect with us on social or join our newsletter community!





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