

Information is Key: Navigating the Medical Field

By Sonji Wilkes

In the bleeding community, patients and their parents should know that they are not alone. Everyone, from Hemophilia Treatment Center (HTC) staff, other medical providers, home health care providers, and pharmaceutical companies, to staff members of local and national organizations, and the patients themselves, has the same goal in mind: the best care and outcomes for the individual directly affected by a bleeding disorder. Whether you are newly diagnosed with a bleeding disorder or are looking to make a change in your treatment or service provider, it's important to examine and thoroughly understand what is important to your family in terms of service.

For a family facing a new diagnosis, the sudden influx of people into your life can be intimidating. Knowing who the players are can be a big help. You may be asking yourself, "Why do they want to help me? What's in it for them? What's in it for **me**?" Simply put, learning how to live with a bleeding disorder is much easier with the support of a dependable team of professionals. Developing a strong relationship with your medical provider can ease many of the challenges you may face over your lifetime.

Shannon Brush, a mom of a son with hemophilia B shares, "Once we had received the diagnosis of severe hemophilia for our son, both his new hematologist and nurse practitioner sat

with us for several hours in the clinic office at a separate appointment and answered all the questions we could think of. They gave us a good idea of what to expect in the upcoming months and years. They were patient, compassionate, and sincere in their approach, making sure we had enough information to feel we could care for our son. In that first year, we called and brought him in whenever we had a concern; sometimes he needed treatment, sometimes he didn't, but we always felt heard. It was very comforting to know they were always willing to see our son and help us to understand this new normal."



Eric Frey of Ohio, a dad of son with severe hemophilia A with inhibitors, explains, "We could not do what we do without the support of our HTC and their staff. They have guided us through initial diagnosis, multiple surgeries, and the development and tolerization of high titer inhibitors. They are our team. They trust us and we trust them. There is give-and-take in the relationship. We sometimes do things differently than what we think is ideal because [our medical providers] are committed to a course of action, and we trust **them**. They sometimes agree to a plan that they do not prefer because they trust **us**. It is a two way street; the trust is mutual. We are in it together and it works. We truly couldn't be where we are without them."



MEET THE PLAYERS

	Hemophilia Treatment Center (HTC) Staff	Home Health Care Providers	Pharmaceutical Companies	Local Member Organization Staff & Volunteers	National Organization(s) Staff (HFA, NHF, COTT, Coalition for Hemophilia B)
What's their role in the community?	<p>Provide comprehensive medical care</p> <p>Notes: Could include</p> <ul style="list-style-type: none"> • Hematologists • Nurses • Physical Therapists • Social Workers • Orthopedists • Laboratory Personnel <p>Sometimes offer 340B pharmacy (factor replacement therapy provider)</p>	<p>Home based delivery of factor replacement therapy, often in conjunction with skilled nursing services</p> <p>Notes: You may or may not have a choice of provider based on your insurance plan</p>	<p>Research, development, manufacturing, clinical trials, marketing and seeking FDA approval of factor replacement therapies and other novel therapies</p>	<ul style="list-style-type: none"> • Provides support, education, and advocacy on behalf of community • Often provides programming and services • Can help facilitate relationships among consumers 	<ul style="list-style-type: none"> • Provides support, education, and advocacy on behalf of community • Provides programming and services direct to consumers and by supporting local member organizations • Can help facilitate relationships among consumers

It is overwhelming when a loved one is first diagnosed. Adding to the burden of learning a new language of hemophilia or von Willebrand Disease, you may be faced with choosing which company to use as your factor product provider. While many insurance plans limit which company individuals can use, it is important to note the key components for service to bleeding disorders families. Shannon had a great experience with her home health care company when her son was first diagnosed. “Our homecare rep came to our home, gave us numbers for the local support organization, and helped coordinate nursing visits when needed. Getting hooked into this new community, from other parents to HTCs to homecare providers, allowed us to feel like we were not alone and would be able to handle whatever came our way.” Eric’s family has used the 340B program at their local HTC and says, “We’ve been so happy with their service that we have not even examined other options.”

Just as having a bleeding disorder is a very individualized diagnosis, what each family needs from a home health care provider or factor replacement therapy provider varies. These helpful hints can help you navigate the decision-making process:



Things you should expect from your home care company or HTC 340B pharmacy, and their employees:

- ◆ Provide, in a timely fashion, prescribed products, supplies, and support as directed by the prescribing medical provider
- ◆ Contact the prescribing medical provider immediately to confirm the need for any new products/supplies the family requests that the prescribing medical provider has not previously prescribed
- ◆ Contact the prescribing medical provider to obtain prior approval for appropriate substitutions if prescribed products or supplies are not available
- ◆ Conduct follow-up needed to ensure adequate inventory of home products and supplies
- ◆ Render services only to the patient for whom they have specific orders from the prescribing medical provider
- ◆ Provide the prescribing medical provider with regular statements of products and supplies issued to the patient
- ◆ Have any contracted nursing service or other representative contact the prescribing medical provider for education, guidance, and orders regarding patient care

Things your home care company or HTC 340B pharmacy and their employees should NOT do:

- ◆ Pressure patients or families to change their current factor distributors
- ◆ Limit access to services for patients and families
- ◆ Contact patients and families to whom their employees previously provided services as representatives of other home care companies or HTC factor programs
- ◆ Provide medical or professional grade psycho-social guidance
- ◆ Make referrals to agencies and community services without working in collaboration with the prescribing medical provider*
- ◆ Provide any non-bleeding disorder products, supplies or support unless ordered by the specific physician who assumes responsibility for the order
- ◆ Provide inducement such as, but not limited to, vacations, payment of household expenses, cell phones, refrigerators, and medical provisions for other family members
- ◆ Waive payment of insurance copays and deductibles without obtaining required financial information

**This does not include mandatory reporting as required by law*

*Adapted from: “What You Should Expect From Your Chosen Home Care Company or HTC Factor Distribution Program,”
Developed by the Region III Federally Funded Hemophilia Treatment Centers*

As new factor replacement and other novel therapies are released into the market, patients and families are considering changing products. There are two types of products currently on the market: plasma-derived therapies and recombinant therapies.

- Plasma-derived therapies are made from human plasma. Plasma is collected by various manufacturers at plasma collection centers, pooled and then separated into different products through a process called fractionation. The fractionation process gives the manufacturer multiple products, including factor VIII (for hemophilia A) and factor IX (for hemophilia B).
- Recombinant therapies are genetically engineered factor VIII and factor IX. The human genes that contain the code necessary for making factor VIII or IX are isolated and then inserted into baby hamster kidney cells or Chinese hamster ovary cells. With the necessary code, these cells are then able to produce factor VIII or IX and scientists are able to separate and purify the cell culture and use it to make factor replacement therapies.

When discussing a product switch with your health care provider, these are some considerations and things to ask about:

Things to Consider When Choosing A Factor Replacement Product

Always consult with your HTC/health care provider to find the best product for you.

Purity

- Plasma-derived vs. recombinant
 - If recombinant, is it first, second or third generation?
- Discuss with your healthcare provider which may be most appropriate for you or your child and the differences in the generations of products.

Efficacy

- Does it work to control bleeding?
- Rate of recovery
- Incidence of inhibitor
- Adverse effects

Convenience

- Longer-acting factors (potentially resulting in fewer infusions)
- Available dosing strengths
- Diluent volume
- Needleless mixing devices

- Storage (expiration date and refrigeration requirements)

Cost

- 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?

Experience and commitment from company

- Clinical experience and research
- Commitment to bleeding community
- Do they offer support resources? Insurance help?

What works for you?

Eric explains that choosing a factor product was done in consultation with his son's HTC. "Our only choice was to switch from a standard factor to an extended half-life factor. After doing our research, it was clear to us that this was best for our child, so we made the switch."

Many insurance plans are limiting the choice of home health providers and specialty drugs. HFA has fielded calls and concerns from families who have been denied services, forced to use a product that wasn't their first choice that did not work for them, mandated to use a pharmacy that did not meet their needs, or forced to undergo lengthy prior authorization processes. It can be an alienating and isolating experience so, with this in mind, HFA established Projects CALLS (Creating Alternatives to Limiting and Lacking Services).

Project CALLS is designed with a personal touch in mind. As a participant you will speak privately with a trained member of the HFA staff about your insurance issues. Depending on your preference, you may call in to speak to someone, send an email, or complete a form to be contacted.

Through your participation in Project CALLS, HFA will collect stories from the bleeding disorders community across the country, collate the data, identify trends, and use the information to build cases for change. If you have been experiencing issues with your insurance company, we want to hear your story! This is an opportunity for you to share your story while helping the entire bleeding disorders community.

You should never feel alone in the process of learning about this sometimes-complex chronic condition. It's not just learning how to identify bleeds or when to seek help, but also knowing that there are professionals who are willing to help you navigate these decisions. Your job as the patient or parent is to gather information and make informed decisions about all aspects of your or your child's disorder. ■■

More about the patients quoted:

Shannon lives in Texas with her husband, Alan, and three boys, Jacob, Peyton (severe IX), and Barrett. She is a former President of the Board of, and currently the Communications and Walk Manager for, the Texas Central Hemophilia Association.

Eric lives in Toronto, Ohio with his wife, Antonina, and their three children, Pax, (8), Pierce, (7), and Pria, (5). Antonina is a first grade teacher and Eric is a theologian.