

**Dean:** How would a family in the bleeding disorders community know they are on one of these programs? And do they need to do anything?

**Colleen:** Employees are usually contacted by mail, either offering a new “concierge” service or case management for their medication and are told that a case manager will contact them to discuss the program.

Readers should know that if your insurance company offers this type of program, please call Cascade. We are advocating at the state and federal levels and want to help patients effectively navigate any changes to their insurance coverage.

The Hemophilia Alliance has compiled the list below, which includes some companies that have initiated alternative funding programs.



### Companies that Use Alternative Funding\*

|                  |                 |              |                |
|------------------|-----------------|--------------|----------------|
| Payer Matrix     | Valenz Care     | Familywize   | Impaxrx        |
| Paydhealth       | Rxconnection    | Health Smart | Sharx          |
| Navitus/Lumicera | Scoutrx         | EHIM         | Scriptsourcing |
| CobaltRx         | Rx Help Centers | Rx Valet     | Claimslinx     |

*\* Cascade Hemophilia Consortium (“Cascade”) does not make any representations or warranties regarding the above companies or programs or whether this list, which was compiled by the Hemophilia Alliance, is accurate, reliable, or complete.*

Language assistance services are available free of charge. Call: 1-800-996-2575.

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-800-996-2575.

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## Emerging Insurance Trends

part 2



Dean Hindenlang, PhD  
Director of Public Policy,  
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When we wrote to you last, we discussed the complex topic of co-pay accumulators and how out-of-pocket costs can be impacted when these types of programs are utilized by insurance providers. Unfortunately, co-pay accumulator programs are not the only efforts that patients in the bleeding disorders community need to be aware of – there is always some ‘new’ effort underway to pass costs along to patient assistance programs, government plans, and to patients. Understanding how you may be impacted can be both a worry and a nuisance. It can also have other implications to your care if you are left uninformed.

That is why Cascade recently selected me to serve as their first director of public policy and to help advocate for patients, when patients need it most. In this new role, Cascade is expanding their efforts to keep an eye on issues that may directly impact you and your family. In doing so, you will have someone that is squarely in your corner, helping to ensure that topics that may impact you are communicated in a timely and effective manner.

With that, we are bringing you my interview with Colleen Joiner, LMSW, as we discuss alternative funding models, what you should know, and how they may eventually affect you and your family. We hope you’ll take a few minutes to read about this growing insurance initiative that could adversely impact you the next time you order factor.

On behalf of all of us at Cascade, we wish you a very happy holiday season, and look forward to connecting in new and expanded ways in the new year!

Dean

## Cascade Hemophilia Consortium Mission

### The Purpose for Which the Corporation is Organized

To enhance the system of care for people with bleeding disorders and related complications, by assuring the lowest possible price for the full range of treatments, HIV and hepatitis related therapies and other medications available to treat their disease; to provide access to these medications for those without insurance or inadequate insurance coverage; to support the comprehensive hemophilia treatment centers in treating and educating consumers and their families so they may become knowledgeable and proactive in managing their own care; to fund research.

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# Emerging Insurance Trend

## Alternative Funding

Dean Hindenlang Interviews Colleen Joiner



Dean Hindenlang, PhD  
Director of Public Policy,  
Advocacy, and Community Impact



Colleen Joiner, LMSW  
Clinical Care Manager, Cascade

## Alternative Funding

**Dean:** I've just started hearing about Alternative Funding. What is it all about?

**Colleen:** To tell you the truth, at this point the alternative funding model won't affect most families. It's a newly emerging trend that we want everyone to be aware of in the event their coverage changes.

Essentially, organizations have designed the "Alternative Funding Model" as a solution to high-cost specialty medications, such as factor products and Hemlibra. Insurance brokers then promote the program to self-funded employers and some union groups. For people who aren't aware, self-funded employers typically set up a special trust fund made up of corporate and employee contributions which is used to pay health claims incurred by employees and their families. Because a self-funded employer is incurring the risk, they tend to have more stake in keeping costs low.

With the **Alternative Funding** model, specialty drugs such as factor are excluded from the insurance plan. In exchange, the employees receive "specialized case managers" who assist or divert them to other resources to cover the cost. In other words, **bleeding disorder products are not covered by the health plan but through other no-cost or low-cost programs.**

Employers are generally charged up to 25% of the costs of the drug with this program, which is still significant.



**Dean:** How is that possible? Where are the Alternative Funding programs diverting costs?

**Colleen:** One example of where the costs are diverted is called the Patient Assistance Program (PAP). PAPs are offered by the pharmaceutical companies that manufacture factor products. Most companies producing factor offer free product on a short-term basis to uninsured patients who meet certain guidelines.

We've also experienced employees getting referrals to Medicaid, the Children's Special Health Care (CSHCS) program, or to the Bureau for Children with Medical Handicaps (BCMh). Why? Because the insurance brokers believe that if factor or Hemlibra are excluded from the plan, the state will cover it. This essentially shifts the expense away from employer plans and onto state, tax-funded programs.



Employers are generally unaware of any of the consequences of alternative funding to their employees. They may have been told that employees won't be denied medications, they will receive assistance and case management, and the employer will save money in the long run. It's true that many patients who don't qualify for free product through various sources are given an exception for insurance coverage, but not all, and usually only after a long intrusive process, including revealing patient and family financial information to the PAPs.

**Dean:** What are the ramifications of an alternative funding program?

**Colleen:** Initially, these programs might not raise a red flag for most families. But there are some things to consider that could have negative implications for the patient and the community in the long run.

It's important to know, PAPs were developed as a stop-gap solution for people who are temporarily without insurance. They're wonderful programs, and serve a great purpose, but they aren't structured to support long-term or medically optimal care. Because your product will come from a PAP, these items should be considered:

- ▶ Vial sizes may vary. Someone who typically infuses one or two vials per dose may need to infuse 5-6 smaller sized vials available through the PAP. Multiple vial infusions can be difficult for some adults, and even more for children, causing concerns about adherence.
- ▶ Factor provided through a PAP usually has a short expiration date.
- ▶ Urgent factor deliveries aren't always possible through a PAP. Medication may be delayed, and this could result in more ER visits, increased costs, loss of work, or further medical issues.
- ▶ There are also financial considerations. To qualify for a PAP, a patient generally must meet income guidelines. Not everyone qualifies, and some incur higher monthly costs for the drug.



Michigan patients who don't qualify for a PAP, are often being diverted to the CSHCS program. In other states, some are sent to Medicaid. Again, these state programs are a valuable resource for the bleeding disorder community and are funded through our tax dollars. If all insurance companies adopt an alternative funding model for specialty drugs, how will this strain the PAP, CSHCS and Medicaid programs?