



DATELINE

F E D E R A T I O N

Special Issue 2017



SPECIAL ISSUE

NAVIGATING PATIENT ASSISTANCE PROGRAMS

PROJECT CALLS

Creating Alternatives to Limiting and Lacking Services

YOU ARE NOT JUST A NUMBER; you are part of a community THAT CARES!

If you have been experiencing issues with your insurance company, we want to hear your story!

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 the number below, send an email, or complete the 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 or a member of your family have been:

- Denied services or have received an exception,
- Forced by an insurance company to “fail” on a product before being allowed to use the product of your choice,
- Mandated to a pharmacy that is not meeting your needs, and/or
- Forced to go through a lengthy pre-/prior-authorization process,

Project CALLS is for you!

To contact us about your insurance issue, please call (202) 836-2530, email projectCALLS@hemophiliafed.org, or visit www.ProjectCALLS.org



Assisting and advocating for the bleeding disorders community since 1994.

Special Issue 2017

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“However, in bleeding disorders (as in some other health contexts), the fact is that co-pay assistance programs don’t drive patients toward more expensive therapies: no generic or cheaper alternative therapies exist.”

Read more on page 6

Dear Reader,

We're all too familiar with the expenses that come with the treatment of a bleeding disorder. With factor concentrates being one of the most expensive drugs on the market, even a person with "good insurance" may see their finances negatively impacted because of the high cost of treatment.

It is imperative that people living with bleeding disorders have health insurance and continue to seek routine care from their doctors. The costs associated with treating a bleeding disorder are so high that anyone involved in the care of a person with a bleeding disorder must understand the ins and outs of their insurance plan to know what financial commitments they'll reasonably face in the year ahead. It is the patient's or caregiver's responsibility to review how the current insurance policy might have changed and ensure they budget accordingly to cover co-pays, co-insurance amounts, deductibles, and other out-of-pocket expenses.

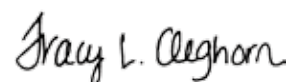
At times this can, of course, trigger stressful conversations. With your family's well-being on the line, things like household finances, health insurance payments, co-pays, and bills can be daunting to budget for and manage. At HFA, we're here to help. This special issue of *Dateline Federation* is intended to serve as a one-stop resource for patient assistance programs you and your family might need to know about in 2017.

We're pleased to publish a comprehensive list of the patient assistance programs available to our community (pg. 8). Outlined in the pages that follow, you'll find manufacturer co-pay programs, manufacturer product assistance programs, and hepatitis C co-pay and assistance programs. Our team works hard to keep this list as up-to-date as possible.

You'll also find an overview of our Helping Hands program (pg. 6). Helping Hands aids hundreds of families each year with urgent basic living expenses, the reimbursement of durable medical items, and medical/education travel and educational support for families affected by inhibitors.

Our staff can offer a wealth of knowledge and expertise so I encourage you to reach out if you have any questions. As a community-based organization working every day to assist and advocate for the bleeding disorders community, HFA is here to support you and your family throughout this journey.

Warm regards,



Tracy Cleghorn
Board Chair

“HFA is here to support you and your family throughout this journey.”

Affording to Bleed

By Sonji Wilkes

We can all agree that factor is expensive.

The Explanation of Benefits (EOB) that arrives in the mail each month is, frankly, horrifying to read. When they include only my son Thomas's factor supply for scheduled infusions, they are still on the far end of the "oh-my-goodness-that's-a-lot-of-money" spectrum. The truly frightening EOBs, however, include extra factor needed for bleeds, lab work, in-patient hospital stays, emergency room visits, and doctor's fees.

In the bleeding disorders community, we do a pretty good job explaining to lawmakers how expensive the life-saving drugs are. We detail why it's vital for patients to have access to their medications. We talk about how increased co-pays, exorbitant deductibles, co-insurance, and out-of-pocket expenses will impact our ability to maintain insurance coverage. That is very important data to share, and we should definitely keep talking about it, but what we often forget to bring up are the day-to-day financial realities of living with a chronic condition.

For a stretch of time we had to visit our HTC weekly, if not more often. I shudder to recall how much money we paid for parking, gas, and Happy Meals for the kids, as they were always famished by the time we were finished.

Our credit rating is in complete shambles thanks to medical debt. Early on, we tried valiantly to keep up with all the hospital bills, using every line of credit we had to pay off the debts. While we kept ourselves afloat, it really came back to bite us when it came time to buy out the lease on our mini-van. The finance guy at the car dealership took one look at our credit report and cringed. Mercifully, he showed us compassion and worked out a deal that wasn't great, but allowed us to keep the car. I had been in an absolute panic not knowing how we would manage without a car to get to medical appointments. The irony was not lost on us that the costs resulting from going to these medical appointments was the reason we couldn't afford the car.

“What we often forget to bring up are the day-to-day financial realities of living with a chronic condition.”

The cost of living with hemophilia is not just the cost of the factor or insurance. It's the personal out-of-pocket expenses for all the other things that are involved in taking care of your children during the course of office visits and hospital stays. Those barely edible meals in the hospital cafeteria add up. Buying a wheelchair adds up. Travel to and from appointments adds up. The total "medical debt"—not just the debt for the actual medicine—is staggering.

We are blessed to have patient assistance programs through our industry partners and local chapter. Families should not feel ashamed to take advantage of these programs—that's why they're there. Even with those resources, we know of families who must turn to food banks to put dinner on the table. Our community cares deeply for each another and I've seen a group of families raise over \$500 to help another family who was in a tight spot. It's amazing and moving to see a group of people who have the same personal and financial issues help one another. Often, families don't discuss the sheer expense of living with this disorder with one another, let alone with people outside the community. It's awkward and uncomfortable to admit our dire financial straits publicly.

“It's awkward and uncomfortable to admit our dire financial straits publicly.”

I teach Thomas that there is no shame in having hemophilia. I want to teach him how to share what living with a chronic condition is like. It's short-sighted and ultimately harmful to reveal only the impacts of bleeds and the cost of insurance; it's time to have an honest conversation without any embarrassment. If we are going to educate and raise awareness about hemophilia and all that it entails, we must talk about the constant and difficult financial ramifications of living with a chronic condition.

The Policy of Patient Assistance

By Katie Verb, JD

Over the past few years, patient assistance programs have come under attack from the federal government, insurance companies, and state legislators. Efforts to derail patient assistance programs have largely been driven by the insurance industry with claims that these programs allow manufacturers to steer patients toward high-cost, brand-name products by offering to pay increased co-pays for patients. Others argue that patient assistance programs simply balance the scales when insurance companies are in essence making medical decisions for patients by using formularies and tiering to put medications prescribed by doctors out of financial reach for patients. What is often forgotten in this battle is the rare and chronic disease community. Medications used to treat these communities often get swept into the tiers with the highest co-pays, with little consideration that no low-cost, generic alternatives exist to treat these diseases.

One of the first attempts to regulate the use of patient assistance programs arose in 2014 from the Center for Medicaid and Medicare Services (CMS). CMS released a rule mandating that insurance companies operating on the Exchange *must* accept premium assistance programs from three types of entities: Ryan White HIV/AIDS programs, state and federal programs, and Indian tribes and tribal organizations. CMS, conversely, expressed concern about *medical entities* providing premium assistance for patients on the Exchange. The effect of CMS's ruling was that insurance companies began to reject premium assistance payments from entities *not* listed, such as non-profits or civic organizations. Indeed, United Healthcare took matters one step further and made patients sign affidavits that they would not accept checks for premium assistance directly from any organizations, on penalty of losing their insurance.

Over the past three years, CMS has refined its position on its third-party premium assistance rule. CMS's most recent rule specifically talked about end-stage renal disease (ESRD) patients who receive third-party premium assistance to purchase private insurance. The rule expressed concern that some dialysis facilities were providing premium assistance as part of a program to inappropriately "steer" Medicare and Medicaid eligible patients toward individual market plans. ESRD patients automatically qualify for Medicare: by steering them toward individual market plans, the dialysis facilities could assure themselves of higher reimbursement rates for dialysis services. Such steering, however, is not necessarily in the best interest of the patient, since ESRD patients who enroll in individual market coverage supported by third parties may lose that assistance, and therefore their coverage, if they change dialysis providers or undergo kidney transplants. Patient assistance programs that serve the bleeding dis-

orders community are unlike the programs targeted by the latest CMS rule. Bleeding disorders patients (unlike ESRD patients) are not automatically eligible for Medicare, so the problem of inappropriate "steering" does not exist. Nor are bleeding disorders patients required to continue on a particular course of therapy, or to continue receiving services from a particular provider, in order to remain eligible for third-party premium assistance. In the context of hemophilia, third party premium assistance programs simply allow patients to purchase the healthcare coverage they need in order to manage their disease.

While the CMS rule deals with premium assistance, co-pay assistance is also coming under fire from state legislators. Most recently, the Virginia legislature considered a drug pricing transparency bill that not only asks for information about how products are priced, but information about non-profits that receive donations from drug companies as well. Regulators and legislators seem to be increasingly concerned over the ethics of patient assistance programs, especially those programs that are linked directly to a product or service.

Similarly, the New Hampshire legislature is weighing a bill that would ban co-pay assistance programs direct from drug manufacturers. The bill's co-sponsors argue that some manufacturers steer patients towards more expensive brand name products through product-specific co-pay assistance programs. However, in bleeding disorders (as in some other health contexts), the fact is that co-pay assistance programs don't drive patients toward more expensive therapies: no generic or cheaper alternative therapies exist.

While HFA firmly opposes legislation banning co-pay assistance, we understand that legislators are desperately seeking solutions to increased spending on pharmaceuticals. Banning assistance for chronic disease communities that rely on high-cost medications puts those communities at risk, however, and leaves them stranded in the middle of a battle over which they have virtually no control.

HFA believes that patients who need products for which there are no cheaper, generic alternatives, also need access to co-pay assistance as long as insurers continue to use formularies and tiering to increase the financial burden of patients with chronic and rare diseases. These patients are the very individuals who most urgently need high-quality insurance, and given the cost of that insurance, these patients need to have access to premium assistance. Unfortunately, it seems that regulators and legislators are telling us that in order to maintain the support we need, just how that assistance is provided might have to be re-thought. ■ ■

Navigating Patient Assistance Programs

By Kandyma Sar

Co-payments and out-of-pocket expenses can be devastating on a family's budget. To offset these costs, many manufacturers of factor products have co-pay assistance programs that can provide a source of relief to you and your family. The HFA team maintains a comprehensive list of programs that are available to the community and updates it regularly. In the pages that follow, you'll find a high-level overview of those programs.



Manufacturer Co-Pay Programs

| Manufacturer | Co-pay/Co-insurance Program Name & Contact Information | Limit Total | Notes: |
|---------------------|--|-------------|---|
| Aptevo Therapeutics | IXINITY Savings Program 1-855-494-6489 | \$12,000 | <ul style="list-style-type: none"> • Must have a valid prescription for IXINITY. • Must have commercial insurance. • No monthly limits unless limit total is reached. • No income requirements. • Co-pay program can be used retroactively for up to 12 months. |
| Bayer | Bayer Access Solutions Kogenate FS Co-pay/Co-insurance Program 1-800-288-8374 | \$12,000 | <ul style="list-style-type: none"> • Must have a diagnosis of hemophilia A. • Must have a private health insurance plan. • No income requirements. • Must first contact Bayer Access Solutions. |
| Biogen | ALPROLIX Co-pay Program 1-855-692-5776 ELOCTATE Co-pay Program 1-855-693-5628 | \$12,000 | <ul style="list-style-type: none"> • Available to those who use ALPROLIX or ELOCTATE. • Must have commercial insurance. • US prescriber and pharmacy required. • No income requirements or caps. • Enrollment forms available via links provided. • Not responsible for costs associated with administration of therapy, such as office visits, infusion costs, or other professional services. |

| | | | |
|------------------------------|--|---|---|
| Caring Voice Coalition (CVC) | Factor XIII deficiency program 1-888-267-1440 | \$8,000 | <ul style="list-style-type: none"> • Must be diagnosed with one of the specific diagnoses that CVC supports. • Must be prescribed an FDA-approved therapy to treat the CVC-supported diagnosis (has to be specifically indicated; no off-label). • Have an active prescription insurance coverage which pays for a portion of the prescribed FDA-approved therapy (does not qualify if prescription has ever been denied). • Income must fall at or below 450% of the Federal Poverty Level based on household size and income. • Must be a US resident. • Other services offered are financial assistance, non-financial services (insurance education and counseling) and disability services. |
| CSL Behring | MySource Cost-Share Program 1-800-676-4266 | \$12,000 for Afstyla, Idelvion, Helixate, or Humate | <ul style="list-style-type: none"> • Must take a CSL Behring eligible product (on-label) for the treatment of von Willebrand disease or hemophilia. • Must currently have active commercial insurance (federal or state insurance programs are not eligible). • Co-pay enrollment requests requires patient consent. • Only products purchased from Specialty Pharmacies (SP), Hemophilia Treatment Centers (HTC) and Outpatient Hospital services will be eligible. • Co-pay program is not retroactive and cannot be transferred. Exception requests may be submitted for consideration. • Must be a US resident. • No financial restrictions apply. Program benefit DOES NOT apply toward out-of-pocket costs for: • Physician office visit co-pays. • Infusion-related costs or ancillary supplies. • Insurance premiums. |
| Grifols | AlphaNine SD Co-pay Card 1-844-693-2286 (844-MY-FACTOR) | \$6,000 (\$500 each month max) | <ul style="list-style-type: none"> • Pay as little as \$0. • No monthly or annual maximums. • Prescription is covered up to the patient's annual out-of-pocket maximum. • No waiting period; patients may use the offer as soon as they enroll. • No income requirements. • Annual program enrollment is required. • Must have commercial insurance. • Patients must have a valid AlphaNine SD prescription. • Restrictions apply. • Helps cover co-pay and co-insurance costs for AlphaNine SD only. It does not cover costs related to physician visits and is not for in-patient use. |
| Grifols | ALPHANATE Co-pay Program 1-844-693-2286 (844-MY-FACTOR) | \$6,000 (\$500 each month max) | <ul style="list-style-type: none"> • Pay as little as \$0. • No monthly or annual maximums. • Prescription is covered up the patient's annual out-of-pocket maximum. • No waiting period; patients may use the offer as soon as they enroll. • No income requirements. • Annual program enrollment is required. • Must have commercial insurance. • Patients must have a valid ALPHANATE prescription. • Restrictions apply. • Helps cover co-pay and co-insurance costs for ALPHANATE only. It does not cover costs related to physician visits and is not for in-patient use. |

| | | | |
|-------------------|--|--|---|
| Kedrion Biopharma | No co-pay program currently available. 1-855-353-7466 | N/A | N/A |
| Novo Nordisk | Co-pay Assistance Program 1-844-668-6732 | \$12,000 | <ul style="list-style-type: none"> • Must be using a Novo Nordisk product for an FDA-approved diagnosis. • Must have a commercial insurance plan. • May apply through web port with link provided (60-day retroactive). |
| Octapharma | Octapharma Co-Pay Program 1-800-554-4440 | Up to \$12,000 for NUWIQ per year Up to \$6,000 for Wilate per year | <p>NUWIQ CoPay Program Wilate CoPay Program</p> <ul style="list-style-type: none"> • No income requirements • Only applies to patients with private commercial insurance • Must have a prescription for NUWIQ and/or Wilate • Other restrictions may apply |
| Pfizer | Pfizer Factor Savings Program 1-888-240-9040 | \$12,000 | <ul style="list-style-type: none"> • Provides co-pay and co-insurance assistance for a Pfizer factor product. • Patient financial responsibility of \$10 per month. • No financial eligibility requirements. • Must be commercially insured with health insurance that covers factor. • Medicare/Medicaid beneficiaries are not eligible. |
| Shire | Shire's Hemophilia Co-pay Program 1-888-BAX-8379 (1-888-229-8379) | \$12,000 | <ul style="list-style-type: none"> • Enrollment can be submitted online or over the phone. • Must have commercial insurance. • Must use eligible Shire hemophilia products. • Eligible patients with private insurance receive up to \$12,000 every 12 months for medication-related co-payment/co-insurance with retroactive assistance for a date of service within 120 days prior to their co-pay activation date. • No income requirements. • Adynovate follows FDA guidelines (approved for 12 years of age or older). |

HFA makes every attempt to provide accurate information regarding patient assistance programs and resources. However, since program policies often change, please contact the manufacturer directly for the most updated information. **This chart has been updated on January 9, 2017.*

For those in the bleeding disorder community who are uninsured, underinsured, or experiencing lapses in insurance coverage, there are also assistance programs to help families facing financial strain get access to factor products.

Manufacturer Product Assistance Programs

| Manufacturer | Product Assistance Program Name & Contact Information |
|-----------------------|--|
| Akorn Pharmaceuticals | Amicar Patient Assistance Program: This needs-based program assists patients in accessing Amicar. Patients must have a prescription and no commercial insurance. Each prescription may not exceed a 90-day supply at a time, with a maximum of three (3) refills and prescriber must document the number of days for which the supply is needed.. Application is valid for up to 12 months. After 12 months, a new application is required. 1-844-202-5909 |
| Aptevco Therapeutics | IXINITY Patient Assistance Program: For patients who are uninsured or experiencing a lapse in coverage to access treatment. Must meet income requirements. 1-855-494-6489 |
| Bayer | GAP Coverage Program: Patients who are unemployed or have a loss or lapse in private insurance coverage; connects you to temporary insurance coverage. Patient Assistance Program: Patients who do not have insurance, lack third-party coverage, or have pending Medicaid approval may be eligible to receive Kogenate FS. 1-800-288-8374 |
| Biogen | Factor Access Program: Patients using ALPROLIX or ELOCTATE who have no prescription coverage, are facing a gap in coverage, or have reached their maximum insurance coverage limit, may be eligible to receive product for free. Other restrictions may apply. For ALPROLIX 1-855-692-5776 For ELOCTATE 1-855-693-5628 |
| CSL Behring | Patient Assistance Program: To be eligible, patients must be underinsured or uninsured. When enrolled, must actively be seeking insurance. Assurance Program: Must currently have private health insurance coverage; this is a certificate program that helps with potential future lapses in private health insurance plans. 1-800-676-4266 |
| Grifols | Grifols PatientCare Program: This program is for patients using ALPHANATE or AlphaNine SD who are uninsured or experiencing a temporary lapse of insurance coverage. 1-844-MYFACTOR (1-844-693-2286) |
| Kedrion Biopharma | No program currently available 1-855-353-7466 |
| Novo Nordisk | Novo Nordisk Product Assistance Program: Provides medication to qualifying applicants at no charge. Eligible patients must have been prescribed a Novo Nordisk product for an indicated condition (check the website for a complete list of eligible conditions), have no insurance coverage, and actively be seeking insurance coverage. Patient must be a documented US resident or on a path to documented status with reasonable likelihood of attaining it. Federal government insurance programs are ineligible. 1-844-668-6732 |
| Octapharma | NUWIQ Free Trial Program allows for up to six (6) doses, or 20,000 IUs, of NUWIQ. A prescription for NUWIQ is required and other restrictions may apply. Wilate Free Trial Program allows for up to 5,000 IUs for Wilate. A prescription for Wilate is required and other restrictions may apply. 1-800-554-4440 |
| Pfizer | Pfizer RxPathways Program: Provides co-pay assistance up to \$10,000, free product, or premium assistance. Must be prescribed a Pfizer specialty drug, must have private insurance with prescription drug coverage, and must meet income eligibility requirements, which are based on household size and prescription. 1-866-706-2400 |
| Shire | Shire Patient Assistance Program: Provides uninsured and financially-eligible patients free product for eligible Shire's hemophilia products. 1-888-229-8379 |

Hepatitis C Virus Co-Pay & Patient Assistance Programs

| Program Name & Contact Information | Limit total | Notes: |
|---|---|---|
| AbbVie Co-pay Assistance Viekira Pak Co-pay Card 1-844-484-3547 | <i>Call for further details</i> | <ul style="list-style-type: none"> • Eligible patients may receive Viekira Pak for as little as \$5 with co-pay card. • Must have commercial prescription insurance coverage for an FDA-approved AbbVie product. • Co-pay assistance is not available to patients receiving prescription reimbursement under any federal, state, or government funded programs. • Patients may not seek reimbursement for value received from the AbbVie HCV Co-pay Program from any third-party payers. |
| AbbVie Co-pay Assistance Moderiba Co-pay Card 1-800-222-6885 | <i>Call for further details</i> | <ul style="list-style-type: none"> • Application must be submitted to consider the following: family size, medication being taken, other special circumstances. • Eligible patients may receive Moderiba for as little as \$5 with co-pay card. • Must have commercial insurance coverage. • Co-pay assistance is not available to patients receiving prescription reimbursement under any federal, state, or government funded programs. |
| Bristol-Myers Squibb (BMS) Co-pay Assistance Patient Support CONNECT Co-pay Program 1-844-442-6663 | For use of Daklinza up to a maximum benefit of \$5,000 per 28-day supply of 30mg or 60mg OR up to a maximum benefit of \$10,000 per 28-day supply of 90mg | <ul style="list-style-type: none"> • You are insured by commercial insurance and your insurance coverage does not cover the full cost of your prescription; that is, you have a co-pay obligation. • You do not have prescription insurance coverage through a state or federal healthcare program, including but not limited to Medicare Part D, Medicaid, Medigap, Veterans Affairs (VA) or Department of Defense (DOD) programs. Patients who move from commercial to a state or federal healthcare program will no longer be eligible. • You are 18 years of age or older. • You are a resident of the US or Puerto Rico. |
| Genentech/Roche Product Assistance Genentech Access Solutions (Umbrella for product inquiries) 1-866-422-2377 Genentech Access to Care Foundation (for patients who do not have insurance, or have high co-pay) 1-888-941-3331 | <i>Call for further details for product specific guidelines</i> | <ul style="list-style-type: none"> • Assists eligible patients with their Genentech medicines free of charge. • Must be prescribed a Genentech medicine. • Certain financial and medical criteria must also be met. |
| Gilead Co-pay Assistance Harvoni Support Path 1-855-769-7284 | The HARVONI Co-pay Coupon Program will cover the out-of-pocket costs of your HARVONI prescriptions after you pay the first \$5 per prescription fill, up to a maximum of 25% of the catalog price of a 12-week regimen of HARVONI. The offer is valid for six (6) months from the time of first redemption. | <ul style="list-style-type: none"> • Eligible residents of the US, Puerto Rico, or US territories at participating eligible retail, specialty, or mail-order pharmacies in the US, Puerto Rico, or US territories. • Coupon not valid for prescriptions eligible for reimbursement in whole or part by federal or state health care programs (e.g., Medicaid/Medicare) or for commercial health coverage that will cover entire cost of prescription. • Allowable to use full value up front. |

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| Gilead Product Assistance Support Path Patient Assistance Program 1-855-769-7284 | <i>Call for further details</i> | <ul style="list-style-type: none"> Provides Sovaldi or Harvoni or Eplclusa at no charge for eligible patients with no insurance coverage. |
| Good Days from Chronic Disease Fund Co-pay Assistance 1-877-968-7233 | <i>Call for further details</i> | <ul style="list-style-type: none"> Provides assistance with out-of-pocket costs for hepatitis C virus prescriptions. Patients must have valid medical insurance coverage. Please note, patients who are applying for co-payment assistance must have at least 50% insurance coverage or more to be eligible for co-payment assistance, excluding deductibles. Patients must have been prescribed a medication that is part of the Good Days formulary. Patients must meet our annual household income criteria. (Note: Program may open and close throughout the year depending on funding.) |
| HealthWell Foundation Co-pay Assistance HealthWell Foundation Resource List 1-800-675-8416 | Up to \$30,000 | <ul style="list-style-type: none"> Must currently receive treatment for Hepatitis C. Must have insurance (private, federal, or state plans acceptable) that covers medication. Assists individuals with incomes up to 400-500% of the Federal Poverty Level. Household number and cost of living are also considered. Must receive treatment in the US. |
| Kadmon Pharmaceuticals Co-pay Assistance Ribasphere RipaPak Co-pay Savings Card 1-877-377-7862 | Eligible patients may save up to \$150 toward each monthly Ribasphere RipaPak co-pay for up to 18 fills | <ul style="list-style-type: none"> Self-pay patients and most commercially insured patients are eligible. Patients residing in Massachusetts and Puerto Rico are not eligible. Patients covered by Medicare, Medicaid, TRICARE, or other federal or state healthcare programs are not eligible. Patients must be five (5) years of age or older to participate. A parent or legal guardian must enroll on behalf of patients under 18 years of age. The Co-pay Savings Card is valid for Ribasphere RibaPak product only. Only one (1) Co-pay Savings Card is required per patient. |
| Janssen/Johnson & Johnson Olysio Co-pay Assistance Olysio Savings Program 1-855-565-9746 | Pay no more than \$5 per fill. \$50,000 annual maximum benefit or 12 months from card activation date, whichever comes first. | <ul style="list-style-type: none"> Must have commercial insurance. Not valid for patients enrolled in Medicare or Medicaid. Offer good only in the US and Puerto Rico. |
| Janssen/Johnson & Johnson Olysio Product Assistance Johnson & Johnson Patient Assistance Foundation 1-800-652-6227 | <i>Call for further details</i> | <ul style="list-style-type: none"> Provides Olysio for patients without public or private insurance or prescription drug coverage. Must live in the US or US Territory and be treated as an outpatient by a licensed US doctor. Must meet income eligibility guidelines. |
| Patient Access Network (PAN) Foundation Co-pay Assistance PAN Foundation Hepatitis C Program 1-866-316-7263 | \$15,000 per year | <ul style="list-style-type: none"> Patient must be getting treatment for the disease named in the assistance program to which he or she is applying. Patient must be insured. Patient's medication must be listed on PAN's list of covered medications. For full list, visit PAN's website. Patient must reside, and receive treatment in, the US. US citizenship is not a requirement. Patient's income must fall at or below 500% of Federal Poverty Level. |
| Patient Advocate Foundation Co-pay Assistance Co-pay Relief Hepatitis C Program 1-866-512-3861 | \$25,000 per year | <ul style="list-style-type: none"> Patient should be insured and insurance must cover the medication for which patient seeks assistance. Patient must have a confirmed diagnosis of hepatitis C. Patient must reside and receive treatment in the US. Patient's income must fall below 400% of the Federal Poverty Guideline with consideration of the Cost of Living and the number in the household. |

Additional Resources

| Program Name | Program Description |
|---|--|
| Assurance Wireless 1-888-898-4888 | Provides a free cell phone and limited number of free minutes to income-qualifying households. <i>Not available in every state, please check website or call for state specific information.</i> |
| AT&T Mobility Lifeline Service 1-800-377-9450 | Provides discounted cell phone service to income-eligible customers. <i>Not available in every state. Call for more information. Certain Tribal Lands also eligible.</i> |
| Colburn-Keenan Foundation 1-800-966-2431 | Provides financial assistance programs to individuals and families living with chronic conditions, with priority placed on those living with bleeding disorders. |
| Healthcare Hospitality Network 1-800-542-9730 | Provides lodging and support services to patients, families and loved ones who are receiving medical treatment away from home. |
| Internet Essentials from Comcast 1-855-846-8376 | Provides low-cost internet service and computers for income-eligible households. |
| Needy Meds 1-800-503-6897 | Provides assistance in accessing patient assistance programs for medications and health care costs. |
| Novo Nordisk NovoSecure 1-844-668-6732 | NovoSecure enrollees can apply for a variety of programs, including competitive scholarships, life coaching with HeroPath, career counseling, and insurance support. Eligibility for programs vary. Must have hemophilia A, hemophilia A or B with inhibitors, factor VII deficiency, factor XIII deficiency, acquired hemophilia, or Glanzmann's Thrombasthenia to apply. Novo Nordisk product usage is not an eligibility requirement. |
| Patient Advocate Foundation 1-800-532-5274 | Provides case management and assistance in accessing health insurance. Co-pay assistance programs are available. |
| Patient Services, Inc 1-800-366-7741 Legal Support Hotline: 1-877-851-9065 | Provides assistance with premiums and co-payments for patients with eligible chronic conditions. Helps families navigate state and federal entitlement programs and provides a legal support hotline for individuals with bleeding disorders to speak with an attorney. |
| Rx Hope | A web-based information resource to help low-income US residents access patient assistance programs. |
| Rx Outreach 1-888-RXO-1234 (188-796-1234) | A patient assistance program that provides discounts on prescription drugs. |
| Safelink Wireless 1-800-723-3546 | Provides a free cell phone and limited number of free minutes to income-qualifying households. <i>Not available in every state, please check website or call for state specific information.</i> |
| Silver Cross 1-800-572-9310 | Provides assistance in accessing recycled and new healthcare equipment. |
| The Wheelchair Foundation 1-877-378-3839 | Provides free wheelchairs for individuals without the means to obtain one. |
| United Healthcare Children's Foundation 1-855-698-4223 | Provides medical grants to help children gain access to health-related services not covered, or not fully covered, by a commercial health insurance plan. <i>Do not need to have United Healthcare to be eligible.</i> |
| United Way 211 Dial 211 | Provides free and confidential information and referrals to local services including housing, food, employment, healthcare, counseling, and more. <i>Check the website or call your local United Way to see if your state offers this service.</i> |
| Verizon Wireless Lifeline Program 1-800-417-3849 | Provides discounted cell phone service to income-eligible customers and residents of Tribal Lands. <i>Not available in every state, check website or call for state specific information.</i> |



HFA's Helping Hands Program

By Elaine Chan, MSW, MPH

At any point, families living with a bleeding disorder can experience financial hardship because of their medical situation. The Helping Hands Program has become a safety net for hundreds of families throughout the years. Helping Hands has provided many families with assistance for expenses like housing, utilities, and transportation. In addition to assistance for these basic living expenses, Helping Hands has helped individuals and families to obtain durable medical items for the care of their bleeding disorders.

Families affected by inhibitors are faced with unique medical and financial needs. The inhibitor community is challenged with bleed management, joint damage, venous access concerns, pain issues, and social and emotional distress. In addition to all these is a great financial burden. In 2016, Helping Hands expanded to provide support for families affected by inhibitors through the addition of Inhibitor Support.

Use the Following Chart to Navigate the Coverage Helping Hands Provides:

| | Emergency Assistance | Items Reimbursement | Inhibitor Support |
|-------------------------|---|---|--|
| <i>What is covered?</i> | Basic living expenses: housing, utilities, transportation | Durable medical items (i.e., medical IDs, protective gear, braces, cooling/heating supplies, fitness support) | Educational travel, medical travel, tutoring/educational supplies |
| <i>How often?</i> | Once per year | Throughout the year, depending on needs/requests | Throughout the year, depending on needs/requests |
| <i>Who can apply?</i> | Individuals and families with a diagnosed bleeding disorder | Individuals and families with a diagnosed bleeding disorder | Individuals and families with a diagnosed bleeding disorder <i>and</i> an inhibitor with measurable titer and/or shortened half life |
| <i>Referral</i> | Referral from eligible referrer* | Referral from eligible referrer and/or self-referral | Referral from eligible referrer and/or self-referral |

*Please reach out to our Helping Hands team for additional information regarding eligible referrer.

Questions and Answers:

Q If I apply for the emergency assistance, am I not allowed to apply for items reimbursement?

Completion of an emergency assistance application does not render you ineligible for reimbursement for durable medical items. Refer to "Items Reimbursement" on the website for complete eligibility details: <http://www.hemophiliafed.org/programs/helping-hands/>.

Q How long does it take to get assistance or reimbursement?

For emergency assistance requests, the process is generally completed within two weeks. For items reimbursement and inhibitor support, the process is generally completed within 30 days.

Q Can I apply for inhibitor support if I had an inhibitor before and it is tolerized?

Unfortunately, inhibitor support is only available to those with an active inhibitor: a measurable titer and/or shortened half-life.

Q How do I know if my request for help was received?

Our program coordinators will contact you within five business days to complete a phone interview for your request of assistance.

Q So I can apply for all three Helping Hands assistance areas if my family member has an active inhibitor?

Yes! All households affected by inhibitors are eligible to apply for all components of HFA's Helping Hands Program including: emergency assistance, items reimbursement, and inhibitor support.

Q I need help with my hospital bill and the co-pay for my medication. Can I get help for those?

Unfortunately, we do not offer assistance in medically-related expenses such as medical bills, co-payments, insurance premiums, deductibles, etc. Please visit our website, www.hemophiliafed.org, to access our "Navigating Patient Assistance Programs" guide for alternative resources and programs.

For additional information or questions, please contact our program coordinators at 202-675-6984 or helpinghands@hemophiliafed.org.

"HFA's been wonderful to my family and we don't know what we would've done without the support.

The Helping Hands inhibitor support assisted us with getting my family back and forth to the hospital for my son's surgeries, port removal, etc.

The help greatly relieved the stress of having our son in the hospital.

Every little bit of assistance makes a difference when your son is living with an inhibitor."



April 6-9, 2017

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Join us in Providence, RI for the largest family-friendly conference for the bleeding disorders community.

Symposium offers community members the opportunity to learn and grow. During our powerful sessions, community members can meet and bond on a personal level with other community members and presenters.

Don't miss out on this opportunity to connect with others, learn, and advocate!



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“I enjoy the interaction. Not just between the speakers and the attendees, but among the attendees themselves.”

“The speakers know how to communicate with the Spanish-speaking community.”

“My favorite part of Symposium was the knowledgeable speakers who could easily and effectively answer the questions and concerns expressed during the presentations.”