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Manufacturers' Product Assistance Programs Financial Q & A

by David Linney

Many manufacturers of factor products offer special programs to supply factor when a patient loses insurance (including reaching a lifetime cap) or has no insurance. These programs are commonly referred to as manufacturers' factor assistance or patient assistance programs. For this article, we will refer to these programs generically as *manufacturers' patient factor product assistance programs (MPFPAP)*.

Program Types

There are different types of MPFPAP. Each has its own eligibility criteria, application process and benefits. Programs should be contacted directly for specific information. Note that programs may require any one or more of the following:

- application completion;
- verification that the patient is ineligible for insurance or other third-party coverage;
- prescription documentation;
- physician/provider contact information;
- patient/family income information;
- initial patient/family contact through a manufacturer's sales representative.

General descriptions of programs sponsored by the major manufacturers follow. Descriptions of program types have been created for this article and may not be used in practice. Information is as of October 2003.

Certificate programs are often compared to frequent flyer miles programs sponsored by airlines. Under this program, factor product credits are earned based on the number of units of a particular manufacturer's product that have been received. Quarterly certificates for unit credits earned are issued. There are limits to how many unit credits can be earned per quarter and per year. Certificates can be utilized or "cashed in" at the time of a loss of insurance, including a loss due to reaching a lifetime cap. Note that the patient must have insurance to participate in a certificate program. Certificate programs have established guidelines for application, eligibility and quantity of factor product.

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From George Levy, President of Hemophilia

Patient and Program Support, Inc. (HPPS)...

With this issue, we launch the companies approved for participation in Hemophilia Patient and Program Support, Inc. for 2004-2005! Take a minute to read about HPPS and the companies that have met the high standards of service required for participation. The selection of a pharmacy/homecare that can provide your factor and the support services you may need at home is an important decision. In our Winter 2004 edition of The Winning Spirit, we provided a lot of information to help you in that selection. Many families called the DVC office to tell us about the range of prices they are being charged for factor by hospital-based homecare companies and for-profit homecare companies, as well. What we learned is that THERE IS A BIG DIFFERENCE IN FACTOR PRICES FROM DIFFERENT HOMECARE COMPANIES!! This is a REAL EXAMPLE:

Recombinate Price from a hospital-based homecare/per unit: \$1.46

Price from a for-profit homecare/per unit: \$.98

Using that real example, based on an order of 30,000 units per month for twelve months, the DIFFERENCE IN THE AMOUNT CHARGED TO YOUR INSURANCE IS almost \$180,000 per year!!!!

30,000 units per month @\$1.46 per unit = \$43,800 per month

30,000 units per month @\$.98 per unit = \$29,400 per month

Be an informed consumer and ask what you are being charged for factor. A few pennies difference in price can make a BIG DIFFERENCE in how the cost of factor impacts your benefits.

Dads in Action

A "Dad's in Action" program is being formed for this year through the Hemophilia Federation. The mission of the program is to forge a stronger bond between dads and their children....to learn not only to listen to what our children have to say, but to hear them. The program helps dads to set family priorities. The objective for this year is to organize regional groups of dads around the Delaware Valley that would meet quarterly in a supportive format and give them the opportunity to learn family life skills and techniques. One of the planned activities will be a father/child outing. If you are the father of a child with a bleeding disorder and would like more information about attending or starting a group in your area, call Art Stinger at 215-674-4492.



We Gratefully Acknowledge...the pledge of support from the following manufacturers for 2004.

American Red Cross
Monarc-M

Aventis Behring
Monoclote-P
Mononine
Helixate FS
Bioclote
Humate-P
Stimate
Gammar-P I.V.

Baxter Bioscience
Recombinate
Hemofil M
Proplex T
Feiba VH
Bebulin VH
Albumin (Human)
Advate

Bayer Corporation
Kogenate FS
Koate-DVI
Konyne-80

Grifols
Alpha Nine SD
Alphanate
SD/HT
Profilnine SD

Wyeth
BeneFixTM
ReFacto

Nabi
Autoplex T
WinRho

Novo Nordisk
NovoSevenTM

May

11 Family Dinner

June

7 Carlino's Golf
30 Wood's Camp
/Session #1

July

23 Wood's Camp
/Session #2

September

24-26 Family Camp
27 Golf Classic

On **November 6-9, 2003**, many local patients, Chapter members and medical providers from our treatment centers traveled to Salt Lake City, Utah to attend the NHFs Annual Meeting. This conference was at a five star convention arena right in the heart of SLC (great site...minimal walking!) There was a terrific youth program, as well and there was lots to do, including visiting the site of the winter Olympics, just a few years ago! The Delaware Valley Chapter sponsored a record number of patients, treatment center staff and DVC leadership. Our very own George Levy (DVC board member and HPPS president) received an NHF outstanding service award for the many hats he wears for our Chapter!! You earned this terrific recognition, George!! This conference is the only one in the United States that brings together top scientists, patients, medical providers and members of industry to discuss every issue related to bleeding disorders. Next year we will travel to Dallas Texas for the Annual Meeting, November 4-7, 2004! If you are a patient with a bleeding disorder and have never been sponsored by the DVC before, it's not too early to write to us requesting some financial help to get to Dallas! *P.S. Philadelphia has just been chosen as the site for the 2006 National Hemophilia Foundation Annual Meeting!! We are already planning some surprises for our guests from around the country!! Stay tuned for more information!!!*

On Saturday, **December 13, 2003**, we had our Chapter **Annual Holiday Party** at Jefferson Alumni Hall in Philadelphia. As in the past, children from the local treatment programs brought their families to a day of food, fun, presents and terrific entertainment! Santa was there with lots of surprises for everyone! Many thanks to Pat, Bill and Patti Johnson and their wonderful committee who put together a day to remember...all year long!! Join us next year for this great event on Saturday, December 11, 2004!!

On the last cold weekend of **January**, Penny and Mark Deeney (DVC super volunteers!!) attended the **NACCHO (North American Camping Conference of Hemophilia Organizations)** in Arizona. This conference, sponsored by Wyeth, brought volunteers from 37 different states to share and learn about camps for the bleeding disorders community. Of course, Penny and Mark brought our Family Camp design with them to share and they came home with a lot of information for the Delaware Valley Chapter Family Camp Planning Committee.

The theme "Blazing a Trail to the Top" and the presentations focused on helping today's kids with bleeding disorders become tomorrow's community leaders!! Many thanks to Penny and Mark for bringing many terrific ideas back with them!! P.S. Don't forget to attend the DVC Family Camp Weekend on September 24, 25 and 26, 2004!!



On **March 10-12**, a delegation from Pennsylvania traveled to DC for "**NHFs Washington Days.**" We spent three days in training to learn about issues that are important to the bleeding disorders community. We made visits to our local representatives and senators to ask for their support on three important issues:

Hepatitis C Prevention and Research

S. 1143/H.R. 3539

Access to Health Insurance

Women's Bleeding Disorders

H. Con. Resolution 314

After making our visits, we were able to get the commitment of many elected officials for these three issues. We have expanded the "Legislative Update" section of this issue of *The Winning Spirit* to give you more detail. Our final day was spent in State Advocacy training. We came away with a lot of tools that we can use for Pennsylvania health insurance reform. If you would like to help us by making visits to your local congress members and writing some letters, please call the DVC office!! Many hands make light work!! We need you!!

Our "famous" Ladies' Committee, under the leadership of Jennifer Sawyer and Lynn Lindquist (co-chairs), held the DVC's **Annual Fashion Show and Luncheon**, on Saturday, **April 3rd!** The theme, "Escape to the Cape" was an experience beyond belief!! Sam Katz, a famous "Distinguished Philadelphian" entertained more than 400 women who supported this event, again this year. Thanks to this wonderful committee who did all of the work, thousands of dollars were raised to fund local needs right here in the Delaware Valley area. Many thanks to our dedicated volunteers who worked so hard to make this day a hit! Next year, the Annual Fashion Show and Luncheon will be held on April 16, 2005 at the Drexelbrook Conference Center. Sadly, the Jefferson House is closing...but we will always cherish our memories of many, many spring fashion shows and the wonderful friends who attended each year. We know they will be back again next year at our new location!!

Save these Dates

Family Camp September 24-26, 2004

Registrations will be mailed with the summer newsletter.

Annual Golf Classic September 27, 2004

Meadowlands Country Club

Invitations will be mailed.

Manufacturers' Product Assistance Programs Financial Q & A

Aventis Behring/Choice Assurance (1-866-415-2164; www.ChoiceAssurance.com) Factor product credit certificates are issued every three months, based on utilization of Helixate FS, Humate P, Mononine or Monoclate-P. Patients can redeem up to one year of product. Maximum amounts redeemable vary by product. Certificates are good for five years after being issued. Patients with health insurance, but not Medicare and Medicaid, are eligible to participate. (The program is administered by a third-party administrator.)

Baxter/Factor Assist Program (1-800-888-4502; www.factorassist.com) Factor product credit certificates are issued every three months based on utilization of Advate, Recombinate, Hemofil M or FEIBA VH. Patients are eligible to earn up to 25,000 units per year in credits and up to 100,000 units in credits over four years. Certificates are good for five years after being issued. Patients with all types of insurance, including Medicare and Medicaid, are eligible to participate. (The program is also administered by a third-party administrator.)

Bayer (1-800-288-8374) A new program is to be launched in 2004. Call the reimbursement help line number listed above for specific details.

Specialty assistance programs are established to provide factor product when a patient is without insurance. Programs have specific eligibility criteria, an application process and factor product benefit limits.

Aventis Behring/Patient Assistance program (1-800-676-4266; www.aventisbehring.com) For uninsured, underinsured and patients with financial hardship, up to a three month supply of Helixate FS, Humate P, Mononine, Monoclate-P or Stimate can be provided. A form is completed by a physician and the patient/family. After three months, patient eligibility is reevaluated and benefits may be extended. A patient does not have to be a user of Aventis products to be eligible for the program, which forwards product to the physician/provider. Emergency factor product needs are considered as well under a separate process.

Baxter/Factor Plus Program (1-800-548-4448) For uninsured and financially needy patients, Baxter resupplies providers with Advate, Recombinate, Hemofil M or FEIBA VH after the product is dispensed. Provider enrollment and patient enrollment applications are required, as is a physician certification form. Initial enrollment is for three months and may be extended up to one year. The maximum amount of product is 80,000 units. In case of medical necessity, this amount may be increased. A patient does not have to be a user of Baxter products to be eligible for the program, but the provider

must be a Baxter customer. Note that this program is not an emergency program (The program is administered by a third-party administrator.)

Bayer (1-800-288-8374) This is a new program to be launched in 2004. Call the reimbursement help line number listed above for specific details.

Wyeth/BeneFix Patient Assistance and Refacto Patient Assistance Program (1-888-999-2349; www.hemophiliavillage.com) For uninsured patients, up to a three month supply of BeneFix or ReFacto is supplied. Up to 75,000 units can be provided. A form is to be completed by a physician and the patient/family. The program has income eligibility requirements and is need-based. However, the program is flexible and extenuating circumstances are considered. A patient does not have to be a user of Wyeth products to be eligible for the program. Product is forwarded to the physician/provider. (The program is administered by a third-party administrator.)

Special request programs are less formalized programs that provide factor product when a patient is without insurance. Manufacturers determine eligibility and quantity of factor product on a case by case basis after a request is made.

American Red Cross/CrossCare (1-877-235-6075; hemaspheres@usa.redcross.org) Benefit approval for Monarc-M is made after contact by the patient/family or healthcare provider. Product is supplied to the treader. A patient does not have to be a user of Monarc-M.

Grifols (formerly Alpha) (1-800-421-0008) Benefit approval for Alphanate, Alphanine and Profilnine is made after contact with a Grifols sales representative.

Novo Nordisk (1-877-668-6777, Option 3) Benefit approval for NovoSeven is made after contact through the reimbursement hotline number listed above. NovoSeven is supplied quarterly, on a replacement basis, to the institution who provides the product.

COMMENTS

- For any manufacturer not listed, contact the manufacturer directly for information about their PFPAP.
- Your homecare vendor should be another resource for information about MPFPAP.
- MPFPAPs should never be considered a substitute for insurance. These programs only provide a limited amount of factor product and do not cover any other medical services.



Access To Health Insurance

A Perspective of the National Hemophilia Foundation Discussed with Legislators at 2004 Washington Days



Access to adequate, affordable health insurance is the top concern today for patients with bleeding disorders. As the safety and availability of clotting factors has improved in the United States, families affected by these disorders face the burden of obtaining and maintaining insurance. In our nation's fragmented insurance market, patients with chronic disorders can be left with few coverage options, debt-inducing out-of-pocket costs and dependence on government and corporate assistance programs.

Because of the high per patient cost of treatment, patients with bleeding disorders face a number of hurdles to obtaining and maintaining insurance and meeting co-payment requirements. Obstacles include:

Access to Affordable and Continuous Insurance

People with chronic and expensive disorders feel limited in their employment and career options, a situation heightened by a lack of alternative insurance options and variances in coverage between plans and states. Many small employers do not offer insurance coverage and those that do, often are unable to sustain insurance for a "high cost" employee. With rising health insurance costs, even large employers are finding it more difficult to maintain comprehensive insurance benefits for their employees.

Insurance markets and programs should be reformed to ensure affordable and continuous insurance coverage is available for all people, regardless of employment, residency, age, income or health status. Potential avenues for expanding coverage include income-related buy-in options into state Medicaid programs and the Federal Employees Health Benefit Program, mandated guaranteed issue requirements for both group and individual policies and removal of pre-existing condition exclusions on all policies regardless of previous insurance history.

Lifetime Caps

Many private insurance plans offer lifetime caps of \$1 million, a figure imposed nearly 30 years ago to give plan participants a sense of protection. Today, these caps are used to "weed" out people with chronic conditions or people requiring expensive

treatments. Caps on even state high risk pools can be as low as \$250,000, limiting the utility of this otherwise highly-beneficial program to people with chronic disorders.

Lifetime caps on health insurance should be eliminated, or at least raised to be commensurate with today's rising health care costs.

Access to All Clotting Factor Products

Clotting factor products are not therapeutically equivalent and do not perform the same way in all patients with hemophilia or related bleeding disorders. These products are biologicals for which there are no generic alternatives. Patients with bleeding disorders require access to the full range of products available to manage their bleeds most effectively, prevent joint injury and avoid hospitalization. Under the guise of cost containment, some health plans and state programs, particularly managed care, seek to limit coverage to a single product or to one product per type of disorder. These programs are not cost-effective and, in fact, can raise costs and result in less than optimal outcomes.

Coverage and access to all clotting factor products should be mandated in all health insurance and prescription drug plans.

Reasonable Out-of-Pocket Requirements

Because of the high costs of clotting factor, co-payment requirements that may seem reasonable for healthy people become unbearable for patients with bleeding disorders. While many private insurance plans do cap out-of-pocket costs, the cap can be as high as \$6,000 to \$10,000 annually, an extremely heavy burden on families who must bear this cost year after year.

Perhaps the heaviest burden, however, falls upon Medicare beneficiaries with bleeding disorders who are responsible for a full 20 percent of their factor cost. The average Medicare-eligible person with hemophilia has a severe form of the disorder with frequent bleeds, disability from joint damage and significant impacts from HIV/AIDS and hepatitis C. Approximately 1,100 Medicare beneficiaries have hemophilia. For these individuals, the Medicare co-payment requirement easily can translate into \$15,000 to \$45,000 annually.

Realizing that patients with hemophilia face the highest per patient treatment cost of all diseases, out-of-pocket expenses should be income-based and adjusted for families and individuals dependent upon high-cost, life-sustaining drugs.



Hepatitis C Prevention and Research

A Perspective of the National Hemophilia Foundation Discussed with Legislators at NHFs 2004 Washington Days

The National Hemophilia Foundation is urging legislators in Washington to become cosponsors of S.1143 and H.R.3539, the Hepatitis C Epidemic Control and Prevention Act. This legislation is needed to promote a comprehensive, coordinated effort for preventing and reducing the impact of hepatitis C.

Background

Prior to 1990, the risk of contracting the hepatitis C virus (HCV) from donated blood or plasma was between 8 and 10 percent for the general population. The risk was amplified for patients with bleeding disorders, as, at that time, clotting factor was manufactured from pools containing plasma from as many as 60,000 to 400,000 donors.

Today, HCV testing and deferral of blood and plasma donors and improved viral inactivation technologies used in the manufacturing of clotting factor have improved the safety of the nation's blood supply and blood products. The toll on the bleeding disorders community, however, remains quite high. The Centers for Disease Control (CDC) estimates 6,200 individuals in the bleeding disorders community are affected, or nearly 45 percent of all people with hemophilia.

Need for Greater Coordination and Outreach

Overall, nearly four million people in the United States are infected with HCV, with transmission by blood or blood products accounting for 10 percent of these cases. Of those affected, an estimated 2.5 million are not receiving treatment. HCV is known as the "silent killer" because, without testing, its presence may not be known until the late stages of the disease.

The Hepatitis C Epidemic Control and Prevention Act would authorize and provide support for a comprehensive prevention, research and medical management referral program for HCV infection. The bill calls for:

1. Development and implementation of a federal prevention, control and management plan for HCV including strategies for education and training, surveillance and early detection and research.
2. Support for state, local and tribal testing/counseling programs, including vaccination against hepatitis A and B and other infectious diseases.
3. Establishment of HCV surveillance databases for monitoring of the disease by the CDC.
4. Establishment of a Liver Disease Research Advisory Board to coordinate research efforts within the National Institutes of Health (NIH).
5. Development of clinical research networks by the NIH to improve treatment and management of HCV, including new approaches to prevention such as vaccines.

Need for Improved Treatments

While diagnosis and treatment methods for HCV are improving, overall the success rate for controlling the disease remains low. Current HCV treatments also produce adverse side effects such as flu-like symptoms, weight loss and depression. Key HCV research priorities for the bleeding disorders community include:

- Basic research to enhance the scientific understanding of HCV and define the natural history of chronic HCV infection.
- More effective, less toxic HCV treatments and management of side effects.
- Treatment recommendations for currently available drugs and updated recommendations for new drugs as they become available.
- Optimal monitoring tests, specifically which tests and how often, as well as indications and mechanisms for liver biopsy.
- Noninvasive markers to predict disease severity among those at greatest risk for end stage liver disease and to identify which patients will benefit most from treatment.

These priorities are mirrored in the recommendations emerging from the 1999 and the 2002 NIH HCV consensus conferences.

Support for Legislation.

Your support is needed to ensure passage of the Hepatitis C Epidemic Control and Prevention Act this year. The Senate bill (S.1143) is sponsored by Senators Kay Bailey Hutchison (R-TX) and Edward Kennedy (D-MA). Congresswoman Heather Wilson (R-NM) is the lead sponsor for the House bill (H.R.3539).

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Hepatitis C Class Action Lawsuit

In the Fall issue of the Winning Spirit newsletter, you should have received information regarding a class action lawsuit for patients infected with HCV (hepatitis C). If you, or someone you know, would like to find out more about this lawsuit, intended to provide a cash settlement for anyone with hemophilia or von Willebrand Disease who meets the criteria for the class, please call the Delaware Valley Chapter office (215-885-6500).

We have applications in the office. If you are not affected by this issue or do not wish to participate, please disregard this notice.

Following is a current cosponsor list for PA and DE for the Hepatitis C Epidemic Control and Prevention Act as of March 2004.

Senate Cosponsors of S.1143

Joseph R. Biden, Jr. (DE)

No co-sponsors from PA
House Cosponsors of H.R.3539
Michael F. Doyle (PA-14)
Phil English (PA-3)
Tim Holden (PA-17)
No co-sponsors from DE

Women's Bleeding Disorders

A Perspective of the National Hemophilia Foundation Discussed with Legislators at NHFs 2004 Washington Days

The National Hemophilia Foundation is urging legislators in Washington to become cosponsors of House Concurrent Resolution 314 introduced by Congresswoman McCarthy (D-NY) to raise awareness about women's bleeding disorders.

Approximately one to two percent of all people in the United States are affected by bleeding disorders, with von Willebrand Disease being the most common inherited bleeding disorder. Women are most affected by the disorder, yet most women and their health care providers have little knowledge of these disorders, leaving the majority of these women undiagnosed and without effective medical treatment. Women are at most risk for traumatic bleeding during childbirth, surgeries and even basic services like dental care. Other symptoms include bruising, nosebleeds and heavy menstrual cycles. Although there is currently no cure, effective treatments are available if the disorder is properly diagnosed.

The resolution calls for:

1. Appropriate screening for women and girls with excessive menstrual bleeding prior to the initiation of treatment. As many as 20 percent of these women have von Willebrand Disease.
2. Evaluation prior to hysterectomy to rule out the possibility of a bleeding disorder. Severe bleeding is a leading reason for hysterectomy among U.S. women of child-bearing age.
3. Referrals of women with a bleeding disorder to a federally-sponsored hemophilia treatment center for comprehensive treatment.
4. Strengthening of public education and outreach campaigns such as the Project Red Flag program conducted

by the National Hemophilia Foundation and the Centers for Disease Control and Prevention.

5. Increased funding for research to improve diagnostic testing and treatment.

Passage of H. Concurrent Resolution 314 is a key step to ensuring millions of women receive appropriate treatment for their bleeding disorder.

Following is a current cosponsor list for PA and DE for the Women with Bleeding Disorders House Concurrent Resolution 314 as of March 2004.

Michael F. Doyle (PA-14)
No cosponsors from DE

If you live in Pennsylvania or Delaware and would be willing to make a visit to your local U.S. Congressman or Senator to ask for their support for these two important issues, please contact the DVC office right away (215-885-6500).

We will be able to give you all the information you need to help your legislators understand how they can become a cosponsor of the bill for Hepatitis and the resolution for Women's Bleeding Disorders. We need your help to get all legislators from PA and DE signed on as cosponsors!!

The Delaware Valley Chapter and the Cardeza Foundation Hemophilia Center are working collaboratively in a project called "I Have von WilleWHAT" to help identify women in Philadelphia County who may have von Willebrand Disease. This year-long project will offer a CME credit course for OB-GYN physicians as part of our activities. For more information about women with bleeding disorders, contact the DVC office (215-885-6500).

**“In the long run,
you hit only
what you
aim at.**



**Therefore,
though you
should fail immediately,
you had better aim
at something high.”**

Henry David Thoreau, American
Naturalist and Writer (1817-1862)

FYI

Baxter Healthcare Corporation announced in July 2004 that the U.S. Food and Drug Administration (FDA) has approved ADVATE (Antihemophilic Factor [Recombinant], Plasma/Albumin-Free Method), rAHF-PFM for the prevention and control of bleeding episodes in people with hemophilia A. ADVATE is the first factor VIII made without any added human or animal plasma proteins and albumin in the cell culture process, purification and final formulation. ADVATE is the first, third generation product used in the treatment of hemophilia A.

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Manufacturers' Product Assistance Programs Financial Q & A

- While certainly not all patient/family special needs requests for factor product are approved, manufacturers in general are very responsive and try hard to be supportive of special needs requests.
- For most manufacturer's programs, supply of factor product is not an issue. However, there may be circumstances (i.e. in the case of a shortage) where supply may be subject to availability.
- Aventis Choice Assurance and Baxter Factor Assist (and potentially the "new" Bayer program) offer a guarantee of factor product credit based on patient utilization.
- The Aventis Patient Assistance Program, Baxter Factor Plus and Wyeth/Patient Assistance Program and BeneFix Patient Assistance Program (and potentially the "new" Bayer program) have established eligibility criteria and product benefit limits, yet administer program benefits with some flexibility.
- The American Red Cross/CrossCare and the Novo Nordisk programs are less formalized but established programs, which administer benefits flexibly on a case by case basis. Grifols' program is even less formal, whereby requests are considered strictly on a case by case basis.
- When a patient/family loses insurance or has no insurance, it is important to consider other health insurance options as well as state, federal and private benefit assistance programs. For help, follow-up with any of the following resources (not necessarily all-inclusive): your hemophilia treatment center; your local/state chapter of NHF; NHFs information and resource center, HANDI at 800-42-HANDI; other hemophilia/bleeding disorder organizations; the reimbursement department of your homecare vendor; and the reimbursement departments of manufacturers.

Previous article taken from HemAware, January/February 2004 Issue. HemAware is a publication of the National Hemophilia Foundation.