There for you with Patient Resources

Educational Materials for All Ages
We realize that it takes more than factor therapy to live life to the fullest. By listening to many members of the hemophilia community, we’ve developed a range of resources that can help from childhood to adulthood.

Resources for Spanish-speaking Patients
Along with offering many of our kits in Spanish, we also provide bilingual healthcare educators at live Baxter events to address the needs of Spanish-speaking patients and their families.

Visit your treatment center or your online hemophilia resource www.thereforyou.com for additional information on tools and resources to help you at every stage of life.
4 The Wonders of Factor
A native of Columbia, South America, Alex Hoyos grew up with mild hemophilia A. Fear of tainted blood at the time meant that his family avoided using factor. Standard protocol for injuries required weeks or months confined to a bed so a clot could form. Now 28 years old and living in the United States, Alex recently discovered the wonders of factor and is enjoying the benefits.

8 HMO Trauma: When Denied Treatment, Defend Yourself
Dealing with an HMO that has denied you or a family member's treatment can be frustrating. Learn the steps you can take to improve your chances of a favorable outcome if faced with this challenging situation.

10 Winter Sport Safety
Winter weather brings with it a host of new and fun outdoor activities to enjoy during the season. While these activities are certainly fun, do not forget about safety. Find out what you can do to stay safe and injury free while enjoying the snow and cold.

14 Scholarship Opportunities
Did you know that numerous scholarship opportunities exist for individuals in the bleeding disorder community? If you or someone you know is preparing for college and has a bleeding disorder, you will want to share this helpful information with them.

16 Hemophilia News

19 Kids’ Corner
Growing up with mild hemophilia A in Colombia, South America, taught Alejandro Hoyos (also known as Alex) two life skills: patience and video game proficiency. Fear of tainted blood product meant avoidance of factor in his family, so treatment for bleeds required lying still in bed for weeks or even months.

“If I had a tooth extracted,” explains 28-year-old Alex, “I had to stay in bed a week or more from the time the clot formed or the clot would fall. Then the wound would open again, and I’d have to start the process all over.”

Although Alex has lived in the United States for nearly 11 years and earned his master’s degree in electrical engineering, lifelong patterns take time to change. It was just a year ago that he took factor for the first time. He was amazed at how quickly his injury healed. It brought to mind the three months of summer vacation he spent in bed after dislocating his ankle during a basketball game.

“I couldn’t believe the bleeding stopped in 10 minutes. I thought man, if I’d taken this back then, I could actually have had a summer.”

All five of Alex’s uncles on his mother’s side of the family have hemophilia of various degrees of severity, and his mother basically grew up taking care of her brothers when they had bleeding episodes. In those days, fear of plasma-based factor tainted with hepatitis C or HIV meant treating episodes with either bed rest or, in case of serious injury, transfusions. Those traditional methods for treating bleeds remained in effect in Alex’s family even after the factor in Colombia became recombinant product. It was partly in the spirit of “if it ain’t broke, don’t fix it,” and partly because the product was expensive. Fortunately, there were caregivers in his native Pereira, Columbia, who were familiar with hemophilia. His dentist, for example, had two boys with hemophilia so she knew the care necessary when treating Alex.

“Actually, there is a network of people with hemophilia in Pereira, people from all walks of life — doctors, dentists, accountants,” says Alex. “If you needed help, you knew who to contact. In addition, there is a nonprofit organization created in 1974 to help people with hemophilia or other bleeding disorders. If someone is diagnosed with hemophilia, their doctor often encourages them to join the organization because it provides information and help with obtaining medicine. Our family simply opted not to use any type of medicine unless it was a critical situation.”

When Alex moved to Florida to attend college at age 17, he had relatives close by. One of his uncles living in the United States told him about the availability of factor and suggested he look into it.
BE PART OF NEXT-GENERATION PURIFICATION

Completely albumin-free manufacturing AND a state-of-the-art purification process

*The chemically defined cell culture medium in which the Chinese hamster ovary (CHO) cells are grown contains artificial insulin but does not contain any materials derived from human or animal sources. XYNTHA contains trace amounts of hamster protein. You may develop an allergic reaction to these proteins. Tell your doctor if you have had an allergic reaction to hamster protein.

**Indication**

- XYNTHA Antihemophilic Factor (Recombinant), Plasma/Albumin-Free is indicated for the control and prevention of bleeding episodes in patients with hemophilia A (congenital factor VIII deficiency or classic hemophilia) and for surgical prophylaxis in patients with hemophilia A.
- XYNTHA does not contain von Willebrand factor and, therefore, is not indicated in von Willebrand’s disease.

**Important Safety Information**

- Allergic reactions are possible with XYNTHA. Signs of an allergic reaction may include hives, rash with itching, chest tightness, difficulty breathing, faintness, or fast heartbeat. XYNTHA contains trace amounts of hamster protein. You may develop an allergic reaction to these proteins. Tell your doctor if you have had an allergic reaction to hamster protein.
- Call your doctor right away if bleeding is not controlled after using your factor VIII replacement therapy; this may be a sign of an inhibitor. Inhibitors have been observed in patients receiving factor VIII products, including XYNTHA.
- The most common adverse reaction in study 1 is headache (24% of subjects) and in study 2 is fever (41% of subjects). Other common side effects of XYNTHA include nausea, vomiting, diarrhea, or weakness.
- XYNTHA is an injectable medicine administered by intravenous (IV) infusion.

Please see brief summary of full Prescribing Information on adjacent page.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

If you do not have prescription drug insurance and need help paying for XYNTHA, Wyeth may be able to help. Visit us at www.wyeth.com or call us at 1-888-999-2349 for more information.

Check out www.xyntha.com and ask your doctor if XYNTHA is right for you.

Antihemophilic Factor (Recombinant), Plasma/Albumin-Free

References: 1. Xyntha™ Antihemophilic Factor (Recombinant), Plasma/Albumin-Free Prescribing Information, Wyeth Pharmaceuticals Inc. 2. Data on file, Wyeth Pharmaceuticals Inc.
Brief Summary
See package insert for full Prescribing Information. This product’s label may have been updated. For further product information and current package insert, please visit www.wyeth.com or call our medical communications department toll-free at 1-800-934-5556.
Please read this Patient Information carefully before using XYNTHA and each time you get a refill. There may be new information. This leaflet does not take the place of talking with your doctor about your medical problems or your treatment.

What is XYNTHA?
XYNTHA is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia A. Hemophilia A is also called classic hemophilia.
XYNTHA is not used to treat von Willebrand’s disease.

What should I tell my doctor before using XYNTHA?
Tell your doctor about all of your medical conditions, including if you:
- are pregnant or planning to become pregnant. It is not known if XYNTHA may harm your unborn baby.
- are breastfeeding. It is not known if XYNTHA passes into your milk and if it can harm your baby.
Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.

How should I infuse XYNTHA?
See the step-by-step instructions for infusing in the complete patient labeling.
You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using XYNTHA.
Your doctor will prescribe the dose that you should take.
Your doctor may need to take blood tests from time to time.
Talk to your doctor before traveling. You should plan to bring enough XYNTHA for your treatment during this time.

What if I take too much XYNTHA?
Call your doctor if you take too much XYNTHA.

What are the possible side effects of XYNTHA?
Allergic reactions may occur with XYNTHA. Call your doctor or get emergency treatment right away if you have any of the following symptoms:
- wheezing
difficulty breathing
turning blue (look at lips and gums)
fast heartbeat
swelling of the face
faintness
rash
hives
Your body can also make antibodies, called "inhibitors," against XYNTHA, which may stop XYNTHA from working properly.
Some common side effects of XYNTHA are headache, fever, nausea, vomiting, diarrhea, or weakness.
These are not all the possible side effects of XYNTHA.
Tell your doctor about any side effect that bothers you or that does not go away.

How should I store XYNTHA?
Do not freeze XYNTHA.
Store XYNTHA in the refrigerator at 36° to 46°F (2° to 8°C). XYNTHA can last at room temperature (below 77°F) for up to 3 months. If you store XYNTHA at room temperature, be careful to write down the date you put XYNTHA at room temperature, so you will know when to throw it out. There is a space on the carton for you to write the date. Throw away any unused XYNTHA after the expiration date.
After reconstituting XYNTHA, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.
Store the diluent syringe at 36° to 77°F (2° to 25°C).
Do not use reconstituted XYNTHA if it is not clear to slightly opalescent and colorless.

What else should I know about XYNTHA?
Medicines are sometimes prescribed for purposes other than those listed here. Do not use XYNTHA for a condition for which it is not prescribed. Do not share XYNTHA with other people, even if they have the same symptoms that you have.
If you would like more information, talk to your doctor. For infusion and storage instructions, you can ask your doctor or pharmacist for information about XYNTHA that was written for healthcare professionals.
This brief summary is based on XYNTHA™ [Antihemophilic Factor (Recombinant), Plasma/Albumin-Free] Prescribing Information W10528C004, revised April 2008.

Wyeth®
Wyeth Pharmaceuticals Inc.
Philadelphia, PA 19101
“When we moved to the United States, I didn’t start taking medication until my uncle suggested doing a little more research on the topic. He has a more serious case of hemophilia than I do. Once I started working and was able to acquire a better insurance plan, I started looking into it and going to a hematologist. My uncle talked to me about Coram and factor, and that’s how I met Coram’s consumer advocate.”

After receiving his degree in electrical engineering in Florida, Alex moved to California for a job. The advent of factor has definitely impacted his life. Although he began jogging and going to the gym in Florida, he has also added rock climbing to his activities. And then there is the dental work he plans to have.

“I’m going to have my wisdom teeth removed at the end of the year. I need them extracted but wouldn’t be doing it if I hadn’t discovered factor.”

The experience that Alex and his uncle have had with the healing capacity of factor has had a far-reaching impact on the family. Despite what Alex teasingly refers to as their “stubbornness,” Alex’s other uncles are starting to come around. One uncle in Venezuela recently had an operation — and the family sent factor to him.

If Alex has any children in the future with a bleeding disorder, they will have to learn patience and video game skills in a way that does not involve lying in bed for weeks or months.

“Yeah, it was a drag,” Alex says. “I don’t recommend having a kid stay in bed for so long.”

Alex and his girlfriend Delia.
“Cost containment” seems to be the catch phrase of the political scene today when it comes to healthcare. How can patients or their allies help themselves if they are denied treatment? Here are some suggestions:

- Try negotiation. Reasonableness always includes a reasonable timetable. When will a decision be made to approve care? Who is the decision-maker? How long will it take to schedule the procedure? These are the types of standards someone negotiating with their HMO or HMO doctor should require.

- Be persistent. Because most patients cannot sue HMOs for a denial or delay of treatment and receive damages if they prevail, the company has an incentive to stonewall. A seriously ill patient may not have the energy for a struggle so others close to them must take on that role.

However, most states have regulations establishing the timeframe that a treatment or coverage decision must be made. Find out what those timelines are. In addition, non-government groups that accredit HMOs may have more stringent timeline requirements. Find out if your HMO is a member of organizations such as the National Committee for Quality Assurance (NCQA), American Accreditation HealthCare Commission/URAC, or the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO). Know that organization's timeline requirements for the health plan's decision-making process.

- Write everything down. Bring a notepad and pen and take notes on what your doctor tells you. It will help keep track of your care, catch any errors, and provide a record.

- If you are denied care, ask for it in writing. You will need a record of the denial if you want to dispute it. Leave a “paper trail.”

- Appeal treatment denial to regulators. Find the appropriate state agency and their rules for filing a complaint. Medicare and Medicaid recipients can take a complaint to the federal Health Care Financing Administration. Patients should be persistent. HMOs do not like having a lot of documented complaints.

- Complain to the accrediting organization. HMOs rely on their accreditation by non-governmental organizations (NCQA, URAC, and JCAHO) for marketing to employers and unions. In addition to copying your documentation to the state regulators, send a copy to any accrediting organization where your HMO is a member.

- Find allies in the medical profession. When medical experts advocate care, HMOs find it harder to deny treatment. Insist on second or third opinions from a qualified professional. If your HMO will not pay for a second opinion, pay out of your own pocket. It could save your life.

- Ask how your doctor is paid. Under new rules, Medicare recipients are entitled to see a summary of their physician’s contract with their HMO, which
gives details of any incentive to withhold treatment. Many states also require that this information be given to plan members if requested. Ask for it.

• Do not take “no” for an answer. Ask if there are treatment options available for you other than those the HMO recommends. If you have a problem, take it up the ladder — fast.

• Have a spouse, loved one or friend present when discussing your treatment plan. Having an advocate present to monitor what is happening around you can be beneficial in ensuring you get the treatment you that need.

• Always maintain a reasonable, professional demeanor in person and in writing. If you lose control, make threats of violence or use foul language, you may simply be dismissed.

• Obtain legal counsel if you believe, or it is apparent, that your efforts at negotiation with the insurance company are unsuccessful.

• If possible, do not give up the right to go to court. Avoid signing arbitration agreements that limit your judicial options. Cross out arbitration clauses and initial them. Some insurers require you to file complicated internal complaints before going to court. Follow these instructions exactly, but do not delay in consulting a lawyer in the meantime.

Jamie Court is a Consumer Healthcare Advocate with the Foundation for Taxpayer and Consumer Rights. Reprinted with permission from United Policy Holders: www.unitedpolicyholders.org
Winter brings a variety of new outdoor sports with different safety precautions. To ensure you and your family’s safety, please review the following suggestions before participating in these fun and much anticipated winter activities.

Sledging

- Make sure the sled is sturdy, easy to maneuver, and the handles are easy to hold. Most important of all is that the sled is in good condition — no parts are broken or missing.
- Sit on the sled facing forward only when going downhill. Do not lie down either head or feet first.
- Dress for weather conditions — gloves, boots, and a coat. Most importantly, wear a helmet (this can be a bike helmet) to protect against head injuries. Avoid scarves or any article of clothing that hangs outside of the coat since they may get caught while going downhill and cause injuries such as choking.
- Choose a safe area — those specifically designated for sledding such as hills without obstacles (trees, stumps, ponds, lakes or streets). Sled on packed snow and avoid icy areas.
- Do not have the sled pulled by a car, truck, snowmobile or any motorized vehicle.

Ice Skating

- Make sure your skates are sharp, in good condition and fit properly.
- If you are skating on a pond or lake, have an adult check the ice to make sure it is safe. The ice should be smooth and at least four inches thick.
- Elbow and knee pads are suggested for younger children.
- When playing hockey, wear thick gloves and a helmet with a face covering.

Tobogganing

- The area should be free of obstacles such as trees, rocks and fences. Also avoid places by lakes, rivers and other icy areas.
- The best place is an area that has been designated for tobogganing. As with sledding, sit on the toboggan facing forward only. Do not lie down either head or feet first.
- Avoid any loose articles of clothing such as scarves or some types of long stocking caps.

Skiing/Snowboarding

- Make sure the equipment is in good and safe condition.
- Helmets strictly designed for skiing/snowboarding are now required at many ski resorts.
- Avoid any loose clothing that may get caught in the towrope or lift.
- Choose ski/snowboard areas appropriate to your level of ability.

continued on page 13
For the treatment of hemophilia A

because being carefree is in his nature... he needs the real protection of Kogenate® FS with BIO-SET®

Real safety is multidimensional
- State-of-the-art purification process
- Zero confirmed cases of virus transmission
- Low inhibitor rates
- Exclusive tamper-evident/anticounterfeiting packaging features

Real efficacy is long-standing
- 20 years of proven clinical efficacy
- 93.5% of bleeding episodes managed with 1 to 2 infusions

Real life demands convenience
- BIO-SET® self-contained, needleless rFVIII reconstitution system
- Small volume diluent for fast, easy treatment
- Grab & Go packaging—compact, complete, convenient

Kogenate® FS with BIO-SET® delivers real solutions for real life

Please consult with your healthcare provider to determine if Kogenate® FS is appropriate for you.

Kogenate® FS is a recombinant factor VIII treatment indicated for the treatment of hemophilia A. The most frequently reported adverse events were local injection site reactions, dizziness, and rash. Known intolerance or allergic reactions to constituents of the preparation is a contraindication to the use of Kogenate® FS. Known hypersensitivity to mouse or hamster protein may be a contraindication to the use of Kogenate® FS.

*No factor VIII inhibitors have developed in the 72 previously treated patients with severe hemophilia A who have received Kogenate® FS for a mean of 54 exposure days. In trials with previously untreated and minimally treated patients, half of the patients have achieved 20 or more exposure days, and the incidence of inhibitor formation (15%) is consistent with that observed in other pediatric studies using plasma-derived and recombinant factor VIII products.

For important safety and use information, please see Brief Summary on adjacent page.

†With the Kogenate® product line.
‡During clinical trials with previously treated patients; n=2585 bleeding episodes.
§2.5 mL for 250 IU, 500 IU, and 1000 IU product sizes; 5.0 mL for 2000 IU product size.


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BIO-SET is a registered trademark of Biodome SAS.

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Kogenate® FS
Formulated with Sucrose
With BIO-SET®

INSTRUCTIONS AND USAGE
Kogenate FS is indicated for the treatment of classical hemophilia (hemophilia A) in which there is a deficiency of plasma clotting factor VIII. Kogenate FS provides a means of temporarily replacing the missing clotting factor in order to correct or prevent bleeding episodes, or in order to perform emergency or elective surgery in hemophiliacs.

In clinical studies with the predecessor product KODEGATE® Antithemophilic Factor (Recombinate), some patients who developed inhibitors on study continued to manifest a clinical response when inhibitor titers were less than 10 Bethesda Units (BU) per mL. When an inhibitor is present, the dosage requirement for FVIII is variable. The dosage can be determined only by clinical response, and by monitoring circulating FVIII levels after treatment (see DOSAGE AND ADMINISTRATION). Because Kogenate FS has similar biological activity to KODEGATE it can be administered in the same manner.

Kogenate FS does not contain von Willebrand’s factor and therefore is not indicated for the treatment of von Willebrand’s disease.

CONTRAINDICATIONS
Known intolerance or allergic reactions to constituents of the preparation.

warnings
None.

precautions
General
Kogenate FS is intended for the treatment of bleeding disorders arising from a deficiency in FVIII. This deficiency should be proven prior to administering Kogenate FS.

In vitro evaluation of the mutagenic potential of rFVIII failed to demonstrate reverse mutation or gene conversion. rFVIII is not expected to produce recombinant human chorionic somatomammotropin.

Carcinogenesis, Mutagenesis, and Impairment of Fertility
In vivo evaluation of the mutagenic potential of rFVIII failed to demonstrate reverse mutation or chromosomal aberrations at doses substantially greater than the maximum expected clinical dose. In vivo evaluation of FVIII in animals using doses ranging between 10 and 40 times the expected clinical maximum also showed that FVIII does not possess a mutagenic potential. Long-term investigations of carcinogenic potential in animals have not been performed.

Pediatric Use
Kogenate FS is appropriate for use in pediatric patients of all ages, including neonates, infants, children, and adolescents. Safety and efficacy studies have been performed in previously untreated and minimally treated pediatric patients (n = 62). Kogenate FS is similar to KODEGATE in its biological activity and may be used in pediatric patients in the same manner as KODEGATE.

Geriatric Use
Clinical studies with Kogenate FS did not include sufficient numbers of patients aged 65 and over to be able to determine whether they respond differently from younger patients. However, clinical experience with KODEGATE and other ADF preparations has not identified differences between the elderly and younger patients. Kogenate FS should be given to an elderly patient only if the benefit outweighs the potential risk.

Pregnancy Category C
Animal reproduction studies have not been conducted with Kogenate FS. It is also not known whether Kogenate FS can cause fetal harm when administered to a pregnant woman or affect reproductive capacity. Kogenate FS Antithemophilic Factor (Recombinate) should be used during pregnancy and lactation only if clearly indicated.

ADVERSE REACTIONS
During the clinical studies conducted in previously treated patients (PTPs), 109 adverse events were reported in the course of 4,160 infusions (2.6%). Only 13 events were reported by the investigator as at least remotely related to study drug. Another 7 events were nonassessable. Thus 20 events in 11 patients were considered to be either nonassessable or at least remotely related to Kogenate FS administration, for an incidence of 0.5% relative to the number of infusions administered. Events that were at least remotely drug-related included: local injection site reaction, dizziness (2), rash (2), unusual taste in the mouth (1), mild increase in blood pressure (1), pruritus (1), depersonalization (1), nausea (1), and rhinitis (1). No FVIII inhibitors have developed in the 72 PTPs with severe hemophilia A who have received Kogenate FS for a mean of 54 exposure days.

In clinical studies with previously untreated patients (PUPs) and minimally treated (MTP) pediatric patients, 18 adverse events were reported by the clinical investigators as at least possibly related to the treatment, including the expected complications of inhibitor development in 8 patients (included in the 10 patients discussed under CLINICAL PHARMACOLOGY), a forearm bleed following venipuncture, constipation, adenopathy, rash, anemia and pallor in one inhibitor patient with gastroenteritis, and serious otitis media.

Post-marketing experience
The following events are principally derived from post-marketing experience and publications, and accurate rate estimates are generally not possible. Among patients treated with its predecessor product KODEGATE, anaphylactic reactions have been reported very rarely, but no cases have been reported with Kogenate FS. Although such serious reactions have not been reported with the use of Kogenate FS, it is possible that these may also occur. Rare cases of dyspnea have been reported with Kogenate FS.

REFERENCES
3. Lusher JM, Arkin S, Abildgaard CF, et al: Recombinant factor VIII for the treatment of previously untreated patients. Kogenate FS Antithemophilic Factor (Recombinate), very rare cases of serious allergic reactions and anaphylactic reactions have been reported, particularly in very young patients or patients who had previously reacted to other FVIII concentrates. Individual cases of anaphylaxis have been very rarely reported. R22(2):1-25, 1998. It have also been reported. Although such serious reactions have not been reported with the use of Kogenate FS, it is possible that these may also occur. Rare cases of dyspnea have been reported with Kogenate FS.
Snowmobiling

• It is recommended that children under the age of 16 not operate a snowmobile by themselves.
• Children under 6 years of age are not considered strong enough to be transported safely.
• Never have more than one passenger on the vehicle.
• Be aware that possible hearing loss due to engine noise exists for young children.
• Avoid scarves or loose clothing that may get caught on trees or in equipment.
• Respect the fact that this can be a dangerous vehicle.

Other Winter Safety Tips

Frostbite

If frostbite occurs, warm the person slowly starting with the trunk area. Warm the arms and legs last because stimulation of the limbs first can drive the cold blood toward the heart and lead to heart failure. Do not rub the affected area. Also avoid caffeine or alcohol as liquids to warm the person. Seek medical attention immediately. Signs of frostbite include a numb feeling in the affected area that becomes flushed, turns white or grayish-yellow, and feels cold to the touch. Wearing protective clothing can prevent frostbite.

Ice

Ice is the leading cause of most winter injuries. Falling on ice can cause injuries to the head, neck, arms and legs from a simple sprain to a severe bleed.

Carbon monoxide

Carbon monoxide is a colorless and odorless gas. It causes symptoms such as sleepiness, headaches and dizziness. If any of these occur, ventilate the house and get to a hospital. Installing a carbon monoxide detector in your home is advised.

Additional Concerns

Take precautions when shoveling snow or ice, using a snow blower, as well as when using heaters and wood-burning stoves or fireplaces.
Hemophilia Federation of America

**Scholarship**

**Amount:** Between one and three $1,500 scholarships.

**Candidate:** Person with hemophilia or VWD attending any accredited 2- or 4-year college, university or vocation/technical school in the U.S.

**Deadline:** April 1, 2009

**Contact:** Hemophilia Federation of America (HFA)

1405 West Pinhook, Suite 101

Lafayette, LA 70503

337.261.9787 or 1.800.230.9797

www.hemophiliafed.org

**HFA Artistic Endeavors Scholarship**

**Amount:** $1,500

**Candidate:** Person with hemophilia or VWD not necessarily attending college. Scholarship can be used for producing a play, writing a book, painting, publishing or another artistic endeavor. Imagination and portfolio required.

**Deadline:** April 1, 2009

**Contact:** Hemophilia Federation of America (HFA)

(Same as above)

**HFA Parent Continuing Education Scholarship**

**Amount:** Two $1,500 scholarships

**Candidate:** Parent of a school-age child with a bleeding disorder. For use in furthering the parent’s education.

**Deadline:** April 1, 2009

**Contact:** Hemophilia Federation of America (HFA)

(Same as above)

**HFA Sibling Continuing Education Scholarship**

**Amount:** Three $1,500 scholarships

**Candidate:** Sibling of a school-age child with a bleeding disorder. For use in furthering the sibling’s own education at a college, university or trade school.

**Deadline:** April 1, 2009

**Contact:** Hemophilia Federation of America (HFA)

(Same as above)

**Bill McAdam Scholarship Fund**

**Amount:** $2,000

**Candidate:** Person with hemophilia, VWD or other bleeding disorder, or spouse, partner, child or sibling planning to attend an accredited college, university, trade or technical school, or certified training program. Applications must be submitted electronically using MS Word or rich text format. Reference forms must be emailed directly from the reference’s email. Use in the subject line: “Your last name/McAdam Scholarship Application.” One professional and one personal reference should be submitted. Do not send handwritten material; previous winners not eligible.

**Deadline:** May 15, 2009

**Contact:** Bill McAdam Scholarship Fund

22226 Doxtator

Dearborn, MI 48128

313.563.1412

mcmcadam@comcast.net

**Calvin Dawson Memorial Scholarship**

**Amount:** Number and amount of scholarships varies

**Candidate:** Florida resident with bleeding disorder attending a college, university or trade school.

**Deadline:** April 30, 2009

**Contact:** Hemophilia Foundation of Greater Florida

1350 North Orange Avenue, Suite 227

Winterpark, FL 32789

800.293.6527

**Christopher Mark Pitkin Memorial Scholarship**

**Amount:** Minimum of two annual $1,200 scholarships

**Candidate:** All members of the hemophilia community, including spouses and siblings. Applicants must be pursuing a post-high school, college or technical/trade school education. People with HIV and hemophilia and their families are encouraged to apply. Southern CA residents given preference.

**Deadline:** August 26, 2009

**Contact:** Hemophilia Foundation of Southern California

33 S. Catalina Avenue, Suite 102

Pasadena, CA 91106

626.793.6192 or 800.371.4123 (Southern CA only)

hfsc@earthlink.net

www.hemosocal.org

**The Kevin Child Scholarship**

**Amount:** $500 and $1,000

**Candidate:** Person with hemophilia or VWD. Must be a high school senior planning to attend college, university or vocational school, or a college student pursuing post-secondary education.

**Deadline:** June 27, 2009

**Contact:** Renee LaBrew, Dept. of Finance, Administration and MIS

The National Hemophilia Foundation

116 West 32nd Street, 11th Floor

New York, NY 10001-3212

212.328.3700 or 1.800.422.6314

Or: Mary Child Smoot at 203.968.2776

**Michael Bendix Sutton Foundation**

**Amount:** Two $2,000 scholarships

**Candidate:** Person with hemophilia pursuing pre-law study.

**Deadline:** March 30, 2009

**Contact:** Michael Bendix Sutton Foundation

c/o Marion B. Sutton

300 Maritime Avenue

White Plains, NY 10601

**SevenSECURE Ulla Hedner Scholarship**

**Amount:** Scholarship of up to $7,000

**Candidate:** Adults with inhibitors planning to attend or currently attending as a full-time student at a college or university.

**Deadline:** May 30, 2009

**Contact:** SevenSECURE

877-NOVO-777

SevenSECURE@rxcrossroads.com

www.novoseven-us.com

**SevenSECURE Adult Education Grants**

**Amount:** Grants of up to $2,500

**Candidate:** Adults with inhibitors seeking training to help improve their career or transition to a new one.

**Deadline:** Year-round

**Contact:** SevenSECURE - (Same as above)

**SevenSECURE K-12 Edu-Grants**

**Amount:** Grants of up to $500 per person per year

**Candidate:** K-12 grade tutoring for any consumer with hemophilia and inhibitors to help families who require additional tutoring or other forms of learning help.

**Deadline:** Year-round

**Contact:** SevenSECURE - (Same as above)

**Note:** Deadlines may change after January 1, 2009. Check websites regularly for updates.
Salvatore E. Quinci Foundation Scholarship
Amount: Two $2,000 scholarships
Candidate: Person with hemophilia or other bleeding disorder accepted into an accredited university, college or vocational/technical school.
Deadline: April 6, 2009 (Download application from the website and submit to address below.)
Contact: Salvatore E. Quinci Foundation, Inc.
178 Florence Street
Melrose, MA 02176
www.sef.foundation.org

Soozie Courter “Sharing a Brighter Tomorrow” Hemophilia Scholarship Program
Amount: 16 $5,000 college scholarships, two $7,500 graduate scholarships, and two $2,500 vocational scholarships
Candidate: Students with hemophilia A or B. Must be a high school senior or recipient of a graduate equivalency diploma (GED), or currently enrolled in an accredited junior college, college (undergraduate or graduate) or vocational school.
Deadline: April 4, 2009
Contact: Wyeth
888.999.2349
www.hemophiliavillage.com

Project Red Flag Renee Paper Academic Scholarship
Award: Two $2,500 scholarships
Candidate: Female with a diagnosed bleeding disorder (includes VWD, hemophilia carrier or other clotting factor deficiency)
Deadline: May 16
Contact: www.projectredflag.org
Anna DeSimone, NHF Director of Education
adeshime@hemophilia.org

Great Lakes Hemophilia Foundation Education Scholarship
Award: Various scholarships from $500 to $2,000
Candidate: Wisconsin residents or attending Wisconsin HTC. College and vocational students; parents of children with bleeding disorders; also looks at re-training adults with bleeding disorders who are finding it difficult to function in their chosen field because of health complications.
Deadline: May 1, 2009
Contact: Great Lakes Hemophilia Foundation
638 N. 18th Street, Suite 108
Milwaukee, WI 53233
414.257.0200 or 888.797.4543

Great Lakes Hemophilia Foundation Individual Class Scholarship
Award: up to $500 per class (maximum award $500)
Candidate: Wisconsin residents or attending Wisconsin HTC. This scholarship provides funding assistance for tuition and enrollment fees relevant to continuing education in a non-traditional or non-degree format. Candidates are individuals with bleeding disorders, parents of young children and spouses of individuals with bleeding disorders.
Deadline: Year round
Contact: (Same as above. Cannot apply for both.)

Hemophilia Foundation of Minnesota/Dakotas
Amount: Number and amount of scholarships varies, average awards $1,000-$2,000 each.
Candidate: Minnesota, North or South Dakota residents with an inherited bleeding disorder pursuing a post-high school education.
Deadline: May 30, 2009
Contact: Hemophilia Foundation of Minnesota/Dakotas
750 South Plaza Drive, Suite 207
Mendota Heights, MN 55120
651.406.8655 or 1.800.994.4363
www.hfmd.org

Hemophilia Foundation of Michigan Academic Scholarship
Amount: A $1,000 scholarship and a $2,000 scholarship
Candidate: Michigan residents within the bleeding disorder community seeking higher education at a college, university or trade school. Open to people with a bleeding disorder or their family members, or family members of people who have died due to complications of a bleeding disorder.
Deadline: April 10, 2009 (applications available in January)
Contact: Hemophilia Foundation of Michigan
1921 W. Michigan Ave.
Ypsilanti, MI 48197
734.544.0015 or 1.800.482.3041
www.hfmc.org

Utah Hemophilia Foundation Scholarship
Amount: Ranging from $500 to $1,500
Candidate: Members of the bleeding disorders community served by the UHF and/or the Hemophilia Treatment Center in Salt Lake City. This includes those who have a bleeding disorder, their spouses, children, and parents enrolled or planning to enroll in a college, university, trade school or technical program.
Deadline: May 12, 2009
Contact: Utah Hemophilia Foundation
772 East 3300 South, Suite 210
Salt Lake City, UT 84106
801.484.0325 or 1.877.463.6893

Huey and Angelina Wilson Scholarship
Amount: $1,000 per semester
Candidate: Louisiana residents with a bleeding disorder enrolling in or attending a Louisiana accredited college or university; full-time student in an undergraduate program. Applicant qualifies for TOPS (Tuition Opportunity Program for Students) offered by the State of Louisiana, or would have qualified had the program existed when applicant entered college.
Deadline: June 15 and December 30, 2009
Contact: Scholarship Committee c/o Libby Fisackerly
3636 South Sherwood Forest Blvd, Suite 450
Baton Rouge, LA 70816
800.749.1680

Joshua Gomes Memorial Scholarship Fund
Amount: $1,000
Candidate: Young adults with HIV/AIDS accepted into or enrolled in a college or university in the U.S. in full-time undergraduate or graduate study
Deadline: TBA
Contact: Joshua Gomes Memorial Scholarship Fund
2700 South Emerson Street
Englewood, CO 80113-1737
www.JoshuaGomes.org

Note: Deadlines may change after January 1, 2009. Check websites regularly for updates.
Guide Launched to Inform Public about GINA


Fully effective November 2009, GINA is the first and only federal legislation that will provide protections against discrimination based on an individual’s genetic information in health insurance coverage and employment settings.

You can access the guide at http://www.geneticfairness.org/ginaresource.html. The guide includes information for the general public, clinicians and healthcare providers, employers, health insurers, researchers, and state officials.

FDA Approves Kogenate® FS for Routine Prophylaxis

On October 8, Bayer HealthCare announced that the U.S. Food and Drug Administration (FDA) approved routine prophylaxis with Kogenate FS Antihemophilic Factor (recombinant). This reduces the frequency of bleeding episodes and the risk of joint damage in patients aged 0-16 years with severe hemophilia A with no pre-existing joint damage. With this important approval, patients are provided with the only factor VIII treatment product in the U.S. to be used to replenish factor VIII levels in a prophylactic manner marks a significant milestone in the care of patients, especially young children, with hemophilia A,” said Craig Kessler, M.D., Georgetown University Hospital and Chair, MASAC. “The results from the pivotal clinical study confirmed that the administration of Kogenate FS to prevent bleeding into the joints was more beneficial to joint health and function than ‘on-demand’ treatment of acute episodes of joint bleeds.”

The FDA approval of Kogenate FS for routine prophylaxis in children without pre-existing joint damage is based on the clinical data from a multicenter trial in the U.S. that included 65 boys with severe hemophilia A less than 30 months of age at study entry. Study participants were followed for up to 5.5 years.

Source: www.smartbrief.com

Warning about Covidien’s Phosphocol Drug

Richard Colvin PhD MD, member of the COTT Board and of the FDA’s Blood Products Advisory Committee (BPAC), prepared the following report:

“On August 29, 2008, Covidien posted a letter addressed to healthcare professionals on its website warning that the intra-articular injection of the radioactive drug Phosphocol has been linked to the development of leukemia in two boys ages 9 and 14 with hemophilia. Phosphocol contains a radioactive form of phosphorus called P32 and has been used for radiosynovectomies to treat the chronic inflammation that results from multiple bleeds in target joints in persons with hemophilia. Although Phosphocol was never approved for use in radiosynovectomies, it has been used “off-label” for this indication. During the past 10 years the number of radiosynovectomies performed for joint disease has gone down with the recognition of a possible link between the use of radioactive material in the joint space and the future development of leukemia.

At this time, we recommend that radiosynovectomy for hemophilia-associated synovitis be discontinued until a better understanding of the link between radiosynovectomy and leukemia development is established. We also recommend that Covidien directly contact all of the Hemophilia Treatment Centers and recommend that the ‘off-label’ use of Phosphocor for radiosynovectomy be discontinued.”

Source: COTT DC Update September 2008

New Recombinant XYNTHA Now Available — ReFacto to be Discontinued

On September 8, Wyeth Pharmaceuticals, a division of Wyeth (NYSE: WYE), announced that product shipments
have begun for XYNTHA™ Antihemophilic Factor (recombinant), Plasma/Albumin-Free, a new recombinant factor VIII product for both the control and prevention of bleeding episodes and surgical prophylaxis in patients with hemophilia A.

XYNTHA is produced using state-of-the-art manufacturing and purification processes designed to reduce the risk of viral contamination. The manufacturing process for XYNTHA is completely albumin-free from start to finish, while the purification process utilizes a unique synthetic ligand totally free of animal materials and a nanofiltration step using a 35-nanometer pore-size filter.

Shipments of the company’s current recombinant factor VIII product, ReFacto® Antihemophilic Factor (Recombinant) in the United States will be discontinued as of May 31, 2009. Wyeth anticipates that many patients using ReFacto may want to talk to their healthcare provider about XYNTHA.

Source: www.wyeth.com

HHS Awards $49.1 Million to States to Increase Access to Healthcare Coverage

On July 21, Health and Human Services Secretary Michael Leavitt announced awards of over $49 million in grants to 30 states that provide health insurance to residents who cannot get conventional health coverage due to their health status. The grants will be used to offset losses states incurred in the operation of high-risk pools, which are typically state-created, non-profit associations that offer health coverage to individuals with serious medical conditions. Grant funds also provide support for disease management for chronic conditions and premium subsidies for individuals with lower incomes. Enrollment in these pools is growing, with more than 200,000 individuals enrolled in state pools.

“These grants will make it more affordable for states to expand access to healthcare through high risk pools for the uninsured,” Secretary Leavitt said. “Individuals who benefit from these pools usually have a history of health problems that make it extremely difficult to find affordable health coverage in the individual market.”

Funds were allocated based on the number of uninsured individuals in each state and the numbers of individuals enrolled in each pool. HHS’ Center for Medicare and Medicaid Services (CMS) administers the program. This year’s grants are in addition to approximately $286 million that states have received since 2003 to support this program.

The 30 states that received grants are: Alabama, Alaska, Arkansas, Colorado, Connecticut, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maryland, Minnesota, Mississippi, Missouri, Montana, Nebraska, New Hampshire, New Mexico, North Dakota, Oklahoma, Oregon, South Carolina, South Dakota, Texas, Utah, Washington, Wisconsin and Wyoming.

Source: hemophiliafed.org

California Implements Budget Cuts

On September 18, the California legislature and governor came together and agreed to an amount for the 2008-2009 Fiscal Year Budget that all parties were willing to accept. The compromise budget creates no new taxes; it does however borrow funds, mostly from future years, to close the current deficit. In terms of specific programs of importance to the hemophilia community, the 10% across-the-board budget cut will be implemented at once in state programs such as the Genetically Handicapped Persons Program (GHPP), which serves many people with hemophilia. It will not be implemented in Medi-Cal (Medicaid) payments to pharmacies, due to a court injunction. Next March 1, the cuts in state-only programs like GHPP will be reduced from 10% to 1%, and cuts in Medi-Cal payments will begin, but only at a 5% level [rather than the 10% originally proposed].

Source: COTT Washington Update, September 2008

CSL Behring Issues a Biologic Recall

On August 19, CSL Behring LLC initiated a voluntary recall of Monoclate-P®, 1000 Unit, lots J91504, J91604, J91705 and J91806, with expiration dates of April 25, April 30, May 2, and June 9, 2010, respectively. This precautionary measure is being taken with the knowledge of the Food and Drug Administration. These lots do not meet the potency specification when stored for three months at 5 degrees C. CSL Behring issued a letter in August 2008, to pharmacies, healthcare providers and home healthcare companies requesting that these lots be returned to the company. Customers who have purchased product directly from CSL Behring will be credited for every returned vial of these particular lots, and the company will pay shipping costs. Call CSL Customer Service with questions about product returns, 1.800.683.1288.

Source: hemophiliafed.org
It is that time of the year again when many people begin to make insurance coverage choices. Typically these changes occur at the end of the year, but some might occur at other times. Your insurance might change for a variety of reasons, including a new job, a change in marital status, or new/different insurance options offered by your employer.

To ensure there is no disruption in your care, contact your home care provider before you select a new insurance plan. Your home care provider can help you choose a plan that meets your current medication needs. In addition, to ensure you select the most affordable plan, your home care provider can determine ahead of time if it will be covered as an “in-network” provider under the plan you choose. If you have already changed your insurance, provide your home care provider with the new insurance information.

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or email factorquest@coramhemophilia.com.

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