

Hemophilia Services
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The Infusion Inquirer



Back to School: A Time to Educate Staff and Assess Your Child's Progress

Each year, when your child returns to school, you have an excellent opportunity to educate the school nurse and teachers about your child's bleeding disorder. It's also a great opportunity to assess how well your child is independently managing the condition.

According to Cazandra MacDonald, patient advocate for Walgreens-OptionCare Hemophilia Services, the nature and frequency of your interactions with school staff depend on the severity of your child's condition. But no matter how severe, "the school needs to know about your child's condition so that they may help in an emergency," she emphasizes. "The last thing you want is for school staff to be uninformed."

How to Prepare for a Meeting With School Staff

While a meeting with school staff is important every year, it is especially important if your child is transitioning to middle or high school, MacDonald says. Some issues to discuss during the meeting include:

- Your child's condition and treatment plan
- A checklist of bleed signs and symptoms
- Any history of your child missing school because of the disorder or related issues
- The protocol for infusing at school
- Availability of storage space in the school clinic for a dose of factor and supplies

If your child is participating in sports, have the coach attend the meeting or, if necessary, schedule a separate one. Before- and after-school caregivers also need to be educated about your child's condition.

[\(continued on p. 2\)](#)

Also in This Issue:

The Clinician's Corner.....	2	Insurance Q&A.....	7
Using Stimat® Effectively.....	3	Going Green.....	8
Greg Thomas: Living an Active Life With Severe Hemophilia.....	4	Hemophilia Centers of Clinical Excellence.....	8
Beating Peer Pressure With High Self-Esteem.....	6		

Back to School... (continued from p. 1)

Give children in middle or high school the option of participating in the meeting. “Perhaps they can give a definition of hemophilia or show the teachers and nurse what their factor looks like,” MacDonald explains. “Give them a piece of the presentation so that they are empowered.”

Children who do not wish to speak about their disorder still should attend the meeting, she advises. “They need to understand how their teachers and others will care for them. Assure them they do not need to say anything, but simply listen,” she says.

Preparing your child for this meeting can be an important training tool, MacDonald says. “Back to school is a transitional time for them in many ways. Be sure that they are taking control of their bleeding disorder along with the other things going on in their lives. Their bleeding disorder will not go away, so they must figure out how to incorporate their newfound activities around the disorder.”

For back-to-school questions, contact Walgreens-OptionCare Hemophilia Services at 866-436-4376.

The Clinician’s Corner

In response to questions received from our readership, Jennifer Maddox, RN, BSN, MHA, addresses topics important to parents of children with bleeding disorders.

What is the appropriate way to apply ChloraPrep®?

ChloraPrep® is a topical antiseptic applied to the skin before inserting a central venous catheter, implanted port or peripherally inserted central catheter (PICC). Comprised of 2 percent chlorhexidine gluconate and 70 percent isopropyl alcohol, ChloraPrep acts rapidly and provides 48 hours of antimicrobial activity.

Often a part of a hemophilia supply kit, ChloraPrep is available in a variety of sizes and applicators. The ChloraPrep® One-Step 3mL Applicator is effective for a skin area less than or equal to 4 x 5 inches. Apply the ChloraPrep solution with back-and-forth strokes for 30 seconds. The back-and-forth action allows the ChloraPrep to reach multiple layers of skin that harbor bacteria. Finally, allow the cleansed area to air dry to ensure maximum antimicrobial activity.

Please talk with your healthcare provider to determine if ChloraPrep is appropriate for the maintenance of your venous access.

To learn more, go to chloraprep.com.

(continued on p. 5)

Back to School – A Good Time to Plan and Organize

- Organize infusion supplies and properly dispose of expired needles and syringes.
- Keep immunizations up to date. Obtain an updated immunization record from your pediatrician.
- Update your child’s MedicAlert® profile.
- Get familiar with Section 504 of the Rehabilitation Act (www.greatschools.net/cgi-bin/showarticle/2777) and the Americans with Disabilities Act to see what educational benefits may be available for your child.
- Consider participating in a local support group for parents of children with bleeding disorders.

Using Stimate® Effectively

Stimate® is a nasal spray that is used to treat mild hemophilia A and mild to moderate type 1 von Willebrand disease (if factor VIII levels are greater than 5 percent).

Children taking Stimate should limit fluid intake while on the medication and at least 24 hours afterward. Also, Stimate should not be used for children less than 11 months old, according to the drug's prescribing information.

“Stimate can be a desirable medication since it is a nasal spray and it is usually cheaper than a factor replacement infusion,” says Tina Dooley, a Walgreens-OptionCare pharmacist. However, she warns, Stimate causes the body to retain water, which in turn dilutes sodium, an essential electrolyte.

A sodium imbalance can cause symptoms including facial flushing, nausea, vomiting, headache, lethargy, appetite loss, irritability, muscle weakness, spasms or cramps. These symptoms can progress to confusion, convulsions and coma. “Serious symptoms should not occur as long as fluid intake is restricted,” Dooley reassures. “A good rule of thumb is to only drink the very smallest amount that satisfies thirst. For more specific instructions, it is a good idea to talk with your treatment center.”

Dooley also advises not to accept a substitute if your physician prescribes Stimate. “There is no approved generic in the same concentration,” she says. “It’s also important to follow your prescriber’s instructions on the amount and duration of therapy and do not exceed this dosing.”

Delivering the Right Dose

To deliver the correct amount of the medication, “prime” the spraying device by removing the cap, holding the sprayer out into the air and pressing down on the plunger four times. The spray bottle will stay primed for a week after it is used. If you do not use it for a week or more, press down on the plunger once to prime it.

Keep track of the number of sprays used. To assure a full dose with each spray, no more than 25 sprays should be used, Dooley says, even if extra medication is left in the bottle.

To learn more about Stimate, go to stimate.com.

Walgreens-OptionCare's Hemophilia Team
Provides Support in Spanish 24/7!
Call toll free at 800-456-1923.

Greg Thomas: Living an Active Life With Severe Hemophilia

Even during his early childhood, Greg Thomas showed strong signs of independence and the ability to adapt to life with severe hemophilia (factor VIII deficiency).

Showing first as prolonged bleeding from his circumcision, Greg's hemophilia was a surprise to his parents, Linda and Rick Thomas, as it was not hereditary in their family.

Rather than taking him to intimidating clinical environments for his factor infusions, Linda and Rick learned how to infuse Greg themselves. By age 7, however, "he just took over," remembers Linda. "He thought he could do it better."

"I knew I could hit a vein better than a nurse or my parents could," Greg remembers. "Once I learned to access a vein, the anxiety of asking 'Did you get it?' was gone."

At age 9, Greg underwent an arthroscopic synovectomy on his knee and ankle joints to repair cartilage and bone damage caused by pooled blood. To recover, Greg worked through seven months of aggressive physical therapy. During the first month, he required a factor infusion every eight hours. In month two, the infusions were needed every day. From months three to seven, he needed to self-infuse every other day or on every physical therapy day. He achieved an outcome better than his doctors anticipated, Linda says.

Greg's self-infusing skills enabled him to participate in his 4th grade class's five-day trip to Washington, DC, without his parents. Because this trip occurred only four months after his surgery, he needed to take a wheelchair on the trip. "His classmates fought over who was pushing him," Linda recalls.

Soon, Greg began to show his athletic inclinations, participating in volleyball, ice and roller hockey, baseball, golf and other sports. Greg also was a Cub Scout and once attended hemophilia summer camp.

As he grew into the teen years and early adulthood, Greg continued to excel at sports. He played high school volleyball and was his high school golf team's only district qualifier. His hockey skills earned him a place on Florida Atlantic University's roller hockey team.

Hockey presents a special challenge for Greg. "He infuses before each game," Linda says. "If he gets hit too hard [by a player] or hit with the puck, he infuses again." She says Greg infuses 5,000 units 10 or 12 times a month to keep his clotting level at 100 percent. "I feel like I bring a lot to any sport I have played, and taking factor to do so was never a big deal to me," Greg says.

Now 25 and living on his own in Florida since age 20, Greg works for a law firm and has a "sweet girlfriend," Linda says. He is a 4-handicap golfer who enjoys playing with his father. Greg also continues to play softball and flag football. He is currently taking a break from playing no-check hockey. Known for his goal-scoring skills, he plans to return.



Greg Thomas on his motorcycle

Linda says that keeping his clotting level at 100 percent is important for Greg due to his active lifestyle and the factor VIII deficiency, which can cause bleeds from something as little as bumping into a table. “Greg proves that a person with severe hemophilia can live a very active life by taking the one added step of taking clotting factors,” Linda says.

Greg says he never let hemophilia get him down. “You will live a normal life if you take control early,” he says. “I thanked my parents years ago for allowing me to be a boy and teaching me to care for myself in a safe manner. Just take your factor, and no one will ever know you have hemophilia.”

Clinician's Corner... (continued from p. 2)

What exactly is a Bethesda Unit?

What does it mean?

The American Heritage® Medical Dictionary defines a Bethesda Unit (B.U.) as a measure of inhibitor activity. The inhibitor binds itself to infused clotting factor, making it difficult to control bleeding. The optimal B.U. score is 0, which means no inhibitors are present.

According to the National Hemophilia Foundation,¹ a positive B.U. result (above 0) means there is a detectable level of inhibitors working against coagulation after a factor treatment. Those with a result of 5 or higher B.U. are usually classified as having a “high-responding” inhibitor level; those who measure between 0 and 5 B.U. are classified as having a “low-responding” inhibitor level.

People with high-responding inhibitor levels often have quick and strong immune system responses against factor (VIII or IX). Using factor is, in many cases, not possible because the inhibitor neutralizes even the largest possible dose of factor. The immune response in individuals with “low-responding” inhibitor levels is slow, producing a low level of inhibitors. To overcome the inhibitors in these cases, doctors may choose to increase the factor units per dose and/or the number of doses a patient infuses.

At the National Hemophilia Foundation meeting in Denver, I heard the term “Malmo.” What is that?

The Malmo protocol refers to the primary prophylactic regimen for treating severe hemophilia, for example, 20-40 units/kg on alternating days. This treatment regimen was named after Malmo, Sweden, the location where the protocol was developed in 1958.²

References

1. Test results. National Hemophilia Foundation web site. <http://www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=234&contentid=413&crptname=inhibitors>. Accessed May 21, 2009.
2. Feldman BM, et al. Tailored prophylaxis in severe hemophilia A: interim results from the first 5 years of the Canadian Hemophilia Primary Prophylaxis Study. *Journal of Thrombosis and Haemostasis*. 2006;4:1228-1236.

2009 Inhibitor Education Summits:
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Summit I
August 27-30, 2009 – Hollywood, CA

Summit II
September 17-20, 2009 – Washington, DC

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for more information.

Beating Peer Pressure With High Self-Esteem

While attending a hemophilia camp in Missouri, social worker Wayne Richards was shocked by a comment made by a teenager—and even more shocked when all the other boys in the group agreed with him.

The comment was “It’s better to ask for forgiveness rather than permission.” A social worker with Walgreens-OptionCare, Richards says most of the boys in the group went on to reveal that they played football with their friends and did not tell their parents.

“For boys with bleeding disorders, organized football with pads and helmets for protection is dangerous. But touch football with no protection at all is treacherous. Why did these boys put themselves at risk? Peer pressure,” Richards says.

Richards says high self-esteem is the best way to combat peer pressure, especially in relation to very popular but risky activities such as football. “When pressured by their peers to play football it’s hard even for boys with bleeding disorders to say no,” he explains. Whatever the temptation—be it alcohol, driving too fast or another kind of risky behavior—“parents can assist their child to foster healthy self-esteem,” he says.

To help their children develop self-esteem, parents must help them feel good about themselves. How do parents do this? The answers are simple, Richards says.

- Tell them you love them
- Spend time with them
- Encourage them to make choices
- Listen to and respect their opinions
- Nurture independence
- Give reasons for rules
- Show appreciation

Richard says that with healthy self-esteem, children and teenagers with bleeding disorders will be better equipped to:

- Handle peer pressure
- Put up with frustration
- Take on responsibility
- Be independent
- Manage negative emotions and criticism
- Appreciate their accomplishments

In a nutshell, there’s a simple formula for self-esteem, Richards says. “Self-esteem equals praising, encouraging, listening, appreciating and, most of all, loving.”

Insurance Q&A

My family has two insurance policies. How do we know which one is the primary plan?

Many health insurance companies use the “birthday rule” to determine which health insurance policy is primary in a dual-insurance home or family when children are listed as dependents on both plans, according to information at insure.com.¹

However, the rule is not a law and is not always used by plans. To be sure, read your insurance policy or membership agreement or contact your plan’s customer service department. Knowing how your plans determine the primary payor may save you from having unexpected medical bills.

If your plan uses the birthday rule, the plan of the parent or guardian whose birthday comes first in the calendar year will be the primary plan for your children’s expenses. For example, if your birthday is May 1 and your spouse’s is October 12, your plan is primary. It doesn’t matter which parent is older. If both parents share the same birthday, the parent covered on his or her plan the longest provides the primary coverage for the children.

There are exceptions to the birthday rule, however, as follows:

Active employment: If one spouse is currently employed and has health insurance through a current employer and the other spouse has coverage through a former employer (COBRA), the plan belonging to the currently employed spouse is primary.

Divorce or separation: If a couple is divorced or separated, the plan of the parent with custody generally provides primary coverage. In some cases, the court assigns more responsibility for healthcare expenses to one of the parents. In these cases, the parent assigned more responsibility has the primary plan but the plan needs to be informed of this arrangement. Another exception is if one divorced or separated parent has a group health plan and the other an individual plan. In these cases, the group plan pays first, regardless of the birthday rule.

A word of caution: The secondary plan will pay remaining costs not covered by the primary plan only if the medical care is a “covered benefit.” The secondary plan will not reimburse you for services it doesn’t cover.

What is an EOB?

EOB stands for “explanation of benefits”—a written statement to you, the beneficiary, from an insurance company or another third-party payor. Issued after a claim has been reported, the EOB indicates how much money you must pay for noncovered charges and how much money you do not need to pay because charges are covered, discounted or applied to a deductible. EOBs also list the amount of the annual deductible applied to date.

Make sure your out-of-pocket payments are consistent with what your EOB says you are responsible to pay. It’s also a good idea to keep all your EOBs in a three-ring binder or file in case billing errors are made.

Reference

1. Birthday rule determines whose health plan covers your children. <http://www.insure.com/articles/healthinsurance/birthday-rule.html>. Updated May 29, 2009. Accessed July 21, 2009.

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Going Green With Walgreens: Recycling Unused Medical Supplies

Unused medical supplies don't need to go into the trash or the Sharps® container. If you don't plan to use your supplies, consider these options:

1. Contact local hospitals, hospices or free clinics to see if they participate in a recycling program or accept supply donations.
2. Check with local veterinarians to see if they can use your supplies.
3. Organizations such as 4 the World (4theworld.org) and the International Children's Fund (icfaid.com) send unused supplies to developing countries. What we see as a castoff may be a treasure to others.

Hemophilia Centers of Clinical Excellence

Our Centers of Clinical Excellence designation is given to offices that consistently provide superior service and support to their patients for a given therapy. They have met rigorous, internally established standards of excellence and uphold those standards through regular evaluation. As leaders in patient care, these locations are responsible for sharing their best practices and helping further raise our standard of care across the company.

Albuquerque, NM	Dallas, TX	Plymouth Meeting, PA
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