INSIDE

Demystifying COBRA

Vicki Jacobs-Pratt and Project Red Flag

Coram Hemophilia Services is Now on Facebook

Jacob Primera Shares the Gift of Knowledge

Females and Bleeding Connected to Hemophilia

A publication of Coram Specialty Infusion Services
Demystifying COBRA

The Consolidated Omnibus Budget Reconciliation Act (COBRA) is an important benefit for people with chronic diseases such as hemophilia and von Willebrand disease. Recently, Quest spoke with Rob Dash, Senior Manager of Reimbursement within Baxter’s Healthcare Economics Department, to unpack the nuances of COBRA.

Vicki Jacobs-Pratt and Project Red Flag

As a woman with von Willebrand disease, Vicki Jacobs-Pratt is passionate about getting more women with bleeding disorders diagnosed so they can get treatment and have a higher quality of life. She worked with the New England Hemophilia Association to launch a program called Red Flag New England, which promoted testing women for bleeding disorders.

Coram Hemophilia Services Now Has a Fan Page on Facebook

Read about Coram’s new initiative to use the social networking site to keep in closer contact with our patients.

Focus on Coram Nurses

Meet Jacob Primera, pediatric nurse for the Malvern, Pennsylvania, branch, in this continuing series featuring profiles of Coram nurses. Also included is an entry form so readers can nominate Coram nurses for future profiles.

Females and Bleeding Connected to Hemophilia

Females with bleeding disorders often go undiagnosed. Learn how you can determine if you are at risk.

Show and Tell – Not Just for Elementary School

When Sonji Wilkes’ 7-year-old daughter had a show-and-tell project at school, she decided to talk about her experience at hemophilia summer camp.

Hemophilia News

Kids’ Corner
The Consolidated Omnibus Budget Reconciliation Act (COBRA) is an important benefit for people with conditions such as hemophilia and von Willebrand disease. It can also be complicated.

Basically, COBRA is a federal law signed into effect in 1986 that provides continuing health insurance coverage to individuals who worked for a large company — more than 20 employees — who suffer what the law calls a “qualifying event.” It also covers dependent children of those individuals.

Although the healthcare reform bill passed in March will undoubtedly impact the bleeding disorders community, it is too early to know exactly how it will play out once implemented. COBRA is an important option for people with bleeding disorders today.

Recently, Quest spoke with Rob Dash, Senior Manager of Reimbursement in Baxter’s Healthcare Economics Department, to unpack the nuances of COBRA.

Quest: From what I understand, COBRA is a government-sponsored program that takes over when employees are covered by a group insurance plan and they become unemployed for certain reasons — in the bleeding disorders community that may apply to a dependent child of the employee, or in some cases an adult with bleeding disorder who may need to go on disability.

Dash: Yes. Basically there are certain qualifying events that determine whether or not a person is eligible for COBRA and how much COBRA extension they are allowed. The individual has to have had employer-sponsored group health insurance. They can be an employee or a spouse or a dependent of an employee.

The basic qualifying event is a termination of employment, voluntarily or involuntarily, or a reduction in work hours. The beneficiary is the employee, and that individual would be eligible for COBRA extension for up to 18 months. Keep in mind that this is the same coverage the individual had when they were covered by the group insurance plan.

Other qualifying events:
  • if an employee gets a divorce or legal separation
  • the untimely death of the spouse
  • the individual becomes eligible for Medicare
  • the loss of child dependent status

So let me break that down. In the case of a divorce or legal separation or death of a spouse, the individual is eligible for COBRA extension for up to 36 months.

The Medicare one is a little tricky. If an employee becomes Medicare eligible, there is a 29-month waiting period before the benefits kick in. Under COBRA, they are able to purchase an additional 11 months of extension. They would have the
Continued: Demystifying COBRA

18 months of COBRA as stated, and then with an additional purchase of 11 months, would be eligible for a total of 29 months, through the Medicare waiting period. That’s one of the things I don’t think a lot of people understand. They have to keep their COBRA coverage going without a break before their Medicare benefits kick in, unless they have other insurance coverage.

The last qualifying event is the loss of child dependent status. Under group insurance there is an age limit to when a child can stay under the parents’ policy. That varies by state, but the current coverage is usually up to age 18 or when they graduate from high school. If they are going on to further education, they would have to be deemed as a full time student — 12 to 15 credits or above — to stay under their parents’ insurance until they graduate from college. If the child is not going to go on to further education, they are able to get COBRA coverage under their parents’ policy up to 36 months. That would be an individual who is graduating from high school but not going to college or into the workforce or the military right away and they need to keep their insurance going.

The parameters are changing under the new healthcare reform bill. The “dependent age” increase up to age 26 is supposed to go into effect in September 2010. The affect I see on COBRA at this point would be just a later “kick in” if a dependent needs to continue on their parents’ policy after age 26. Once they lose their dependent status (age 26), they would still be able to utilize COBRA extension for 36 months.

Dash: When the employee suffers a qualifying event, the employer is responsible for sending out the paperwork within 14 days, which gives the employee the option of accepting COBRA or denying it. Once the employee receives that paperwork, they then have 60 days to reply.

Quest: In which cases might a person deny COBRA?

Dash: If they find insurance in the interim or they pick up employment. What is important to remember is that if the employee or dependent has a 63-day break in insurance coverage, they are going to hit a pre-existing condition clause in the insurance they take out, which can create a 12- to 18-month waiting period. People need to figure their plan of action going forward. If they are not going to find an individual policy or employment within that period, they need to make sure they activate their COBRA extension.

It is also important to note that if they do get employment or an individual policy, there is a waiting period of up to 90 days before the policy goes into effect, and that would put them past the 63-day period.

Quest: And if they have that 63-day break, it will mean a waiting period for pre-existing condition of more than a year?

Dash: Correct.

Quest: And that’s a big problem if you have hemophilia.

Dash: Yes. Until we know how the healthcare reform will play out in real time, the insurance company would not have to pay for any claims due to that condition.
Quest: Can you talk about the American Recovery and Reinvestment Act (ARRA) part of the stimulus package?

Dash: ARRA, signed into law in February 2009, has a provision that allows eligible employees who are involuntarily terminated from employment through a large employer to receive up to a 65 percent reduction in their COBRA premium. This also extends to the employee’s dependents covered under COBRA. On December 19, 2009, the President signed into law the Department of Defense Appropriations Act of 2010, which extended the premium subsidy for an additional two months — January and February 2010. The time period an individual is able to receive the premium reduction was also increased to 15 months. Most recently an amendment to the ARRA, under the Temporary Extension Act of 2010, extended the eligibility period through March 2010.

Also, those who do not have group health insurance through a large employer — whether they have an individual policy or coverage through a small employer — may be eligible for not only insurance continuation but for the COBRA premium reduction. Some states have enacted laws through a “state continuation” or “mini-COBRA” provision. Individuals should always review their certificate of coverage (insurance contract) or their state’s department of insurance. The Centers for Medicare and Medicaid Services (CMS) recently developed a new web site for information regarding all aspects of the COBRA extension and premium subsidy. Individuals can go to www.ContinuationCoverage.net or call their help line at 866.400.6689.

The employers should be giving notice to the employees of their right to take advantage of the premium reduction. However, I have heard of cases where the employer was lax in sending out notification. So it is important that the individual work with the HR department or plan administrator to make sure they are getting notification that they can take advantage not only of COBRA but the premium reduction. I would not just leave it up to the employer to notify them.

Quest: Part of that is that if they don’t get notice of their COBRA option within two weeks of suffering a qualifying event, they need to contact the employer to get the paperwork.

Dash: Yes. Once they have decided to take the COBRA extension, they then have 45 days to make their first premium payment. What I always tell patients is, whatever plan of action you think you might take, when you get that notification, always mark ‘yes.’ The reason for this is so they do not exhaust that 60 day maximum time period for the election of COBRA extension.

Quest: So they have 45 days to make the first premium payment after electing to take COBRA, and if they get employment or other insurance coverage, they can drop it. It’s a lot easier to disengage from COBRA than to engage after the 60 days.

Dash: Yes. Patients also should keep in mind that they have to keep up with their financial obligations. If they miss a COBRA payment, they can be dropped from COBRA immediately.

Note: The material presented in this interview is for informational purposes only and is not to be relied on as advice by readers; readers need to contact their provider/insurer if there are questions about COBRA, coverage, etc.
As a woman with von Willebrand disease, Vicki Jacobs-Pratt is passionate about getting more women with bleeding disorders diagnosed so they can get treatment and have a higher quality of life. Surveys conducted by the Center for Disease Control have shown that on average, it takes 16 years for a woman with a bleeding disorder to be diagnosed from the onset of symptoms.

“If a woman goes to her doctor and tells him she thinks she’s bleeding more than normal, or bruising,” Vicki says, “often it will be dismissed as an Ob-Gyn issue. If it’s bleeding gums, it’s a dental issue. Bruising? She’s just clutzy. So it’s important to educate the local healthcare community that women can and do have bleeding disorders. Von Willebrand disease affects up to 1 percent of the population, men and women combined. Women need to be diagnosed before they have a hysterectomy because they can’t deal with bleeding for 21 out of 28 days.”

When Vicki worked for the New England Hemophilia Association, she was involved in the initial launching of a program called Red Flag New England. They received funding through the National Hemophilia Association, CSL Behring, and local grants to organize Project Red Flag. At first they did not get many responses from women. After considering why that was, they realized it was because there were not many women. At that point they discussed ways to bring attention to the under-diagnosed demographic and decided to focus on medical and dental conventions.
“We started with the State Nurse’s Associations and the School Nurse’s Associations,” Vicki explains, “setting up a booth in their exhibit halls. Then we did some with Yankee Dental, which draws about 22,000 dental professionals annually to Boston.”

Vicki and her fellow Project Red Flag volunteers attended some 30 conventions a year for four years. Their goal was to create dialogue with as many medical professionals as possible so that, if they saw a woman who might have a bleeding disorder, they would recall the booth and its message. The repeat appearances paid off in viable results.

“At one school nurse’s meeting, I had three different women come up to me,” Vicki shares. “They each said, ‘I referred a girl for diagnosis for von Willebrand disease and she came back positive, and that’s because you were here last year.’ That was a huge validation because if those three women came up to me at one meeting, then I know others have soaked up the information.”

Although Vicki is not currently working on any Project Red Flag programs, she serves on the PRF consumer task force and continues to pursue any opportunities to spread the message.

Coram Hemophilia Services Now Has a Fan Page on Facebook!

When researching hemophilia on Facebook, we found many support groups and organizations. In addition, many hemophilia chapters are now using Facebook to advertise their fundraisers and events.

Coram began discussing how it could use the social networking site to communicate with its patients in their local areas, with their local consumer advocates. Each Coram advocate has signed up and has been authorized to have an account with their Coram email so that they may be able to respond should a patient or consumer make a request.

As the year unfolds and we attend local events, Coram will be posting pictures and stories to share on Facebook to support our commitment to our patients and the community. Our goal is to help raise hemophilia awareness in the local communities and show support to other bleeding disorder organizations and chapters.

In the future, Coram plans to post general discussion topics and webinars and use Facebook to send out event invitations to our Facebook “fans.”

Coram will monitor what is placed on the site before it is posted in order to ensure the site is accurate and professional.
Jacob Primera

*Shares the Gift of Knowledge*

Jacob Primera is the veteran “go-to” guy at Coram’s Malvern, Penn. branch. He has been a pediatric nurse since 1985, and with Coram for 16 years. And we can thank an old girlfriend for that.

“I was a paramedic and met a girl who was in nursing school,” he explains. “She asked if I wanted to go to school with her, so I said, ‘Sure, I’d go to the end of the world for you.’ So I went to nursing school.”

It turns out that was just the right career choice for him. Jacob is passionate about his job as a pediatric nurse. He started in a hospital setting, but when he got married (not the old girlfriend) and had children, he wanted more flexibility than 12-hour shifts and doubles provided. Coram offered just what he was looking for.

“This job is really rewarding when you see kids getting better and going back to school and behaving as kids,” he says. “And it’s really about helping the whole family. It may start with the child, but they become part of the bigger picture.”

Jacob’s specialty is intravenous medications, including clotting factor and antibiotics. He has been with the Malvern branch so long that he has become one of their key resource people.

“I teach the nurses the ropes,” he says with a smile.

Jacob’s hemophilia patients seem to “come in bunches.” He will see quite a few over a short period of time and then one or two spaced out over months. But the goal for these patients is not to see them. The goal for Jacob and his fellow Coram nurses is to get these kids on a path of independence.

Another aspect of his job that Jacob finds rewarding is passing his knowledge on to patients and families.

“We provide a resource for patients beyond nursing care,” he explains. “We listen a lot to their problems or concerns. We’re there to listen and to teach, and that’s one of the things I really enjoy about my work — sharing this knowledge with them and giving them the training to take care of themselves.”

Jacob Primera does not just treat injuries and disease conditions but he also taps into the well of knowledge he has gained over the years to empower his young patients. He gives them the ability to live a better life and improve their disease situation.

*FOCUS on Coram Nurses is a recurring series that highlights the caring and dedication of Coram nurses across the country. Use the entry form on the right to nominate nurses from your local Coram branch to be featured in a future issue.*
We are looking for interesting stories about Coram nurses whom you feel deserve special attention for their work in hemophilia and/or von Willebrand disease. If you would like to recognize your nurse for his or her exceptional care, please complete the entry form below. The editorial panel at Quest will select nurses for an interview or the nurse may write their own story to be published in an upcoming issue.

Nurse's name: ______________________________________________________

Nurse's branch: ______________________________________________________

What makes this nurse stand out? ______________________________________

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

Your contact information (name, office phone, email address, cell phone): ________

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

Please mail to: Coram Specialty Infusion Services
ATTN: Marketing & Communications
555 17th Street, Suite 1500
Denver, CO  80202

Email to: communications@coramhc.com

Or fax to: 303.672.8670
Females and Bleeding Connected to Hemophilia

by Aggie Gilbert, RN
Females with bleeding disorders are rare and often go undiagnosed. So, how can you know if you are at risk for such a disorder?

Genetically, some females are “obligatory carriers” and others are “possible carriers.” If a girl’s father has hemophilia, she is an “obligatory carrier.” However, carrier females can have a normal level of factor VIII or IX and have no abnormal bleeding problems.

Females with lower than normal levels of Factor VIII or IX — either obligatory or possible carriers — may have bleeding problems. The severity of bleeding for these females will depend on the actual level of factor they have. A normal factor level for VIII and IX is 50 percent to 150 percent or more; a person’s inherited factor level can be any level from 0 percent to 150 percent or more.

The second red flag for females is having a male relative with hemophilia. They can be at risk for a lower than normal level of factor VIII or IX, whichever factor deficiency the male has.

Genetic mutations can and do occur in about 30 percent of the total population of hemophilia. When a mutation happens, it can produce a carrier or a child with hemophilia even with no family history of a bleeding disorder. Remember that once the mutation has occurred, the family history continues. If the mutation occurs and only female children are born, it can be tricky to recognize. There have been cases where generations of female carriers have been born before a male child showed up to clarify the bleeding diagnosis. Sometimes many female relatives in an extended family have undiagnosed bleeding problems. Some of these women have opted for surgeries to control bleeding, such as a hysterectomy because of prolonged bleeding during menses for several years, which also causes anemia. Many times, long menses and other bleeding is seen as a “family thing,” so it is accepted as such.

The most common bleeding disorder for females is von Willebrand disease (vWD). Again, a family history may indicate such a condition.

So what needs to be done?

If there are females in your family who have easy bruising, bleeding after invasive procedures or dental extractions, and longer than normal periods, they should have their factor levels checked. There are also other medical conditions that can manifest in bleeding, and they need to be investigated.

When a female is at risk of bleeding from low factor VIII or IX levels, testing should be done. The earlier the age of the child, the sooner a treatment plan can be put into place. Even though it will be many years before a small child will need to know her carrier status, she may have a very low level of factor and may have bleeding after an accident or injury. Time is of the essence in an emergency, so it is important to know ahead of time if she will need factor-raising medication.

Once a female knows she is a carrier, she may have several questions about what this means to her. Beside the bleeding issues and having a treatment plan for herself, she may wonder about the possibilities of passing on the hemophilia or vWD to her child. There are considerations for her to make about who to tell and when to share this information with friends or a prospective spouse.

There is no absolute time and way to do this. The staff at a nearby Hemophilia Treatment Center (HTC) is well qualified to guide and support women through this process.
Congresswoman McCarthy Introduces Bleeding Disorder SAFE Act

March 2010 — Congresswoman Carolyn McCarthy (D-NY) has introduced legislation to promote awareness of and screening for all bleeding disorders. H.R. 4846, the Bleeding Disorder Screening, Awareness, and Further Education (SAFE) Act is the first bill directed at the bleeding disorders community since Congress passed the Ricky Ray Hemophilia Relief Fund Act in 1998. If adopted into law, the bill would:

- Provide funding for screening of young people for bleeding disorders, including at school.
- Increase research funding aimed at improving diagnostic and treatment options, and understanding prevalence of bleeding disorders.
- Provide funding to promote greater awareness of bleeding disorders among physicians, other healthcare professionals and the general public.

Hemophilia, von Willebrand disease (vWD), and other inherited bleeding disorders affect millions of men and women in the U.S. While hemophilia is often diagnosed in childhood, the vast majority of individuals with bleeding disorders remain undiagnosed, often seeking inappropriate treatment for symptoms that, at times, could be life threatening. For undiagnosed women, in particular, health risks can be further compounded by heavy menstrual periods and prolonged bleeding following injury, surgery, and childbirth.

Source: hemophilia.org

XMRV Virus Threat Investigated

An infectious virus linked to two diseases is drawing the attention of public-health officials, who are investigating the potential threat to the nation’s blood supply.

It isn’t clear if the virus, known as XMRV, poses a danger, and public-health officials say there isn’t evidence of spreading infection. But because of concern over the potential for widespread infection and preliminary evidence that XMRV is transmitted similarly to HIV, officials are quickly trying to determine if action is needed to protect the blood supply.

XMRV was discovered in 2006 when it was found in tumor samples from men with a rare form of familial prostate cancer. Research has also linked the virus to chronic fatigue syndrome and found it in measurable levels in the blood of healthy people. But the evidence isn’t conclusive, as several other studies failed to find XMRV in the blood of people with chronic fatigue syndrome, and it isn’t known how prevalent the virus is or whether it causes disease.

Efforts are under way to find effective tests for the virus and determine its prevalence, led by a working group funded by the National Institutes of Health and including federal agencies such as the FDA and the Centers for Disease Control and Prevention. Blood banks, academic institutions, and at least one advocacy group are also involved.

Source: online.wsj.com (Writer: Amy Dockser Marcus)

Recall of Infusion Set Needles Manufactured by Nipro for Exelint

January 26, 2010 — FDA notified healthcare professionals of a Class I recall of Exel/Exelint Huber needles, Exel/Exelint Huber Infusion Sets and Exel/Exelint “Securetouch+” Safety Huber Infusion Sets, manufactured by Nipro Medical Corporation for Exelint International Corporation due to ‘cores,’ the cutting or dislodging of silicone cores or slivers from the ports into which they are inserted.

Inspections conducted in October 2009 of Nipro facilities found that their needles ‘cored’ in 60 to 72 percent of tests. The reason for this coring is related to design and manufacturing processes, which the FDA continues to investigate. The FDA will update the public if there are new developments.
Hospitals, clinics, and patients who have needles from these lists should immediately stop using these affected products and return any unused products to Exelint International Corporation.

There are more than 2 million units impacted by this recall in distribution nationwide. Recalled needles were manufactured from January 2007 to August 2009. Units subject to recall have a lot number that begins with “07,” “08,” “09,” and one of the product codes or catalog numbers noted in the FDA news release.

**Note:** This recall does not affect any Coram customers.

**Carriers May Opt for Safe Caesarean Delivery**

A December 2009 article published in the journal *Haemophilia* suggests that caesarean delivery should be considered a viable option for carriers of affected infants with hemophilia. The article was authored by W. Keith Hoots, MD, National Institutes of Health in Bethesda, Md., and Andra H. James, MD, Duke University Medical Center in Durham, N.C. James is a member of the National Hemophilia Foundation’s Medical and Scientific Advisory Council (MASAC).

Caesarean delivery is a well-established method of delivery, with U.S. rates increasing since the 1970s. While there are several reasons a provider might recommend this mode of delivery, often it is selected as a way to decrease the likelihood of neurologic damage to the fetus.

James and Hoots state that while in most cases, vaginal delivery of an affected child will not result in an intracranial hemorrhage (head bleed) — one of the primary concerns for babies with hemophilia — the labor period can be unpredictable. “A planned vaginal delivery puts a woman at risk of an abnormal labor and operative vaginal delivery, both of which predispose to intracranial hemorrhage. Furthermore, vaginal delivery does not eliminate the risk to the hemophilia carrier herself,” explained the authors.

Conversely, a planned caesarean delivery reduces the risk of intracranial bleeding by approximately 85 percent. James and Hoots further assert that risk can be “nearly eliminated” by carrying out a planned, elective caesarean delivery prior to labor.

**2010 Inhibitor Summits Planned**

People with hemophilia A or B with inhibitors and their families will come together for the 2010 Inhibitor Education Summits, a weekend of education designed to improve overall health and quality of life. This year’s summits are being held August 5-8 in Houston, Texas, and August 19-22 in Boston, Mass.

Having an inhibitor can seem overwhelming at times, when even daily life can be a challenge. This can affect your well-being in ways that only other people with this condition can understand. The annual Inhibitor Education Summits connect people with inhibitors, their caregivers and members of their support network with expert health-care professionals. They also connect attendees with others who can share their experiences and suggest coping skills.

New this year: multiple educational tracks; youth camp activities for children 4-12 years old; coping mechanisms for improving the psychological well-being of patients and caregivers.

To register or for more information, visit [www.nhfindicators.org](http://www.nhfindicators.org) call 877.560.5833 or e-mail: inhibitorsummits@hemophilia.org.

**Source:** hemophilia.org
by Sonji Wilkes

My seven-year-old daughter recently had a show-and-tell project at school and decided to speak about her summer camp experience this past year. While helping her prepare for this project, I explained to Nora that the reason she was able to go to camp is that her brother has hemophilia. Our family talks about hemophilia quite a bit, but this was the first time any of my children had to talk about it in front of others.

Nora struggled, trying to define hemophilia in a sentence or two beyond “My brother gets pokes.” To help steer her, I turned to our boxes of hemophilia education resources. I honestly hadn’t realized that our collection of brochures, kids’ literature and journal articles had grown so vast in five short years. I literally pulled out three boxes of information for one simple, five-minute, first-grade presentation!

Then and Now

I took an interesting stroll down memory lane, looking through the non-inhibitor hemophilia literature our HTC staff had dropped off at the hospital shortly after Thomas’ birth and hemophilia diagnosis. That stack of information was nearly a foot tall. I remembered carefully reading each brochure, digesting a little at a time as soon as I felt ready to tackle the shock of a hemophilia diagnosis. I recalled how thankful I was to have varying pieces of education, in varying degrees of detail.

Then, as I dug through the papers, I came across the solitary brochure we received after Thomas’s inhibitor diagnosis. At the time, very little consumer-friendly inhibitor education was available. It was a completely different diagnosis and information-gathering experience. Ultimately, I found the inhibitor resources I needed, but they didn’t fit in a dusty cardboard box.

The Buddy System — How Not to Get Lost

Our family attended the first Inhibitor Education Summit, sponsored by Novo Nordisk in 2005. It was truly inspiring. Sitting in educational sessions specific to life with an inhibitor satisfied my craving for information. But I found that simply talking with other parents and patients who live with an inhibitor gave me all the resources I needed. Brochures,
scientific data, and papers can teach you the technical aspects of inhibitors, but patients and caregivers embody the practical aspects of surviving and thriving with an inhibitor. For instance, at that meeting I heard useful tips for storing ancillary supplies; and this was the first time I heard another parent lament about a son who developed a bleed just walking across a large parking lot.

Many inhibitor patients have told me about the value of networking with other patients. Because our community is small, inhibitor patients often become close and speak regularly via phone calls, email, and internet social networking sites. The Inhibitor Education Summits and inhibitor rap sessions at NHF annual meetings are widely popular: these are great opportunities to not only gain “book” knowledge, but to form lasting, meaningful relationships and gather tried-and-true tips. As in the show-and-tell days of elementary school, there is much to be learned from your peers. Thanks to relationships developed at such meetings, buddies can help you navigate the maze of inhibitor care, from bleed management and treatment to insurance, coping, and inhibitor eradication strategies. My buddies are invaluable as our family weaves its way through the intricacies of inhibitor management.

**Ask and Ye Shall Receive**

Since that inaugural Inhibitor Education Summit, more inhibitor education materials have been written. The Inhibitor Education Summits have increased in scope by offering summits specific to adults living with inhibitors. When the inhibitor community spoke with a collective roar, declaring a need for more resources, our pharmaceutical, home healthcare, national and local hemophilia organizations and partners delivered. Anyone who has done research projects for school can attest that sources of information come from all areas; in the inhibitor community, we’re lucky to have our technical sources — and each other.

*Inhibitor Insights is a PEN column sponsored by Novo Nordisk, Inc. © LA Kelley Communications, Inc. Reprinted with permission.*
Kids’ Corner

FactorQuest now available on CD!
For copies of the FactorQuest game CD, email communications@coramhc.com.
You can also play FactorQuest online at www.coramhemophilia.com.

Dinosaur Word Search

Can you find these dinosaurs?
ankyllosaurus
apatosaurus
brachiosaurus
brontosaurus
dimetrodon
edaphosaurus
iguanodon
pachycephalosaurus
plesiosaurus
protoceratops
pterodactyl
spinosaurs
stegosaurus
triceratops
tyrannosaurus rex velociraptor

Helpful Parent Tips
Tip submitted by Sochi Frank
Are you having trouble keeping Emla cream over the port site? Try applying a small blob of Emla cream over the port site and cover it with a Transparent Semipermeable Membrane (TSM). Do not press the TSM directly on the cream but around the cream area. This will help keep the cream in place until you are ready to infuse.