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When Ziva Mann’s older son, Shai, was about to begin preschool, she found a wonderful advocate in Judi, the director of the preschool. Unfortunately, when her younger son, Akiva, started in a different preschool, there was no “Judi” to be found. Ziva gives valuable tips for being your child’s advocate.

Community Alert: Changes in Insurance Options for TRICARE Patients

Last fall, military families in the TRICARE network were notified by Express Scripts, Inc., the pharmacy benefit manager (PBM) for TRICARE, that they would have to choose from a small, select list of providers to serve their clotting factor needs in the future.

Focus on Coram Nurses

Meet Joshua Clarke, Nurse Administrator for the Austin and San Antonio branches, in our series opener featuring profiles of Coram nurses. Also included is an entry form so readers can nominate Coram nurses for future profiles.

Scholarship Opportunities

More than 20 scholarships are available for people with bleeding disorders, sponsored by a variety of hemophilia foundations and associations, as well as Baxter Pharmaceuticals’ Education Advantage Scholarship Program for People with Hemophilia A and Inhibitors.

Triple Treats — Three Times the Fun This Year for Hemophilia Campers

Coram Specialty Infusion Services is pleased to sponsor the Triple Treats program for 45 hemophilia camps, reaching 4,000 children with hemophilia and other bleeding disorders.

Hemophilia News

Kids’ Corner
Periodically, I put on my nicest shirt, walk into a roomful of teachers — and wish I could hide under the table. But I can’t advocate for my sons from under the table, so I sit, bundle of papers in hand, a list of our legal rights rippling through my brain, and hope that someone here will smile, listen, and above all, work with me. We may have rights, but it takes teamwork — and a caring partner — to achieve those rights.

When Shai was two, I met Judi, director of a local preschool. I poured out our story: Shai’s hemophilia, the inhibitor, his ballooning list of serious allergies, my fears and hopes. She listened carefully and, astonishingly, smiled. “Every child has needs,” said Judi, simply. “Let’s figure out how to meet Shai’s needs.” And she did, while I watched and learned.

Under Judi’s eye, I filled out Shai’s first individual health plan (IHP), condensing the overwhelming medical mess into a single, clear page. I learned how to build a positive working relationship with the teachers. Until Judi, I’d thought that advocacy was a battle: me against them. But she believed that advocacy means creating a partnership of shared goals, shared effort, and frequent, honest communication. We became friends, and Shai was happy at preschool. Judi’s good will traveled with us to kindergarten. “They are good partners,” she promised the new school. So that August, I walked into a room packed with smiling, soon-to-be partners — and Shai bounced into kindergarten.

Seeking a Partner, But Finding One Size Fits All
A year later, Judi had moved out of town, and now my younger son, Akiva, was ready to start at a different preschool. That September, I strolled confidently into a meeting with preschool staff. I described Akiva’s unusual, aggressive allergies. I explained that he needed more accommodations than the average allergic child, more even than most children with multiple allergies. I pulled out Akiva’s IHP, which I’d prepared with help from his physician, and asked if we could think together about allergy management. The preschool director held up a hand. “I have a system for allergies,” she said, and left.

My smile froze: there was no Judi here. Instead, there was a system, built to handle medical oddities like us, a one-size-fits-all system for allergies.

The teachers and I tried teamwork: quick conversations in hallways, phone calls, emails. But agreements were broken or forgotten, and Akiva got sick from his allergens. Holding him as he wept and coughed, I realized that their system didn’t fit us. And I couldn’t change it.

Determined, I asked for another meeting. There were no smiles as I described Akiva’s latest allergic reaction and how close we’d come to calling 911.

“We need to figure out how to meet Akiva’s needs,” I urged. “Could I see your allergy management plan?”

I stared at their plan, horrified at the gaping holes: an incomplete list of Akiva’s allergies and inadequate accommodations to help avoid an allergic reaction; no mention of cleaning up allergen-laden foods or
communicating with us in the event of a reaction. I compared the school’s plan to our detailed, doctor-approved IHP and shuddered. But the director believed her plan — the system — was fine, and the teachers followed her lead.

“We don’t understand why we’re here,” a teacher admitted. “Will Akiva be at school tomorrow?” Slowly, painfully, I shook my head.

Then I swung into action. I called the state board of education and a free legal hotline to ask about the preschool’s legal responsibilities. I studied resources like Wrightslaw\(^1\), pestered an advocate specializing in disability and education, and contacted the national food allergy association (FAAN)\(^2\).

“Schools can assume that they know enough about allergies,” a FAAN senior staffer warned me. “And they don’t slow down to learn more.”

Akiva’s preschool didn’t just fail to slow down; they badly underestimated his needs. Later we learned that this preschool director had believed that Akiva couldn’t be as allergic as I’d claimed, which may explain why she chose their system over Akiva’s IHP. I knew our rights. We could sue for discrimination or breach of contract or file a formal complaint. But a lawsuit wouldn’t get Akiva back into preschool — only a partnership would, and I didn’t have one.

**Seeking a Happy Ending, and Finding an Advocate**

For weeks, I’d shake my head when I spoke to Akiva’s preschool director. No, I wouldn’t sign a waiver promising not to sue if Akiva got sick. No, I wouldn’t

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**Be a Good Advocate**

Advocating for your child is a challenge for which few of us are trained, but the skills are simple:

**Know your rights.** There are many resources — internet, print media, as well as people in the community — to help you learn.

**Your Child 101.** Develop an IHP or a similar document to help the school understand your child’s needs. Ask your Hemophilia Treatment Center to review the IHP with you to make sure it is accurate. Invite the school to “slow down” with you; every child is different, even with the same diagnosis.

**Find a partner.** A school nurse, teacher, or other partner who understands your child’s needs can work with you to use the school’s resources to meet those needs. Ask yourself: Is my child’s teacher or school a good match for our family?

**Nurture partner relationships.** Show your appreciation! Bring homemade cookies or handmade thank-you cards.

**Know your resources.** These include free legal hotlines, advocates specializing in children with medical needs, your state board of education, and more.

**Remember:** You have an audience. Your children do not need you to be the perfect advocate, but they do need to see you try. If something is not working, dust yourself off and try again.
Parents of children with bleeding disorders have a lot to deal with on a daily basis to make sure their children remain healthy and safe. It hardly seems fair that they should also have the burden of dealing with insurance issues, but that is part of their reality.

Last fall, military families in the TRICARE network were notified by Express Scripts, Inc., the pharmacy benefit manager (PBM) for TRICARE, that they would have to choose from a small, select list of providers to serve their clotting factor needs in the future. Numerous HTCs and home care providers, including Coram, have been cut from the Express Scripts’ network, while Express Scripts’ own specialty pharmacies remain in-network. Unfortunately, many TRICARE families who have been using Coram and other providers since their children were born were asked to choose from a narrowed list of specialty pharmacies. Unlike Coram, many of these do not meet standards of service established by the Medical and Scientific Advisory Council of the National Hemophilia Foundation.

The Historic Perspective
In 2002, when factor products started to become more expensive as a result of medical advances, insurance companies who had clients with thousands of employees began hiring pharmacy benefit managers. The job of the PBMs was to monitor costs for hemophilia products, examine employees’ claims, manage their prescriptions, and find ways to lower premium costs for employers.

However, between 2002 and 2004, the PBMs began buying home care companies in order to establish their own specialty pharmacies to sell factor. Although some may see this as a potential conflict of interest, the nation’s three largest PBMs, including Express Scripts, are now among the most dominant factor providers in the country. Today, factor providers such as home care companies and hemophilia treatment centers compete to become “in-network” with an insurance company. Usually the insurance company limits the number of in-network providers, but also offers numerous choices for their clients within that list.

Express Scripts is the PBM hired by the Department of Defense to monitor military families covered by the TRICARE Pharmacy Services benefit. Therefore, Express Scripts’ recent notification that their “in-network” provider list would be sharply cut has forced many families to scramble for a new, unfamiliar provider.

The Care Provider Perspective
Express Scripts’ decision to cut Coram out of their network is a cause of concern among its nurses. One of these concerned nurses is Joshua Clarke, this issue’s subject for the Focus On Coram Nurses feature. Not only do Coram nurses receive intensive training in their specialty, but they also develop relationships with pharmacists and drug representatives, and are able to troubleshoot specific patient situations.

“I can see their eyes; I can see what they’re going through,” Josh explains. “I’ve taken classes to be educated in this specialty. I think the TRICARE patients are losing an expertise — the knowledge and care that Coram nurses provide — that could cause issues down the road.”

“Also, Coram has an advocacy program that is very active in the hemophilia community. Parents can always call their advocate if they are facing any issues; a pharmacy is not going to provide that.”
Joshua Clarke, Austin and San Antonio

Josh Clarke came to Coram in 2004 after two years of working as a critical care nurse for cardiac transplant patients in an ICU. This hard-working young man immediately got the attention of his supervisors. He started as a primary nurse case manager, then became team leader. Three years ago was promoted to nurse administrator over the Austin branch, and one year ago, also took charge of the San Antonio branch.

“I worked as both a primary nurse case manager and nurse administrator for about three years before becoming a supervisor,” Josh explains. “During that time I saw patients — roughly 50 to 60 a month — then came back to the office and did managerial work, and went back out and saw patients again. Now I have full-time supervisors in both Austin and San Antonio, so they help me run the day-to-day operations.”

A few years ago, Coram’s national director called Josh concerning a military family that lived about 140 miles from the Austin branch. The baby needed to be infused twice a day with factor VIII, at 6:00 a.m., and then again in the evening.

“The family was nervous because there was no nurse in that area who could deal with the high acuity of the patient, who was 16 months old,” Josh explains. “I basically spent three nights in a hotel. I did the infusion in the morning, then drove back to Austin to see patients, drove back again for the evening infusion, and stayed overnight so I could do the morning infusion again.”

When he went to see the patient, he brought materials and equipment to teach the parents how to infuse the baby.

“I brought training materials with a chest and a port, and let them practice a lot. It’s basically a technique where you have to get a feel for it and then get the courage to stick something through it. For people who aren’t nurses, that is scary, especially with a baby who is screaming and kicking. But they got the hang of it.”

The baby developed an inhibitor, but the parents were able to handle the multiple doses required, thanks to Josh’s training. Josh continued to visit the patient and his family to provide moral support.

This wasn’t the first time Josh went above and beyond for a patient, and it won’t be the last. He may not be on site as much these days, but those who are, count on him to step in when and where he is needed. Josh is a good example of the professional, caring nurses that Coram is proud to have on its team.
FOCUS on Coram Nurses

We are looking for interesting stories about Coram nurses who 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 Hemophilia Services
ATTN: John Louis/Quest
6 Spring Mill Drive
Malvern, PA 19355

Email to: quest@coramhemophilia.com

Or fax to: 610.722.1712
Scholarship Opportunities Abound for the Bleeding Disorder Community

More than 20 scholarships are available for people with bleeding disorders. Sponsored by a variety of hemophilia foundations and associations, they run the gamut from awards for teens heading to college, to those already in a university, to parents and siblings of people with bleeding disorders.

The Hemophilia Federation of America, for example, offers an Educational Scholarship, a Sibling Continuing Educational Scholarship, a Parent Continuing Educational Scholarship, and an Artistic Encouragement Grant. Information and applications can be found at www.hemophiliafed.org. (Be advised that applications must be postmarked by April 30, 2010.)

A helpful, one-stop website for information on many scholarships is LA Kelley Communications, www.kelleycom.com/scholarships. Here you will find specific information on scholarships offered by a number of organizations.

Baxter Announces New Scholarship Program

Baxter Pharmaceuticals has added their Education Advantage Scholarship Program for People with Hemophilia A and Inhibitors to the list of aid for people with bleeding disorders.

The program includes a university scholarship for students pursuing a bachelor’s degree at a four-year college or university; a community college and technical scholarship for students attending community college or seeking vocational/technical certification; and GED assistance for students who pass the GED Test.

In addition, strong applicants who do not qualify for the need-based aid may still be eligible for merit-based scholarships of up to $1,000 per year.

Scholarship decisions are made on the basis of financial need, academic achievement, extracurricular activities, and other factors. The program is open to patients using any brand of factor VIII therapy. Visit www.myeducationadvantage.com for more information.

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change my mind about the accommodations he needed. And, no, Akiva couldn’t come back.

At home, Akiva wandered around wearing his backpack. “Am I going to peeschool today?”

“No, not today,” I said, and he collapsed.

Shai was upset. “They should listen to you,” he insisted, “and be doing teams with you.”

I heard Judi’s echo in Shai’s words, and hugged my little hemophilia advocate. Then I found my nicest shirt, my bundle of papers, and walked into yet another room, in another preschool. “Let me tell you about my son, Akiva,” I told the staff in that room. And they listened.

1. Wrightslaw (http://wrightslaw.com) is a resource for families, teachers and advocates working with children with disabilities.

2. FAAN: Food Allergy and Anaphylaxis Network (www.foodallergy.org) is a national organization for families and individuals with food allergies.
This year, Coram Specialty Infusion Services is pleased to provide 45 hemophilia camps with the Triple Treats program, reaching 4,000 children with hemophilia and other bleeding disorders.

Triple Treats supplies campers with three entertaining core components:

- **A Ceremonial Native American Tipi**
  Decorated with a traditional Native American design, the eye-catching 10-foot high tipi will be placed in a central camp location for all counselors and campers to see. It will be the focal point for all camp ceremonies, and major announcements. It will also serve as a common meeting place for campers and visitors alike.

- **Color-Me Parachute**
  Campers will have a blast decorating this 12-foot parachute with the multi-colored markers provided and using it for a number of entertaining games. It comes with a book and DVD for ideas and tips on how to play different games using the parachute, including some that use a rubber ball that comes with the parachute. The games have been designed to be age-appropriate and safe for the campers.

- **Buddy Rings**
  Each camper gets two red, silicone rings so that he/she can share one with a friend or family member to signify the solidarity between them in support of hemophilia awareness.

Campers will celebrate camp milestones and listen to announcements at the tipi, decorate and play games with fellow campers using the parachute, and demonstrate hemophilia awareness and solidarity by wearing and sharing the Buddy Rings.
Swiss Company Enters the U.S. Blood Coagulation Market

The U.S. Food and Drug Administration (FDA) has approved Octapharma USA’s wilate® for the treatment of spontaneous and trauma-induced bleeding episodes in patients with all types of von Willebrand disease (VWD). Wilate® is a newly developed, high-purity, double virus inactivated von Willebrand Factor/Coagulation Factor VIII Concentrate (Human) that demonstrated efficacy for all types of VWD, including pediatric patients, in four prospective clinical trials utilizing both objective and subjective criteria.

Wilate® is also indicated for patients with mild or moderate VWD in whom the use of desmopressin is known or suspected to be ineffective or contraindicated. Wilate® is exclusively derived from large pools of human plasma collected in U.S. FDA-approved plasma donation centers.

The FDA approval of wilate® marks the entrance of Octapharma USA into the U.S. blood coagulation market, with product availability scheduled for early 2010. Octapharma USA is the rapidly growing U.S. division of Octapharma AG, one of the largest plasma products manufacturers in the world.

Source: Octapharma USA

Hemophilia Inhibitor Genetics Study (HIGS)

Initial results from the Hemophilia Inhibitor Genetics Study (HIGS) were announced at the 51st Annual Meeting of the American Society of Hematology in New Orleans, La.

HIGS is an investigation of genetic factors associated with the occurrence of inhibitors to replacement factor VIII (FVIII) among people with hemophilia A. Through a collaboration with two other multi-center studies — the Hemophilia Growth and Development Study and the Malmö International Brother Study — a combined cohort was formed to conduct a study to test the hypothesis that antibody development to FVIII is mediated by immune response genes. Approximately 14,000 markers from over 1,000 genes were genotyped and analyzed. The analysis was adjusted for other factors related to inhibitors to allow a clearer picture of the genetic relationships. A total of 114 markers were significantly associated with inhibitor status.

“HIGS is a unique study combining scientific contributions from academia, government, and industry to address an issue that is central to the clinical care of people with hemophilia,” explained Professor Erik Berntorp from Malmö University Hospital, Lund University, the principal investigator of the research.

HIGS investigators will build on the results of the initial analysis of the study with follow-up including more intensive examination of selected genes, and replication of study results in an independent cohort.

Inhibitors are antibodies that develop in approximately 10 to 15 percent of people with hemophilia A, and in 20 to 25 percent of those with severe hemophilia A. They are considered the most severe complication of hemophilia, since their presence interferes with optimal control of bleeding, thereby affecting health and quality of life, and increasing the cost of therapy.

Source: Lund University Press Release

Coram Earns an Award of Excellence for its Children's Hemophilia Camp Program

Coram Specialty Infusion Services has been honored with an Rx Club Award of Excellence at the 23rd Annual Rx Club Show in the category of Premiums/Promotions. The Rx Club Show honors the creative aspects of pharmaceutical product advertising and promotion. The show is judged in various categories by a distinguished panel of industry experts and is based solely on creative concept and execution. There were approximately 2,100 entries from throughout the United States, and several foreign countries, and 612 won awards.

Coram’s hemophilia camp program winning entry, “Buddy Tags” was sent to 45 camps serving over 4,000 children with hemophilia in 2009. “Buddy Tags” was an interactive program designed to help campers meet new friends,
while enabling them to keep in touch with those friends (new and old alike) after the camp season was over.

**New Technique for Cleaning Prions from Surgical Instruments**

Novapharm Research has regulatory approval in Australia and the European Union (EU) for its enzyme-based technology to deactivate the protein molecules of prions. Researchers at the University of Melbourne have created a solution to deactivate prions, which are the infectious proteins that cause Creutzfeldt-Jakob disease (CJD) and can be transmitted via surgical instruments.

The human prion is resistant to both heat and chemicals and is reported to be much more difficult to deactivate than the animal form of the infective agent which causes well-known diseases, such as mad cow disease in cattle and scrapie in sheep. A paper describing the technique was published earlier this year.

**Novel Treatment for Hemophilia Caused by Nonsense Mutation**

New Jersey-based PTC Therapeutics has initiated a phase IIa clinical trial of ataluren in patients with nonsense mutation hemophilia type A and B (nmHA and nmHB). Ataluren is a powder that is taken orally three times a day and has been used to treat other disorders caused by a nonsense mutation. The trial is a multi-centre, open label, dose escalation study. The main goals of the trial are to determine whether treatment with ataluren can result in an increase in factor VIII or IX levels and whether the drug can safely be given to people with severe hemophilia caused by a nonsense mutation.

Nonsense mutations occur in both hemophilia A (nmHA) and hemophilia B (nmHB); they account for approximately 10 percent to 30 percent of all hemophilia cases. In hemophilia, a nonsense mutation occurs when an interruption in the genetic code — a change in part of the DNA strand — causes a disruption of the “translation” of key genetic messages. This premature disruption then blocks the synthesis of factor VIII (hemophilia A) and factor IX (hemophilia B) proteins, causing poorly functioning clotting factors and often severe bleeding symptoms.

**Helixate® Approved for Prophylaxis in Children Under 16**

CSL Behring’s Helixate FS recombinant factor VIII concentrate has been approved by the FDA for routine prophylaxis in children with hemophilia aged 16 or younger who do not have pre-existing joint damage. This approval was based on a multi-centre trial of 65 boys younger than 30 months, in which magnetic resonance imaging (MRI) of joints documented that prophylactic use of the product resulted in less joint damage (7 percent) than did an on-demand therapy strategy (42 percent).

**Cash Contest for Girls with Bleeding Disorders**

MyGirlsBlood is a non-profit organization that seeks to connect women and girls with bleeding disorders worldwide for mutual support and education. The organization also offers an essay contest on www.mygirlsblood.com that features cash prizes for winning essays. Any girl in the world with a bleeding disorder can submit an essay.

**Website and Program for Inhibitor Patients**

Inhibitor patients can apply for financial aid, find educational materials, and receive insurance advice at www.changingpossibilities-us.com. Novo Nordisk’s Seven-SECURE® program can help patients manage the costs that inhibitors entail. Experts on hemophilia with inhibitors can answer questions about financial, insurance, and educational support in a confidential and cost-free environment.
Dinosaur Fun Facts

Pterodactyl means “winged lizard.” The wings of a pterodactyl are not like that of a bird. Pterodactyls had four “fingers” and three of them would end halfway down the wing. The fourth finger would extend out to the very end of the wing. The wings were made of a leathery substance that attached to the arm and the extended fourth finger. The wingspan of a pterodactyl could reach up to 40 feet wide.

The pterodactyls tended to live in caves and trees near the sea and ate large insects. They were one of the only flying reptiles during the period of the dinosaurs.

Did You Know?
• Pterodactyls lived throughout the Cretaceous and Jurassic Periods.
• Pterodactyl fossils have been found throughout Europe, North America, Australia, and Africa.
• Some pterodactyls had a coat of fur and were thought to be mammals.

Source: www.dinosaurfacts.org