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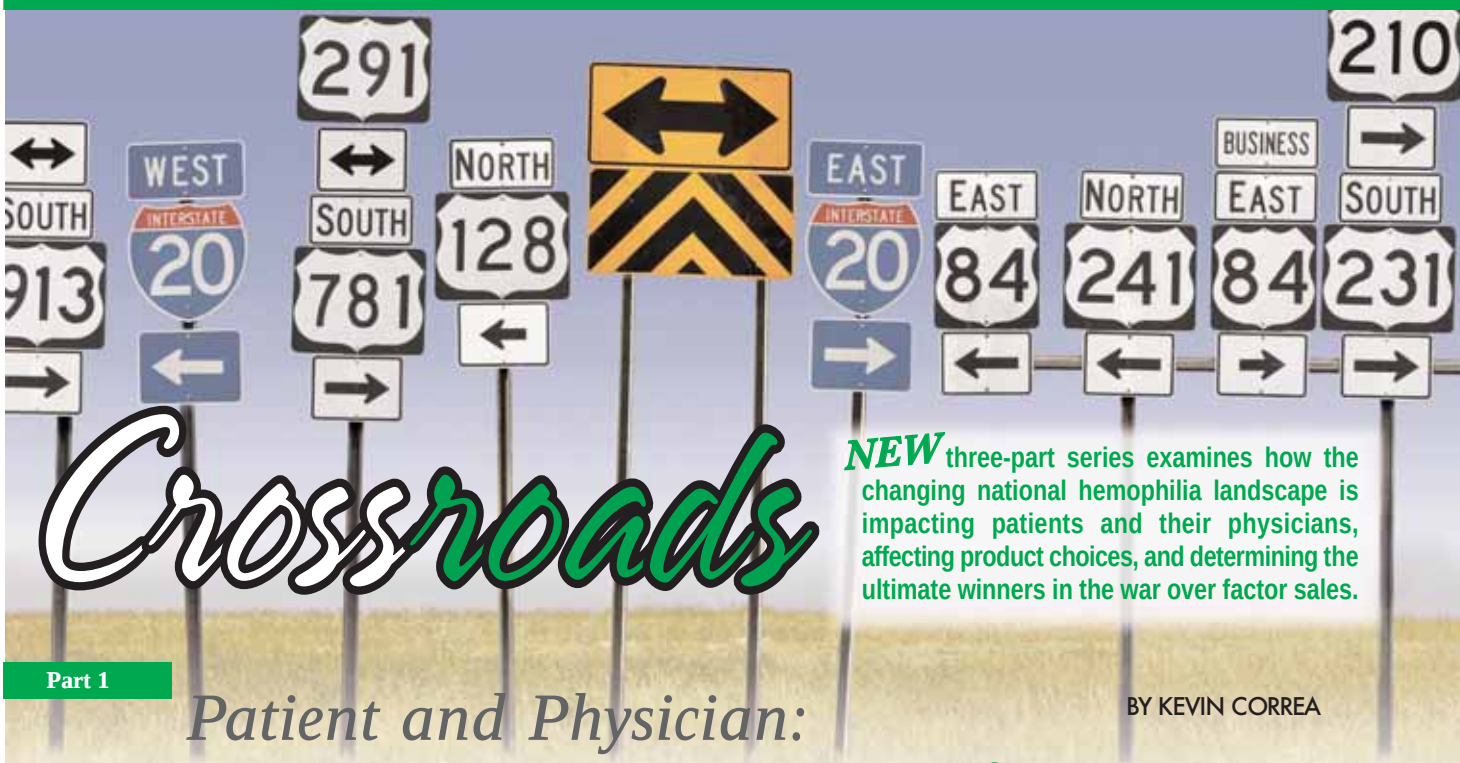
Parent Empowerment Newsletter



Crossroads

NEW three-part series examines how the changing national hemophilia landscape is impacting patients and their physicians, affecting product choices, and determining the ultimate winners in the war over factor sales.

Part 1

Patient and Physician: Communication and Conflict in a New Hemophilia Era

BY KEVIN CORREA

When a person with hemophilia finds the right hematologist and hemophilia treatment center (HTC), you might think Cupid has been busy with his quiver of arrows. *We love him*, or *she's a godsend*, or *the staff is like family*, are all common accolades. But for the hemophilic patient who fails to make this happy connection, working with the HTC system can be fraught with stress and tension. And even when personalities mesh, the hemophilia industry itself may unravel the relationship.

With HTCs and home care companies competing for factor sales, physicians vying for research dollars, and insurance companies entering the specialty pharmacy arena, big business and medicine are colliding. Unfortunately, the hemophilia community is caught in the middle. A lot of money is at stake, and many patients are getting lost in the mix.

It's up to the patient to make sense of the ever-changing hemophilia landscape. Now more than ever, patients and families have a wealth of knowledge at their fingertips. Thanks to the Internet, we have information we only dreamed of twenty years ago. Today, patients can be better equipped to successfully navigate the turbulent waters of the hemophilia industry.

From Knowledge to Empowerment

Dr. Joe Walker,* a hematologist at a metropolitan hospital, stresses that good communication is the centerpiece of a successful patient-physician relationship. "To be effective, communication has to take place as a dialogue, not simply doctor dictating and patient listening," he says. "As doctors, we need to appreciate that each patient and family is unique, and we must engage in dialogue within that context."

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* Names of patients, parents and physicians have been changed for anonymity.

inside PEN

welcome

Sherrell Portrait Design

Have you noticed what's been happening to the hemophilia community nationwide? If not, it's time you did. Just as economic decisions made in Washington, DC, will eventually impact every single person, decisions made at the top of the hemophilia industry will impact you, as a parent or patient. *PEN*'s job? To share the current facts and changes, clarify the issues, and prepare you to self-advocate and protect your healthcare choices.

"Crossroads" is a three-part series examining how the ever-changing national hemophilia industry is affecting us as consumers. Like some hemophilic evolution, new products are entering the market; companies are gobbling each other up to survive; less adaptable companies are being winnowed out; and competition over scarce dollars is becoming fierce.

We foretold these changes in "The Coming Storm" (*PEN*, Feb. 2005). The big bang that led to our current evolutionary road is this: insurers woke up. They saw how factor prices and usage were eating into the bottom line of employers and state budgets. So they began reducing reimbursements for factor, and applying restrictions to lower costs. It's as if our community has lost its forest for feeding, and the lack of food is causing pressure and anxiety. Friendly competition is now fierce. As the hemophilia industry evolves, we are at a crossroads with many relationships in our community. I've selected three to examine this year: (1) patient and physician (May); (2) plasma-derived and recombinant factor concentrate (August); (3) homecare companies and 340B programs (November).

In this issue, Kevin Correa writes that big business and medicine are colliding, and he thoughtfully reveals some underlying causes. Kevin explains how to maintain a healthy and productive relationship with your healthcare providers in changing times.

As always, camaraderie among patient groups like NHF, HFA and COTT can strengthen and protect our community – our "species" – as we all travel the road of change. These groups have wisely proclaimed that we cannot stay as we are. We must adapt to survive. We must acknowledge that change is occurring, and that we'll see cuts in profits, cuts in workforce, cuts in donations, and insurers competing with us for dollars.

We're on the road of no return: change will continue. Increasingly, we'll all need to defend our choice of products and treatments to those who pay for them. The more you know about the structure of your community from a business perspective – and hemophilia is big business – the faster you'll spot change and adapt to it, to survive. Being a survivor means taking the best road for you. How? By understanding your treatment and insurance options, knowing your rights, and advocating for the best medical care possible.

PARENT EMPOWERMENT NEWSLETTER MAY 2009

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inbox

This [Feb. 2009] is an excellent edition.

Dr. Harold Roberts
University of North Carolina
CHAPEL HILL, NORTH CAROLINA

My son is three and has severe hemophilia A. Thank you so much for writing *Raising a Child With Hemophilia*. It got me through the first scary year, and it has remained my go-to reference.

Julie Wrasse Van Winkle
NEBRASKA

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BY CAZANDRA CAMPOS-MACDONALD

Photos: Cazandra Campos-MacDonald

The Missing Piece of the Puzzle

I knew what was happening in that room. It was a memorial service at National Hemophilia Foundation's Annual Meeting, for those who had passed away from complications of a bleeding disorder or had served in the community. Should I go inside? Did I belong in that group? My heart said yes. And when it was time, I stood up and said his name out loud: "Ronald Julian Campos was my brother."

My earliest memory of Ronnie was when I was seven years old, and my family visited my paternal grandparents' graves in San Diego, Texas. Ronnie was buried in the same grave as my grandfather. There was no headstone. And I found it odd that my mother did not get out of the car. Many times we made the same trip after that memorable visit, and she never did get out of the car. I thought, *he was your son. Why are you just sitting there?*

Over the years, I asked my parents about my brother, and they changed the subject. Once I caught Mom at a good moment. She told me that Ronnie had the most beautiful eyes, and that he died of jaundice. He lived only five days. I had so many unanswered questions: How does a mother deal with losing a five-day-old baby? Did my parents ever discuss their loss? Could jaundice really kill you?

My first son, Julian, was born on June 23, 1996. Oh, how beautiful he was! He was like a china doll. His skin was so soft and smooth; his rich, black hair went in every direction; his fingers and toes so tiny and delicate. I never understood love at first sight until the moment I laid eyes on my Julian.

The next day, my world was turned upside down.

Julian had been circumcised. As I held my precious son, I felt warmth in his diaper. Unwrapping him, I saw that his diaper was red, like a brand-new crayon. My mother was in the room with me. I calmly called the nurse and said, "I think the doctor needs to check my son."

After the nurse whisked Julian away, my mother looked at me with terror on her face and said, "What if he has hemophilia?"

"Hemo *what?*" I exclaimed. Deep down, I knew something was terribly wrong, but it was nothing I could even entertain at that moment. The diagnosis of severe hemophilia A came the next day. To say that I was devastated cannot even begin to describe the range of emotions pulsing through me. My mother immediately said, "Don't tell anybody."

Mom died five weeks after Julian was born. It wasn't until years later that I began to question why she wanted me to keep hemophilia a secret, and her words came to haunt me.

In 2005, my second child Caeleb was born. The doctor ran a factor level on Caeleb as a precaution, and he was diagnosed with severe hemophilia A. This diagnosis was harder than the first! How could I have another child with hemophilia?

I began to wonder, *what did my mother know? What did she not tell me?* My father had become ill with dementia, so I couldn't get answers from him. Then in 2006, I called a paternal aunt. When I asked about my brother's birth, she said, "The only thing I remember is that he was horribly bruised when he was born." I think my heart stopped beating for a second. It was almost as if a sense of relief washed over me. My brother, Ronnie, had hemophilia. Mom's comments made sense now. She had suspected hemophilia in Julian.

I spoke with clinicians, who all gave the same opinion: jaundice can be the result of a head bleed, and most likely that's what happened to my brother. I know in my heart that it's true. Whether my parents both knew about Ronnie's hemophilia will always be a mystery. Was Mom praying that my children wouldn't have hemophilia? Did she keep the secret? Or did my parents know that hemophilia was a possibility, and Ronnie's head bleed went unrecognized? So many questions will never be answered, but I have accepted that.

But one piece of the puzzle has been found. I know the connection, and it brings me great peace. My brother's legacy is part of who my sons are. It is part of who I am. That God has entrusted me with two extraordinary lives is one of the greatest gifts I count myself blessed to have received. Hemophilia or not.

Cazandra lives with her husband, Joe, and sons Julian and Caeleb in the desert of southern New Mexico. She is currently developing her ministry to women through inspirational speaking. She spends most weekends hiking in the mountains with her family.

BY SONJI WILKES

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Inhibitor Insights is a *PEN* column sponsored by Novo Nordisk, Inc.

CommUNIcation: *You and I*

Everything changes after an inhibitor diagnosis, including your relationship with your medical team. Stress can lead to communication glitches that the patient with a complicated inhibitor can't afford. Communication problems can harm the trust between patient and physician when you need it most.

A 2007 *Consumer Reports* survey found that most patients are "highly satisfied" with their physicians: 77% of respondents reported being treated with respect. But the survey also found that problems do arise from communication issues.[1] The most common communication barriers for inhibitor families and their HTC? Selecting the best treatment regimen, choosing a product, and deciding when to start ITT. To secure the best therapy for your child, you'll need to develop some advanced communication skills.

Talking to Your Team

The key to good communication is developing a respectful relationship that includes active, informed listening and assertive dialogue. You need to be persistent and objective, and own up to your own biases. Tools for effective communication include *paraphrasing* what the other person is saying, and *taking the emotion out* of the situation.

Paraphrasing means restating using different words. Your doctor may say, "We've had good success in our patients with ITT and can normally tolerize patients within 18 months." To show your understanding, you could respond by paraphrasing: "You're saying that in your experience, 18 months is generally long enough for ITT, but it isn't an exact estimate. Right?"

Remove your personal biases and try to look at treatment issues objectively. Focus on the problem, not on the emotions that cloud it. Or postpone discussion if emotions can't be contained. One mother noted that taking some time to make a decision regarding switching factor products helped clear her concerns and allowed her to gather the needed information.

Make Decisions with More than Just Blind Faith

How do you become an informed listener? Inhibitor patients and families must be proactive in researching and understanding all treatment options. Gather information from journal articles, manufacturer educational material, conferences and symposiums, and conversations with your physician. National Hemophilia Foundation (NHF) offers free resources on a variety of topics: call 800-42-HANDI.

In my own family, when our doctor first proposed Rituxamib, an immunosuppressant therapy, I refused to consider it. I allowed my biases and emotions to interfere with communication. But the conversation never ended. With profound patience, the doctor described the benefits of the therapy each time we saw her. She consulted colleagues in hematology and other fields; she educated us for over a year before we finally agreed to try the new therapy. If she had been forceful or used guilt to persuade us, we would never have agreed. Because of her continued effort and compassionate understanding, we made an *informed* leap of faith in our son's treatment.

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1. "Most Patients 'Highly Satisfied' With Physicians, Still Room for Improvement." www.aafp.org/online February 14, 2007 (retrieved March 16, 2009).

BY LAURIE KELLEY

A New Law, A Mother's Dream: *Coverage for College Students*

Your college student with hemophilia or VWD might miss many college classes and tests because of a bad bleed, surgery or inhibitors. Medical absences can put young people at risk of losing their student status or being terminated from college. Traditionally, if children lose their student status, they might no longer be covered under their parents' insurance.

A 22-year-old advocate changed this for all US college students with chronic disorders. Michelle Morse was diagnosed with colon cancer while a junior at Plymouth State University in New Hampshire. Despite intensive rounds of chemotherapy, Michelle stayed in school after learning her parents would have to pay over $1,000 per month to retain her health insurance if she took a medical leave of absence. Like many insurance policies, hers required full-time student status at college to be covered.

Michelle's mother lobbied the New Hampshire legislature for a bill to require health insurance companies to cover Michelle if she took a medical leave of absence. After several years' effort, on June 25, 2007, Rep. Paul Hodes (D-NH) introduced a bill that on October 9, 2008, became Public Law 110-381 – "Michelle's Law."

Michelle's Law prohibits a group health plan from terminating coverage of a dependent child due to (1) a medically necessary leave of absence from a postsecondary education institution; or (2) any other change in enrollment at that institution that begins while a student is suffering from a severe illness or injury, and results in the loss of full-time student status. The law applies only to full-time students who are already dependents on a health plan, and does not require insurance companies to cover any new procedures or new individuals. The law simply prevents insurers from terminating coverage.

Michelle, who was born in Stoneham, Massachusetts, and grew up in Manchester, New Hampshire, eventually earned her bachelor's degree in childhood studies from Plymouth State University, despite her illness. Sadly, she died November 10, 2005, of colon cancer at Elliot Hospital in Manchester. Her brief life inspired a state law, signed on June 22, 2006, that became a national law to help millions of students who suffer from chronic disorders.

Please make your insurer aware of Michelle's Law if your child with a bleeding disorder requires time off from college due to medical treatment.

For more information:
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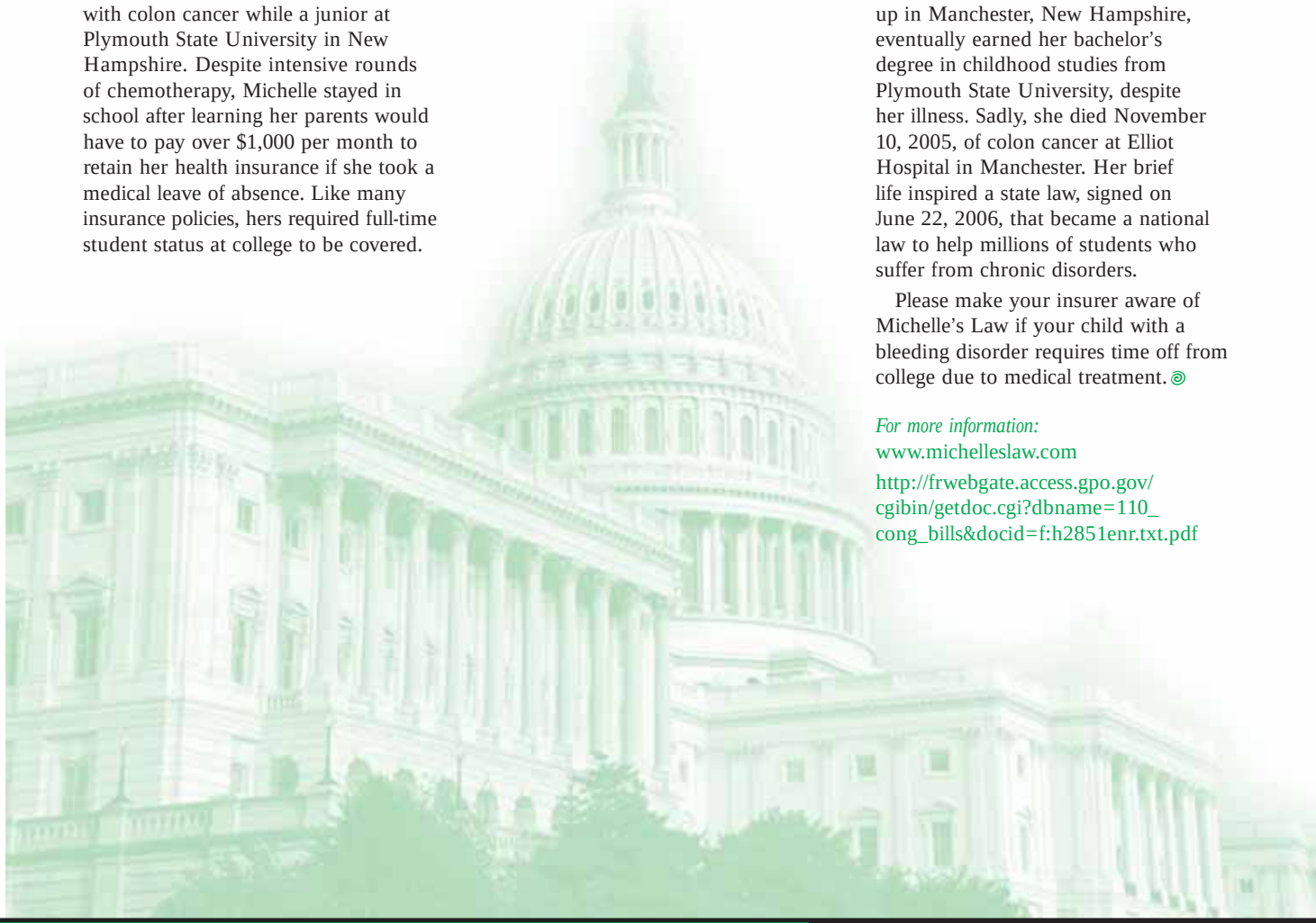

BY KEVIN CORREA

Transitions is a *PEN* column sponsored by Baxter BioScience

There's a New Chef in Town

Most of us know what we should and should not eat to stay healthy. Nonetheless, every few years the government releases guidelines designed to help Americans make healthy food choices. Since 1992 these guidelines have taken the form of a pyramid, divided to reflect the amounts of certain food groups we should consume. If this pyramid represents the gold standard in nutrition, many young men's diets more closely resemble mud huts. It's not difficult to picture the young bachelor in his first apartment, sitting at the wobbly card table eating mac 'n' cheese – for the fifth time that week. The transition from diner at Mom and Dad's table to head chef is a tough one, and if not taken seriously, it can result in unhealthy weight gain.

MyPyramid.gov
STEPS TO A HEALTHIER YOU

Maintaining a healthy diet is particularly important for people with hemophilia. Helen Tayag, licensed dietician and nutritionist at the Hemophilia and Thrombophilia Center at Rush University Medical Center, cautions that anyone with a weight problem is at higher risk for heart disease, high blood pressure, osteoarthritis and diabetes. "But having hemophilia and carrying extra weight invites the additional consequence of placing increased stress on joints," she notes. "Diet and exercise are crucial in the management of hemophilia. And with the limitations that hemophilia often puts on exercise, eating a healthy diet takes on even greater importance."

Moving Out and Ordering In

For many teens living at home, maintaining a healthy diet is relatively easy – as long as Mom and Dad serve healthy meals. But eating right becomes more complicated once young adults move out of the house.

Tom, a young man with hemophilia, tells a fairly common tale. He ran and swam during high school and was physically fit. But when he left for college, he admits, "Nutrition wasn't high on my list of priorities." Like many college students, Tom ate out almost every day, and foods like pizza became diet staples. When graduation rolled around, in addition to a degree, Tom had gained an extra 30 pounds.

Several studies of college students suggest that weight gain like Tom's is common. An Indiana University study found that 86% of male students gained an average of 14 pounds by their senior year. The studies don't offer concrete explanations for the gains, but among other factors, researchers suspect increased alcohol consumption, decreased physical activity, and a social life that revolves around food.

Back to Basics

Because he felt unhealthy, Tom decided to get back in shape. The experience gained from swimming and running in high school gave him the basic knowledge he needed to start exercising again. "I did a lot of research on the Internet and read plenty of magazines until I found a nutritional plan that I thought would work." Tom cut out all fast foods and began cooking for himself. Eventually, he lost all the excess weight.

Helen points out that Tom's approach was great because it worked for him, but she advises patients to start slower. Often, removing one offending item from a diet can have a major impact. For one hemophilic boy it was soda. Helen didn't advise him to cut out all junk or fast food, but he had to give up soda. "He did," she says, "and in a year he had lost a lot of weight."

Helen bases her approach on the idea that for people to willingly change their habits, they must see results. That's why she advocates changing one small thing at a time, like eliminating soda.

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It Takes Two to Tango

So much of what's written about effective patient-physician relationships focuses on what makes a good doctor. But to be an effective self-advocate, you need to become a good patient first. Some tips to help you out:

BE PREPARED for your appointments. This means anticipate the hematologist's questions and have answers ready. Bring your own questions, written out.

LISTEN to your hematologist. Don't just nod when you don't understand something he said.

SPEAK UP when you have a concern. Ask why your doctor is recommending a particular brand of factor: is it for medical purposes, commercial purposes?

OBTAIN SECOND OPINIONS when you're in doubt. Don't worry about your hematologist's feelings. She's a professional.

REMOVE EMOTION from the equation. (Easier said than done when your child is the patient.)

FOLLOW THROUGH on the treatment plan.

FOLLOW UP with questions that arise after you've left.

Do you suspect a conflict of interest? Are you being forced to use a particular HTC by your insurer, and do you take it out on your HTC team? Don't let the conflict fester and get worse. Remember, you have rights in this relationship – including the right to be involved in and make decisions about your care plan.

Beyond that, remember that you are a consumer and you're paying for a service. You should be satisfied with the service you receive. Would you continue bringing your car to a mechanic you didn't trust? Of course not, and that's just your car!

As intimidating as it may seem, speak up. Your doctor isn't a mind reader. If you sit idly by, your doctor may misinterpret your silence as tacit approval.

If talking with your hematologist doesn't satisfy you, it's probably time to seek further assistance. Many hospitals offer patient advocacy programs. The patient advocate acts as a neutral party and attempts to resolve conflicts between patients and the hospital. The addition of a neutral third party to the equation might be all it takes to work through an impasse with your care team.

For whatever reason, sometimes the conflict grows beyond resolution. When you've reached this point, it may be time to seek treatment elsewhere. This can be unnerving.

Finding a new hematologist and care team might be as simple as investigating the hospital across town – easy if you live in a city like Boston, Chicago, or Dallas. Not so easy if you live in a rural area. For Molly and her son Blake, it meant moving to an entirely new city. It took a few years, several doctors, and lots of effort, but Molly says the results were worth it: they finally found a team they're happy with. "We've had good doctors and we've had bad doctors. It makes all the difference in the world having a team in place that we know will do what it takes to work with us."

One of the key components Molly looked for in her son's care team was the commitment to work with the family over the long term. "We're not looking for doctors to cure him," she says. "We're looking for guidance that will give my son a good quality of life. His needs will change over time. And that means we need someone who's in it for the long haul."

This is a crucial point. You're fostering a long-term relationship with your physician, and if you're not happy with the care you receive now, chances are pretty good you won't be happy later.

Fortunately, most families are happy with the care they receive from their HTC. The HTC model has revolutionized hemophilia care and improved quality of life. But as the industry evolves, parents and patients must continue to educate themselves and be mindful of conflicts that might affect the level of care they receive. Protect and nurture the partnership you have with your physician, because it's one of the most important relationships of your young child's life.

Kevin Correa, *Transitions* columnist for *PEN*, lives in Georgetown, Massachusetts, with his wife Patty and three young children. He earned a degree in social anthropology from Harvard University.

Dripping on the Independence Dance

BY ZIVA MANN

I cheered Shai on — until the drip became a flow, washing away his confidence and undermining my support. An opportunity lost? No — a step, a twirl in our dance together, and opportunity was back. Or was it?

A slim, steady thread of blood trailed from Shai's nose, and he touched it gently, fascinated. Watching him, I had a crazy thought: at six years old, maybe Shai could handle a small nosebleed.

So we started with a drip and a plan. It was simple: when Shai's nose bled, he could apply pressure, and presto! He'd have a bit of independence and empowerment. I gave him a tissue and asked, "Do you know how to hold pressure on your nose?"

He gave me the hairy eyeball. "Of course. I press here, hard, and hold on." He demonstrated on my nose, squeezing until I winced. "I can do this," he told me earnestly – urgently – "I want to do this."

And he did. Shai sat confidently, his fingers white from applying pressure. I tried to look relaxed, but failed. When the bleeding stopped, Shai casually tucked a tissue in his pocket ("Just in case, Mom") and cheerfully vanished.

I felt triumphant and good-mommyish, and pretended that fostering independence could be just this simple. It isn't, of course. Independence can happen when Shai is ready to manage a skill. It lets me show Shai that I'm proud of him, that I trust him to do something on his own. That's a powerful message, but just because he wants to be independent doesn't mean that he has the skills; and just because he has the skills, that doesn't mean he has the maturity to pull it off.

It's so easy to get this wrong. Independence offered at the wrong time turns into a wail: "*Mo-om*, do I have to?" And even if I find the magical moment when Shai's skills, maturity, and desire align, there's no guarantee of a happy ending. No guarantee of success. Independence isn't a careful series of steps forward; it's a series of dance steps – forward, then back, then forward. Box step until I'm baffled. And believe me, I often am.

As the weeks passed, the nosebleeds continued. Still, I cheered Shai on – until the drip became a flow of blood, washing away his confidence and undermining my support. I began to worry that Shai's technique wasn't reliable enough to keep the bleed from escalating. Should I hold pressure for him? Support him?

We're losing our opportunity, I thought glumly, and watched my visions of independence twirl away. I began to hover during the bleeds, and Shai glared at me. But as he watched his blood continue to drip and stain, Shai stopped glaring, and his eyes grew wide. He forgot the pride and sense of power he'd found in holding pressure himself, and he just wanted the bleeding to stop. Now.

Shai handed the nosebleed management back to me, telling me to fix it. I tried, but Shai's got a largish, long stretch of vein running close to the surface of the nostril. I could clamp the vessel and use factor to create a clot, but the broken, healing vessel would still be there, a fault line waiting to be triggered. And it was triggered, over and over, until Shai was a tangled mess of emotion. He'd been so wonderfully determined – and so right – to take over his nosebleed management. But as the bleed spiraled out of control, fear drove him back, and he grew angry. He lied, tried to skip doses of Amicar®, and complained about holding pressure. He simmered, then roared. Then became silent.

I sat down next to him one afternoon, and leaned back. "This is pretty yucky, hey?" I asked. Not quite meeting my eyes, he nodded. "We try all these tricks," I mused, "but the nosebleeds come back anyway." Shai was quiet. "Makes me crazy," I suggested.

Shai looked up. "Can the doctors help?" he asked.

"They're trying," I said ruefully, "but they're as frustrated as we are."

Shai thought this over. "Are the inhibitors making me bleed?"

"I don't think so," I told him, "but I do think we need some help from a nose expert."

Shai relaxed. "Yes."

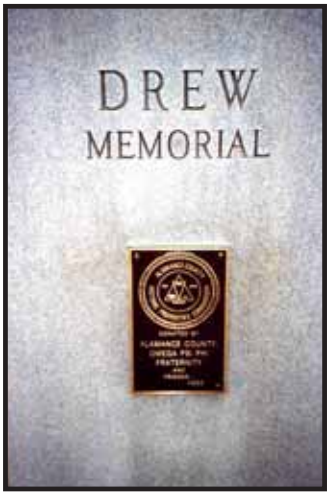
A couple of days later, grinning and cocky in the operating room waiting area, Shai showed the anesthesiologist where to place an IV. His nose was cauterized in a slow, careful procedure by an ENT disinclined to take chances. As we left, Shai argued that we should go back – he was having fun! Why do we have to leave? The nurses laughed as we hauled him away.

Two weeks later, the nosebleeds came back, dragging with them my fears and frustration. But to my surprise, Shai was back too, nervous but determined to hold pressure. Step forward, step back, twist into a frustrated knot, then step forward again. These lessons on independence and responsibility never end, and Shai and I will be stumbling forward, backward, and sideways for years.

Or, better yet, maybe we'll dance.

BY RICHARD J. ATWOOD

Remembering Dr. Charles Drew



Photos: Richard J. Atwood

Just north of the small towns of Haw River and Green Level, nestled in the surrounding farmland of central North Carolina, a stretch of State Highway 49 is named for Dr. Charles Drew. A monument stands by the road, clearly marking the location of his fatal car accident in 1950. Why is Dr. Drew so publicly recognized in rural North Carolina, where he never even lived? To find out, I spent an afternoon visiting his accident site, and later, I read more about his life.

Charles Richard Drew was born in 1904 in a segregated section of Washington, DC. As a black child, he learned the realities of racism in American society, and understood the need for qualified doctors. Early on, he acquired his motto, "Excellence of performance can overcome racial bias," which he continually applied: he graduated from Amherst College and earned his medical degree from McGill University College of Medicine. For his subsequent dissertation at Columbia University, Dr. Drew compiled everything known about the preservation of blood. He was then employed as a surgeon on the medical school faculty at Howard University in Washington, DC.

World War II loomed, exposing the need to collect, test, preserve and transport blood for wounded soldiers. Dr. Drew proposed using plasma rather than whole blood as the solution when he organized the Blood for Britain program, and later the American Red Cross blood banks. The development of blood banks at military bases and hospitals across the country resulted from these war efforts. Yet for no scientific reason, the military continued to segregate the stored blood of white soldiers from the blood of minority soldiers.

At 2:00 am on Saturday, April 1, 1950, Dr. Drew and three other black physicians left Washington, DC, for a non-stop drive to Tuskegee, Alabama, to attend a free clinic and a medical conference. Dr. Drew slept the first part of the journey, but near daybreak he took over driving the Buick Roadmaster. At 8:00 am, after rounding a slight bend in Highway 49 heading south, Dr. Drew drove off the road into a field and rolled the car. Of the passengers, only Dr. Drew suffered serious injuries, and his life could not be saved at the nearby hospital in Burlington, North Carolina. He was 45 years old.

Although Dr. Drew did not work directly with hemophilia or other bleeding disorders, his significant contributions in

plasma storage, blood safety, and blood banking were vital to subsequent developments in hemophilia treatment. Today he is known as the Father of American Blood Banks.

Dr. Drew's outstanding career has been recognized in a variety of ways. The US Postal Service issued a commemorative stamp to honor him in 1981. His portrait hangs in the National Portrait Gallery, the National Institutes of Health, and American Red Cross headquarters in Washington, DC. A medical school in Los Angeles and many hospitals have been named for him.

Many inspirational biographies for younger readers highlight the accomplishments of this renowned physician who improved the lives of all Americans. Most are short and easy to read, explain basic principles of blood, and include timelines, glossaries, resources, and photographs. I especially recommend the following juvenile and young adult books:

- Whitehurst, Susan. *Dr. Charles Drew: Medical Pioneer*. Chanhassen, MN: The Child's World, 2002. Journey to Freedom: The African American Library series.
- Trice, Linda. *Charles Drew. Pioneer of Blood Plasma*. New York: McGraw-Hill, 2000. Ideas on Trial series.
- Mahone-Lonesome, Robyn. *Charles Drew. Physician*. New York: Chelsea House, 1990. Black Americans of Achievement series.

Other juvenile and young adult books about Dr. Drew:

- Hardwick, Richard. *Charles Richard Drew. Pioneer in Blood Research*. New York: Scribner's, 1967.
- Salas, Laura Purdie. *Charles Drew: Pioneer in Medicine*. Mankato, MN: Capstone, 2006. Fact Finders Biographies: Great African Americans series.
- Schraff, Anne. *Charles Drew: Pioneer in Medicine*. Berkeley Heights, NJ: Enslow, 2003. Famous Inventors series.
- Stelson, Caren B. *Charles Drew and the Blood Banks*. Boston: Houghton, 2006. Life Science: The Machinery of Our Body series.

Dr. Walker emphasizes that the most successful medical practices do the best job helping to educate patients, empowering them to take over the management of their hemophilia. To this end, the Internet is an unparalleled tool in the hemophilia patient's arsenal.

"An educated consumer is our best consumer," asserts Dr. Walker. "The Internet is a wonderful resource. We encourage our new parents to digest as much [hemophilia] information as possible, and to join support groups. The Internet really facilitates this."

Two decades ago, parents had little information to help them learn about their child's hemophilia. Today, it's almost the opposite. As with most subjects on the Web, not all the information you'll find on hemophilia is completely accurate.

When contemplating the veracity and value of any information, always consider the source. Dr. Walker recognizes this Internet shortcoming and muses, "I just wish there were some sort of filter on it."

Dr. Karen Reynolds, a pediatric hematologist, concurs but still encourages her patients to use the Web: "Even when the information they read about a procedure or drug is wrong, it leads to productive discussions."

In the quest for knowledge, the National Hemophilia Foundation (NHF) website is a good beginning: patients will find basic information about hemophilia, resources like newsletters and bulletin boards, and contact information for local chapters. Laurie Kelley's book, *Raising a Child With Hemophilia*, is an invaluable resource for parents. Laurie addresses a wide range of pertinent subjects, from tackling the toddler years through transitioning to adulthood. Another educational read is *Hemophilia*, by Michelle Raabe (see Headlines, page 17).

By absorbing as much information as possible, you'll gain confidence and become more adept at deciphering the intricacies involved in medical treatment and the terminology used by

The Chronic Care Model

The US healthcare system is designed to rapidly address acute illnesses and injuries. But because the system focuses on cure rather than care, most people with chronic medical conditions experience gaps in care. Because of the emphasis on solving the immediate problem, other aspects of healthcare that contribute to long-term health and quality of life may be ignored.

Fortunately, for people with bleeding disorders and those with cystic fibrosis, this isn't the case. Regional centers of excellence, which use a multidisciplinary approach to deal with all aspects of patient care, greatly increase long-term health and quality of life. For people with bleeding disorders, these are hemophilia treatment centers. The benefits of HTCs are dramatic: patients are 40% less likely to die from a hemophilia-related complication, and 40% less likely to be hospitalized for bleeding complications. In the mid-1990s, Dr. Ed Wagner and the MacColl Institute for Healthcare Innovation conducted research on improving healthcare for people with chronic conditions. Their research culminated in the Chronic Care Model (CCM), which incorporated many of the practices already employed by HTCs.

For HTCs and the CCM, a key goal is to create an educated, empowered individual capable of effectively self-managing a condition: the patient — *not the doctor* — must manage his hemophilia.

Converting a patient into a savvy self-advocate capable of spotting — and fixing — potential problems with his care requires effective patient education. When patients or parents report having a good relationship with their hematologist, they often say they "do their homework" to prepare for medical interactions. While patient knowledge is valuable, creating a truly empowered patient may require a shift in focus for some treatment teams: from simply promoting patient knowledge about hemophilia, to increasing the patient's confidence in his ability to manage hemophilia. Unfortunately, surveys of HTCs have found that patient and family education materials and practices vary widely from center to center.*

In order to instill this level of confidence in patients, HTCs must use quality instructional materials and effective teaching methods. The care team should help patients

- set goals that build their hemophilia management skills;
- identify barriers that prevent them from reaching their goals;
- mutually develop a plan to overcome those barriers.

If you haven't done it already, speak with your HTC team today to develop a personalized set of goals and a road map to help you reach them. Your willingness to share the responsibility of managing your hemophilia will strengthen your relationship with your hematologist.

* *Issues in Comprehensive Pediatric Nursing*, 7.4–5 (1984): 217–231

physicians. In turn, you and your hematologist are more likely to be on same page, speaking the same medical language. As your knowledge of hemophilia management grows, you'll be on more equal footing with your physicians. And once you've achieved greater equality, you'll begin to develop mutual trust.

Building Trust

There's probably nothing so crucial to a healthy patient-physician relationship as developing trust. And trust must run both ways.

According to Nancy, mother of three sons with hemophilia, trust isn't a quality that sprouts overnight. "The relationship that we have with our HTC is one of mutual respect that we built over time."

Nancy appreciates how her HTC staff trusts her judgment. With the HTC over two hours away, it's not convenient to hop in the car every time an issue arises with one of her boys. "We've gotten to the point in our relationship where I'll call the HTC because I'm not certain I need to bring one of my sons in. I'll speak to a nurse and tell her the problem, and she'll say, 'Mom, what do you think?' because she trusts my judgment. Together, we come up with a plan."

Deferring to Nancy's intuition isn't just a courtesy. The HTC is acknowledging that over the course of their relationship, Nancy has consistently demonstrated good judgment and comprehension about managing her sons' hemophilia. This same courtesy is unlikely to be extended to the parent of a toddler recently diagnosed with hemophilia, because the requisite level of trust has yet to fully develop. Apart from time, this synergistic relationship requires mutual respect between patients and physicians.

Tara, whose nine-year-old son has hemophilia, had several disagreements with her son's first hematologist. They didn't see eye to eye on the treatment the physician recommended. "In the end," says Tara, "I completely mistrusted him. I wouldn't have believed him if he said my shoe was untied." The family has since found a team of hematologists with whom they couldn't be happier. Tara notes, "Our lives have been simplified and enriched knowing that we have an extremely knowledgeable and caring team looking after us."

Tara's experience illustrates that trust is as much about personalities meshing as it is about feeling the doctor is capable of delivering appropriate care. While you don't have to be best friends with your hematologist, if you don't respect him or her, the relationship won't work.

Dr. Reynolds believes that respecting parents' opinions is key to fostering a successful relationship. "I've worked with hemophilia patients for years," she says, "but I don't have a child with hemophilia, and I have to give parents their due. Parents know their kids; it's like they have a sixth sense and know when something's wrong."

Yet even when parents trust their physicians, and that trust is reciprocated, the structure of the hemophilia industry can strain the relationship.

Where Money and Medicine Mix

Hemophilia is big business. The United States alone sees over $2 billion in factor concentrate sales annually. Unfortunately, hemophilia patients increasingly find their medical care impacted by their care provider's bottom line.

Of the approximately 140 HTCs in America, about half sell factor. This wasn't always the case. Prior to the 1992 establishment of section 340B of the federal Public Health Service (PHS) Act, HTCs could not offer competitively priced drugs. But 340B has enabled them to purchase drugs at steeply discounted prices, making the HTC pharmacies competitive with other factor distributors, such as home care companies. Although HTCs can purchase factor at reduced rates through 340B, the price that HTCs charge for factor is not regulated and varies widely. Some sell factor at significant discount; others charge as much as or more than home care companies.

For an integrated system like an HTC to be effective in the profit-conscious US healthcare system, it must have reliable and diverse funding sources. HTCs are feeling the pinch from a decade of flat federal funding, increasing numbers of Medicaid patients, decreasing insurance reimbursement rates, and funding cuts from the hospitals and universities that host them. And in that time, the patient population at most HTCs has more than doubled. So factor sales have become an increasingly important revenue stream. In fact, without the revenue generated by factor sales, many HTCs would have to shut their doors. Most HTCs are under constant pressure to generate revenue to fund their programs, or else risk closure – pressure that sometimes clouds their judgment. And where money and medicine mix, conflicts can follow.

When Jane and her family relocated to a new city, they soon started having issues with their HTC over purchasing factor.

"The HTC's pharmacist would sit in on our checkups, after which he'd ask if we wanted him to fill an order for our factor," Jane says. "While it comes across as a suggestion and not overt pressure, it makes you uncomfortable. And whether it's a legitimate concern or not, it makes you think that money – and not necessarily patient care – is their motivating force. It undermines my confidence in the treatment we're receiving."

The pressure some patients and families feel to purchase factor through HTCs has them questioning the HTC's ethics, which can tarnish the trust they've developed with their caregivers.

Patients should know this: if your HTC has a 340B eligible pharmacy, federal law mandates that the HTC offer you a choice of provider – this means listing local specialty pharmacies and home care companies. And if you decide to purchase factor elsewhere, the HTC cannot refuse to provide you with medical or clinical services. In other words, you can't be coerced into using the HTC pharmacy services for your factor purchases.

In spite of this provision, Jane's story illustrates how conflicts can arise due to factor sales through HTCs.

In addition to factor sales, another aspect of HTC practice casts a cloud over some patients' interactions with their care team: research.

Research and Conflicts of Interest

HTCs have a rare resource: hemophilia patients! And because many HTCs are affiliated with university teaching hospitals, it's not uncommon for staff clinicians to participate in hemophilia research. In some cases, patients feel that their care takes a back seat to that research.

One mother of a hemophilic son comments, "I feel that research is our hematologist's primary focus, not my son's care. More often than not, we deal with nurses, and it seems they are given great latitude in determining our treatment. I walk away not certain we're getting the best care. That's not a slight against the nurses. I simply want my son to be seen by 'an expert.'"

If patients at some HTCs are often seen by nurses or physician's assistants (PAs) instead of hematologists, does that mean that research is keeping the doctor away from the patients? Not necessarily. In the comprehensive care model (CCM) as practiced by many HTCs, nurses, nurse practitioners and PAs play an important role in patient care. For many patients, the HTC nurse is their primary contact. The nurse may even help patients determine the severity of a bleed or the proper course of treatment over the phone – a rare thing outside of the HTC comprehensive care model. If your HTC typically schedules routine appointments with PAs or nurses, and you want to see a physician, then you should request a consultation with your physician when making your appointment.

Some patients question the involvement of HTC physicians and staff in conducting clinical trials of a pharmaceutical company's factor products and delivery devices – activities accompanied by an influx of pharma dollars in support of the HTC staff conducting the research – only to have the HTC recommend or solely prescribe that company's products. Even if no laws are broken, the appearance of impropriety is enough to strain the patient's relationship with the HTC. As one parent put it, "Something about it just feels dirty and unethical."

Can pharma dollars really influence patient care? Ellen and her husband Karl joined an HTC when their son was diagnosed with hemophilia. The couple read extensively about product choices and treatment plans. After diligent research, they sought a prescription for a recombinant factor product from their hematologist. They were surprised when the doctor vehemently disapproved of their factor choice and recommended a different product. This raised some red flags. Why was the doctor so adamant?

When Ellen asked for clarity, the hematologist explained that in her opinion, the recommended recombinant product was the safest product on the market. This confused Ellen, who had read that all recombinant products were considered safe. When she pushed the doctor on this point, the relationship rapidly deteriorated.

But Ellen didn't yield, and insisted on using the product of her choice. "To this day," she says, "Our hematologist avoids us. It's like we don't exist." Karl adds, "Her actions made it clear. It was her way or the highway."

After speaking with other parents at their HTC, Ellen learned that those who had insisted on the same factor product Ellen had requested met with similarly cold treatment. Because this HTC is a major research center and receives pharmaceutical

funding, Ellen wondered if market forces – not individualized patient care – dictated factor recommendations.

The blurred line between objectively practicing medicine and conducting research for pharmaceutical companies isn't unique to hemophilia. National disquiet is growing over the potential conflicts of interest that arise as physicians receive payments or "transfers of value" (gifts, tickets to sporting events, vacations) from these companies. Recent studies indicate that physicians more often prescribe drugs from pharma companies with whom they are affiliated than prescribe comparable drugs of pharma competitors.

Over the past few years, attempts have been made to introduce "sunshine" legislation to address these conflicts of interest. Sunshine legislation would require pharma to disclose payments or transfers of value to physicians, making conflicts of interest easier to identify.

One such piece of legislation is the Physician Payments Sunshine Act of 2009 (S. 301) resubmitted in February 2009 by US Senators Chuck Grassley and Herb Kohl. According to Senator Grassley, "The goal of this initiative is to establish transparency and the accountability that comes from disclosure. It's become clear that the federal rules in place to manage conflicts of interest in research aren't enforced as they ought to be, and there's an opportunity to strengthen them here, as well."

Although the Sunshine Act did not make it through Congress, it did catch the eye of the Pharmaceutical Research and Manufacturers of America (PhRMA), which has introduced its own voluntary code of ethics – perhaps in an effort to forestall the passage of more stringent federal sunshine legislation. In January 2009 PhRMA issued its own Code on Interactions with Healthcare Professionals. According to PhRMA, the code is founded on the principle that a "healthcare professional's care of patients should be based, and should be perceived as being based, solely on each patient's medical needs and the healthcare professional's medical knowledge and experience."

Although not part of the Sunshine Act or the PhRMA code, ideally sunshine legislation would go a step further and require physicians to make disclosures to their patients about potential conflicts of interest. If you are considering switching factor products, or even wondering why your child was prescribed a particular product, it would help to know whether your HTC conducts clinical trials or your physician consults for pharma.

And Then There's the 800-Pound Gorilla

One of the greatest sources of stress, if not conflict, in the patient-physician relationship has little to do with the patient or the physician. It's insurance.

Even when you have the best hematologist and a care team you think you couldn't live without, insurance can potentially drive a wedge between you and your healthcare providers.

When a family first learns their child has hemophilia, they must digest an enormous amount of medical information. And potentially more confusing, they must also learn to navigate the labyrinth of rules and restrictions mandated by their insurance carrier. In many instances, insurance companies seek to manage skyrocketing healthcare costs by limiting choice: choice of physician, choice of factor product, choice of factor provider, and even choice of treatment regimen.

After Jane's family relocated, they intended to maintain their relationship with their home care company, but their new insurance wouldn't cover it. Although this is not uncommon, some insurance companies' interventions go beyond simple cost-cutting measures like this.

Remember that $2 billion in US factor sales? Some insurance companies want a piece of those sales. In some states, insurance provider Anthem requires hemophilia patients to use either the specialty pharmacy PrecisionRx or the patient's HTC pharmacy. Interestingly, both Anthem and PrecisionRx are subsidiaries of WellPoint – the largest publicly traded commercial health benefits company in America. Naturally, many patients with longstanding relationships with their home care companies aren't happy with this "choice." They can either purchase factor with money that funnels back to their insurance company, or they can purchase factor from their HTC.

Even when a change in jobs doesn't necessitate relocation, switching to a new employer's insurance plan can separate patients from the HTC they trust. Kim, mother of a son with hemophilia, recalls, "When my husband took a new job, his insurance forced us to switch from Children's Hospital Boston to New England Medical Center." Initially, the family was upset, leaving behind longtime relationships. But the change worked out in the end, because as Kim explains, "We grew to like NEMC just as much!"

In the event that an insurance issue does arise, don't let it affect your relationship with your care team. Remember that administering care and collecting payment for that care are two distinct pieces of the healthcare puzzle.

When Things Go Wrong

If a conflict occurs with your HTC, assess the problem and then quickly address it. Is it simply the result of clashing personalities? Are *you* having difficulty effectively communicating? Do you perceive your hematologist as arrogant, or distracted by research?

Insights... continued from page 4

When Coach and Quarterback Disagree

Unfortunately, not all families have a give-and-take relationship with their HTC team. Sometimes having a phone conversation or face-to-face meeting is nearly impossible: your doctor is booked solid, engaged in research, or just busy. Sometimes the conversation is easy to arrange, but the doctor doesn't offer solutions or explanations – just "take it or leave it" advice.

Marie[2] needed multiple visits with three different treatment teams before she trusted her hematologist to make decisions about her son's inhibitor. "You must have someone you feel confident in," she advises. "Our doctors spend time with us during our visits to make sure we get all our questions answered."

Angela had to learn how to communicate effectively. "I have to be very concise and direct: 'tell me exactly' and 'explain this again.'" When discussing a previous ITT performed at another HTC, "our doctor kept insinuating that she would have done it differently. After several conversations, I finally asked, 'What *exactly* would you have done differently?' and she told me. Her answer explained so much! But if I'd never asked that question, I would never have understood."

Penalty Flag: Aggressive Communication

"My doctor is open to my suggestions," says Todd. "In the beginning, it was very much *her* making decisions and not expecting too much pushback from me." But when Todd wanted to try a new protocol, he was assertive: "I sent her the actual study. She called me and said, 'I don't see anything in here that indicates that this would work.' I literally told her which page, column and paragraph to read, and then she said, 'Okay, we'll give it try.' When I know what I'm talking about, she will listen. But I usually have to *study* for these discussions!"

It takes patience, flexibility and mutual respect to forge a positive relationship with your medical team. Judy Kaufman, CPNP, of Kansas City Regional Hemophilia Center, points out, "There's a huge difference between assertive advocacy and aggressive behavior." Assertive communicators are attentive and impartial, using "I" statements: "I think we should explore this option." Aggressive communicators are reactive, employing intimidation and blame.[3] Kaufman stresses, "It's a lot of work to try to get through aggressive communication to get to the point. Remember that the HTC staff really wants the best for you and your child. Adversarial communication does not help get the needs met."

There Is No "I" in TEAM

Parents should consider themselves valued team members in their child's care. Communication is a two-way street that involves all parties working toward a common goal. Ask questions, gather information, be an active listener, and own up to your own biases.

Knowing that your HTC team has reviewed your child's treatment plan and inhibitor history is a huge source of comfort. But the real comfort comes from being engaged in communication and decision-making. It takes united effort from everyone – patient, parent and provider – to achieve the best medical outcomes.

2. Names of parents have been changed for anonymity.

3. Antai-Otong, Deborah. *Nurse–Client Communication: A Life Span Approach.* Jones & Bartlett, 2006.

Transitions... continued from page 6

In spite of the fact that a high percentage of her young patients with hemophilia have weight issues, Helen isn't disheartened: with counseling, between 60% and 70% do lose weight. She only wishes they'd had a better understanding of diet and nutrition *before* it became a concern. Helen believes that education has to start in the home.

It Starts with Mom and Dad

Parents can help prevent their children's potential struggles with diet and nutrition by instilling good eating habits early. This means not simply putting good foods on the table, but helping young children understand why one food is chosen over another. Teaching proper diet and exercise should be as much a part of educating them about their hemophilia as explaining topics like self-infusion and R.I.C.E.

By providing a basic understanding of nutrition, parents lay the foundation for young adults to make good decisions about their diet once they're on their own. Helen recommends the

manufacturer

Insurance Help with Baxter's CARE

CARE is a new comprehensive insurance assistance program from Baxter BioScience, designed to help members of the hemophilia community proactively manage their health insurance situations. Open to all hemophilia A patients and inhibitor patients, regardless of current therapy or insurance coverage.

To enroll in CARE, contact your Baxter representative or call toll-free: 888-BAXTER9

Staying Fit with Fun and Safety

GameFaces™ is an online program that encourages people with hemophilia A to keep active by participating in real-life physical activities: baseball, tennis, golf, Nintendo® Wii®. Series of customized challenges is based on the individual's age, disease severity, and current level of physical activity. Participants who complete a contest April 14–July 7, 2009, will be entered in a drawing to win a Nintendo Wii game console.

For information: www.hfsgamefaces.com

New Factor IX Product in Studies

Inspiration Biopharmaceuticals has announced the initiation of a phase I clinical trial of IB1001, its recombinant factor IX product. The study will examine safety, tolerance and pharmacokinetics compared to Wyeth's BeneFix. If this study is successful, patients will be followed for a six-month phase II/III trial period that will implement either an on-demand or prophylaxis protocol. IB1001 uses Inspiration's proprietary recombinant protein manufacturing technology, which the company says results in a greater protein yield.

For information: www.inspirationbio.com

New Product for FI Deficient Patients

CSL Behring's RiaSTAP is an intravenous human fibrinogen concentrate, indicated in the US for acute bleeding episodes in patients with congenital fibrinogen deficiency, including afibrinogenemia and hypofibrinogenemia. Already available in Europe under the trade name Haemocomplettan P, RiaSTAP is the first and only treatment approved in the US for this rare bleeding disorder, which affects approximately one person per million, or 150–300 Americans.

For information: IBPN, March 2009

manufacturer

Inhibitor Educational Support Brochures

Series of brochures by Novo Nordisk that educates about topics of interest to inhibitor patients: introduction to inhibitors, surgery, traveling with inhibitors, ER visits, school teen issues, adult issues.

For information: www.novonordisk-us.com/biopharm or ask your HTC

nonprofit

Want to Go to San Francisco?

NHF's 61st Annual Meeting is being held in San Francisco this year, October 29–31. For first-time attendees only, NHF is offering a limited number of Educational Participant Grants. Applicants may apply for grants in one or more of the following categories, for a maximum of three nights and four days: airfare, hotel, related expenses, registration fees. Applications must be postmarked by Friday, June 26, 2009.

For information: www.hemophilia.org or sroger@hemophilia.org

Lean on Me

Education and Support for Adult Men with Hemophilia

Hemophilia Federation of America's Blood Brotherhood program provides information and support on topics for men with hemophilia, age 25 and older. Group meetings bring men together to learn and share experiences on nutrition, exercise, retirement, financial planning, career advice, insurance. Program includes national calls, webinars, chatrooms, in-person meetings. Sponsored by Baxter BioScience; implemented by HFA in partnership with the CDC.

For information: www.hfabb.org

nonprofit

medical

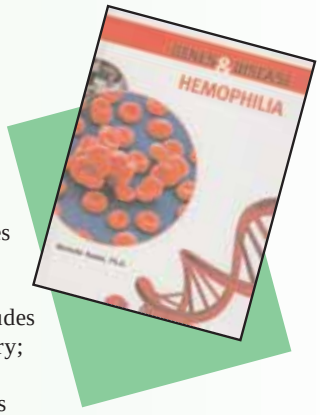
Mad Cow Disease Proteins Found in British Hemophilia Patient

In February 2009, the first evidence of variant Creutzfeldt-Jakob disease (vCJD) transmission in a patient with hemophilia was confirmed. The patient, a 70-year-old British man, died. He did not die of vCJD and showed no symptoms. He had been treated with a British-made clotting factor concentrate manufactured in part from the plasma of a British donor who went on to develop symptoms of vCJD. The patient had received British plasma-derived clotting factor concentrates prior to 1999, before the use of UK plasma for the production of clotting factor concentrates was banned.

This is the first time vCJD has been found in any of the 4,000 British hemophilia patients who received plasma-derived clotting factor concentrates between 1980 and 1998. But it's not known whether this patient contracted vCJD from his factor concentrate, or by other means, such as eating vCJD-contaminated beef. CJD is a fatal brain disease first classified in the 1920s. In 1996, doctors reported a variant of the disease, vCJD, the result of exposure to the agent that causes Bovine Spongiform Encephalopathy (BSE, or "mad cow disease") in cattle. There is no test to screen for vCJD, and no treatment. Although vCJD is rare, since 1995, 164 people in Britain have died from vCJD, with just one death last year. UK plasma has not been used in the UK or elsewhere since 1998 for the production of clotting factor concentrate.

For information: www.hemophilia.org, www.ppta.com, www.cott1.org, www.haemophilia.org, www.hpa.org.uk

New Book on Hemophilia



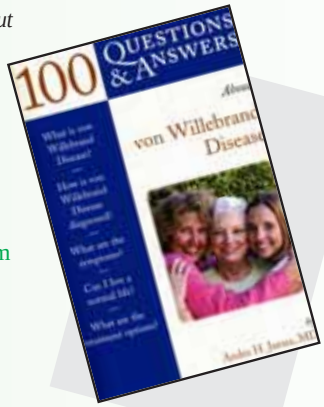
Hemophilia by Michelle Raabe (2008) is a hardcover, scientifically detailed, colorfully illustrated and easy-to-read book that focuses on the science behind the treatment, symptoms and genetics of hemophilia. Includes stories of hemophilia's history; explanation of how various treatments are made, such as plasma-derived and recombinant; and how gene therapy might work. $35.00 (approx.)

Available on www.amazon.com

New Book on von Willebrand Disease

100 Answers and Questions About von Willebrand Disease by Dr. Andra James (2009) covers medical and nutritional information related to VWD in Q&A format. $14.00 (approx.) softcover

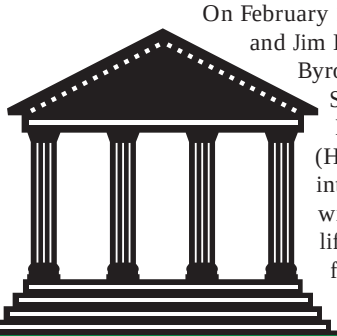
Available on www.amazon.com or from Jones & Bartlett: www.jbp.com



medical

advocacy

Lifetime Caps Bill Introduced



On February 13, 2009, Anna G. Eshoo (D-CA) and Jim Langevin (D-RI), with Senators Byron Dorgan (D-ND) and Olympia Snowe (R-ME), introduced the Health Insurance Coverage Protection Act (H.R. 1085; S. 442). The legislation, introduced in both houses in 2008, will set a $10 million minimum lifetime cap on health insurance, with future increases based on inflation.

advocacy

COBRA Help After Layoffs

Among the provisions of the new stimulus package signed by President Obama are subsidies for unemployed workers continuing their healthcare benefits through COBRA. Employees who have been involuntarily terminated between September 1, 2008, and December 31, 2009, with annual incomes less than $125,000 (single) or $250,000 (couple), are eligible for COBRA premium assistance. Those eligible may receive a 65% subsidy toward their healthcare premium for up to nine months. The subsidy took effect March 2009.

Source: www.worldofworklawblog.com

Inbox... continued from page 2

When "we" have a bleed

Just wanted to let you know how much I enjoyed Ziva's article [Feb. 2009]. I read it out loud to Ana and Alexander, and it got us talking about what defines hemophilia, who can have it, and how Shai could have infused his mother! Thanks so much; articles like this one are meant for sharing.

Susi von Oettingen
NEW HAMPSHIRE

Thank you so much for publishing the article by Ziva Mann. Growing up as the only child in my family with hemophilia was tough, especially as a girl. After Isaac was born and we got the diagnosis of hemophilia shortly after delivery, I was saddened that he would experience life with hemophilia. But I was also strangely overcome with gladness that I would not travel this road of hemophilia anymore alone. Now I have someone to experience this with, and not just the tight-knit community of the hemophilia family. I felt the power of Ziva's son as he cared for his mom, and I imagine that he felt the same way that I did. Hemophilia is no fun, but together, the road is so much smoother.

Danielle Nance
WASHINGTON

inbox

"Welcome" to Adulthood

Welcome [Feb. 2009], which talked about Tommy, made me think of my son Nick. I am still a mom and bug him to death. I, too, write emails, send him publications or articles, forward information, and keep on him. I wonder if he reads and understands it all at age 21. His dad and I were proud of him when he drove all the way to Little Rock to see the doctor about a knee synovectomy. He returned home and told us all about the appointment. But at other times, I fear he doesn't keep up with giving himself factor when he should.

Nick's a senior at college, and I worry that he doesn't understand that he will soon be on his own: there's health insurance, taking care of himself, working for a living, and needing to be at work each day. He'll be 22 this summer. Oh, the years went by fast!

Gail Throop-Staley
RHODE ISLAND

Blood, Sweat and Tiers

I heard briefly at the last Inhibitor Summit in Denver about some insurance companies switching coverage for factor to the prescription drug benefit under tier 4. From my understanding, some people have already experienced this switch, which results in a larger out-of-pocket expense since typically co-pays for prescriptions do not count toward deductibles, coinsurance, or out-of-pocket maximums – at least they don't on my plan. Our social worker sent me an article about it too. I've recently noticed a tier 4 prescription drug level with my insurance plan, but they have not changed our coverage for factor… yet.

Corby Lust
ARIZONA

Being Honest

I want to thank Kevin Correa for speaking to me about the *Transitions* article "Be Honest. Just Not Too Honest" [Feb. 2009].

I have had many good comments from people who read the article, so you know the topic has been pulled to the forefront of their minds. I have been asked to do a presentation on this subject, and I will refer them to the *PEN* article as a resource.

Keep up the good work.

Bobbie Kincaid
Community Advocate – Illinois & Indiana
Accredo's Hemophilia Health Services

Adopting a Child with Hemophilia

LA Kelley Communications sent a request to all readers about a boy in China who is available for adoption.

I wish my husband and I were in a place to adopt this boy, but we are not. I would like to share our story with you in case we can be of help to the family that adopts this boy.

We are the adoptive parents of a boy with moderate hemophilia A. We had never heard the word *hemophilia* before. But when we got the call, we did our research online. We also called hemophilia clinics and learned what life could be like for us. In the end, we decided to proceed with the adoption. We realized that we would have time to react to a bleed and could manage hemophilia. I consider food allergies more serious and life threatening, and thus frightening for me. We have had ZERO regrets.

Should a family with no hemophilia experience consider adopting this boy, we would be glad to share our experience with them. It was tough to explain to family and friends, who often asked if we were crazy. They now know that hemophilia is not something to fear. My niece and nephew have become volunteer counselors for New England Hemophilia Association (NEHA) family camp, and my nephew is applying to become a camp counselor at Hole in the Wall Gang Camp – all because of our son, Shane, and his life with hemophilia.

I pray that this boy finds his loving, forever family very soon. When my husband and I considered a second adoption, we said we would only want a child with hemophilia. Now that I've received your email, I wonder if this is my message from God to do it now. But we are not in a financial place to adopt again. I know another family that has gone through the home study for their second adoption; I will share this information in case they would consider adopting a boy with hemophilia.

It has been interesting for my husband and me as we meet other families of kids with hemophilia. We hear their comments: they wish their kid didn't have hemophilia, they cried when they

found out, they won't have more kids because it could mean passing on the gene again. It's hard for us to hear those comments, because we just don't understand it.

For us, there was no question. Maybe it's that we didn't have the years of seeing our fathers and brothers live with the disease as it was before technology provided more treatment options. Or maybe it's that our child has moderate hemophilia, not severe. Still, we have no regrets and now embrace the hemophilia – even when I stick Shane three times without success.

Kathy Secinaro
NEW HAMPSHIRE

Ed. note: The child was successfully adopted one week after the email seeking a family.

Project SHARE

All of the factor VIII donated has been used for Mr. Prakash Gandhi, who needed removal of an infected prosthesis. Thank you for having made this possible.

Dr. Mammen Chandy
INDIA

On behalf of the patients and their families, I appreciate your support for this significant lifesaving assistance, and once again I thank you and Dr. Fayeze for your collaborations.

Mohammad Amirzad
QUEBEC, CANADA

Thank you very much for helping Vitug. We welcome even the recently expired product. We can now properly address his necrotic and infected thigh muscle.

Flerida Hernandez, MD
PHILIPPINES

What a surprise! Today I got the factor. This will immensely help to organize the much-wanted children's camp. We will probably hold this camp February 22–24, 2009, in Barkul, Orissa, the largest backwater sea, with lots of dolphins and a navy base station. Thank you very much.

Ujjal Roy
INDIA

The shipment arrived today, which is probably the reason I am so happy. Thank you very much for helping me again!

Felix Negoita
ROMANIA

Thank you for the donation of factor. I must say that the factor contributed to the success of our visit to India! We used some of it for surgery, as well as for acute treatment of bleeding. Thank you so very much.

Dr. Prasad Mathew
Medical Director
University of New Mexico
Department of Pediatrics

I would like to thank Project SHARE for its generous donation of factor for my son Dipin Shakha, which saved his life. My son started to vomit and complained of a headache suddenly. We took him to Bir Hospital for consultation. We learned that he had a brain hemorrhage and needed factor concentrate immediately. I received eight vials of factor VIII from the hemophilia care unit. After that, he recovered and was discharged from the hospital.

After two weeks, the symptoms repeated. Again we took him to Bir Hospital, and bleeding was seen in the brain. This time I received nine vials of factor VIII concentrate. He was then discharged, and we are caring for him at home. Mr. Dipin may need more factor to recover completely. So I have requested that Nepal Hemophilia Society store the remaining donated factor for my son to be used in the emergencies.

I would like to thank Project SHARE for its generous support for my son, which saved his life. My family is grateful to Project SHARE and NHS.

Ram Kaji Shakhakarmi
NEPAL

Thank you a whole lot on behalf of my nephews in Guyana and their parents. You must be a wonder sent from heaven, with lots of blessings waiting to be bestowed. We will be forever grateful.

Gerald Monize
FLORIDA

inbox

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Parenting Moment

Your children need your presence more than your presents.

~Jesse Jackson

Making the decision to have a child is momentous. It is to decide forever to have your heart go walking around outside your body.

~Elizabeth Stone

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the hemophilia newsletter by families & for families

Inside: PATIENT AND PHYSICIAN: COMMUNICATION AND CONFLICT IN A NEW HEMOPHILIA ERA