PEN

inside

Hemophilia Information, Advice, and Angst in the Internet Age

Kevin Correa

About a year and a half ago, Sarah Reeves was feeling a little stressed. The stay-at-home mother of three young children was packing up her household and moving her family across the country. Matt, Sarah's husband, had lost his teaching job in California and found a good opportunity in New York. To say that Sarah and Matt were under pressure would be an understatement. Topping it off, Sarah was six months pregnant, and considering a home birth.

Sarah and Matt's third child, Elijah, has severe hemophilia and was born at home with no complications, before they knew he had hemophilia. To make a home birth decision this time, Sarah and Matt gathered all the information they could find on the disorder, which eventually led them to the Internet.

Sarah also emailed LA Kelley Communications. The staff offered to share her email with others in the bleeding disorder community, in the hope of finding another family that had experienced a home birth:

> *My husband and I have three children. We've had all three births at home with a midwife. Our youngest was diagnosed with severe hemophilia A at four months . . . We had no complications at his birth . . . Now, we are expecting our fourth baby, and I found out I am a carrier. I was hoping to find a hemophilia mom who has had a home birth . . . Did you have complications? . . . I appreciate any input you have to offer.*

The term *home birth* is potentially volatile. Add hemophilia to the equation, as Sarah did, and you may have a powder keg.

Sarah received more than 20 responses to her email. Almost none were from families who had experienced home birth, but all had a lot to say. Some were supportive, others were not, and some were simply hurtful.

"At the time, I felt really bad," says Sarah. "Some of the responses hurt a lot."

Indeed, the emotional component neutralized much of the advice Sarah received. Her experience raised questions about how members of the community seek and share information online:

- How reliable is the information and advice offered, especially medical or treatment advice?
- Where is the line between parental advice and medical advice?
- How do you handle negative interactions online?

In Sarah's case, the hot-button issue was home birth. But it could just as easily have been circumcision, ports, or immune

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welcome


Sherrell Portrait Design

These are astonishing days. Healthcare reform has dominated the news, blogs and chat rooms. On Tuesday, March 23, President Obama signed into law H.R. 3590, the Patient Protection and Affordable Care Act. This legislation, among many other things, abolishes pre-existing condition exclusions and lifetime caps. This is what our national bleeding disorder advocates and your state chapters have been battling for years to attain – but there's fine print. Please continue reading and learning about what healthcare means for you, your family, and our nation.

Speaking of chat rooms and blogs, though I'd love to explore healthcare reform here in PEN, we decided it was time for a little break. In this issue, we'll look at things much closer to home, like your email inbox!

Do you network online in the bleeding disorder community? Do you contact other families, gain information, and relieve some stress? Do you become enlightened, or enraged?

We decided to explore what it's like to get advice and information from other families in the 21st century via the Internet. We do this through the eyes of Sarah, a young pregnant mom who only wanted to find someone who shared her experience – but got a whole lot more.

In pre-Internet 1987, because I couldn't get enough information to satisfy my appetite for knowledge about hemophilia, I launched my book and then my business. Life has radically changed since then as the world has gone wireless, ether, viral and digital, but it's not without dangers and worries. Read our cover story and learn how to navigate the world of online advice for families with bleeding disorders.

Of course, the Internet is a blessing. With it, we solicited and found – in one week – a family for a young orphan with hemophilia in China. With it, we raised $17,000 in two days, to help offset the adoption and travel fees. We rely on the Web daily, to bring us news about people with bleeding disorders in 50 countries that desperately need factor. You may have received our recent mailing about Project SHARE. In this issue of PEN, read a very special story about a factor donation. It will give you goosebumps, and it gave 50 boys in the Dominican Republic the time of their lives.

The Internet shrinks our world, and binds our bleeding disorder community just a little bit closer, each day. This issue of PEN will show you how to protect your boundaries of thought and emotion, while still allowing for bonding and sharing.

inbox

PEN February 2010

Your most recent PEN is great. It is a really nice overview of current and future products. The article is both easy to understand and detailed. Kudos for continuing to bring valuable tools and resources to the community! Many thanks.

Kimberly Haugstad, MBA

Executive Director, Hemophilia Federation of America

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Tony D'Ambrosio

Cheryl Nineff D'Ambrosio

Girls with Bleeding Disorders: Building a History

When I married Tony, I became stepmother to Teresa and Maria (ages 13 and 10), who have severe factor V deficiency* and require treatments with fresh frozen plasma (FFP) to control bleeds. Within a few months, I thought I had entered the plot of a disaster movie. To me it was horrific. But to them, it was normal.

At first, much of the information I found on bleeding disorders related to boys and men. Now, after spending the past 17 years learning the ropes, I'm used to the smiling urgent care physicians who enter the exam room and say, "Wow, I heard there's a girl with hemophilia in here, and I just had to stop by and see for myself!"

Taking the girls for treatments, sleeping overnight at the hospital during extended bleeding episodes . . . this became a normal part of my life. Often, when I spent time with my best friend, one of my daughters was having or recovering from a bleed. "You have to write a book," said my friend, "because nobody will believe what your life is like!" And I finally did just that. I thought, if doctors are still fascinated by a girl with a bleeding disorder in the 21st century, then somebody had better write it all down.

Finding a voice to write my book wasn't easy. What my stepdaughters really think and feel, I will probably never know. But as a new stepmom, I went from relaxed and fun-loving to protective and grouchy, and I *can* tell you how they felt about that. So I decided to write this book in my own voice – a nearly hysterical mother of two girls who seem to bleed all the time.

I had a complex story to tell, a history to share. Many times I had brought my laptop computer to the hospital and taken copious notes in real time, so there was no question about the precise number of hours involved in the delay in getting treatment, the miscommunication between staff due to shift changes, or the problems that sometimes ensued from a lack of trust between parent and medical team.

Luckily, we now have an agreement with our urgent care provider that our daughters will immediately receive FFP – no questions asked – whenever we call. We treat first, and we run tests afterward.

But it wasn't always like this. Doctors are trained to diagnose a problem, order tests, and evaluate each situation. But tests don't stop a bleed. Often, we'd sit in the ER for hours, waiting to get the FFP ordered and infused. When I'd explain that my girls were bleeding, I'd get the raised eyebrow as if to say, "Well, I don't see any blood on the floor."

We each bring our own perspective to any situation. I have a business background, and just as I do at work, at the hospital I wanted to see an effective organization where team members understand their roles and are motivated to get the job done. When I presented a process flow to one ER manager, showing who-calls-who when we need FFP, it involved multiple roles across multiple organizations. The time from FFP order to infusion was sometimes as long as 12 hours. Why, I wondered, couldn't this process be done more effectively?

Our interpersonal dynamics changed dramatically when we enlisted help from our hemophilia treatment center, Puget Sound Blood Center Hemophilia Care Program. And the time it took to get FFP infused dropped to just two or three hours. Now, that's something to write about!

I wasn't afraid to publish my experiences in my own voice. Not everyone will agree with my opinions, and that's fine. Honestly, I was more scared *not* to publish my book. If there's nothing in writing a decade from now, I thought, it will be my fault. It became my personal mission to be a good reporter and to make a contribution to the world.

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* *Ed. note*: Factor V deficiency is not hemophilia. It is extremely rare: about 1 person in 1 million. Also called Owren's disease, labile factor deficiency, proaccelerin deficiency, or parahemophilia, factor V deficiency differs from factor V Leiden, which is more common and results in increased blood clotting.


Kerry Fatula

Kerry Fatula

The Oldest American with an Inhibitor

Hemophilia and inhibitors are complex conditions, and stories of misdiagnosis and mismanagement are familiar. But fortunately, such stories are far less common than they once were.

Perry Stone, 87, has mild to moderate hemophilia A. And he thinks he may be the oldest living American known to have an inhibitor. Recently, Perry told me the story of how he handled "mysterious bleeding" until the diagnosis was finally made.

Perry was born in 1923 in Chicago, to immigrant parents. His Russian mother and Romanian father had no known family history of hemophilia, and Perry was the only one of their five children to experience mysterious, prolonged bleeding. In his early childhood, Perry commonly had nosebleeds that came unexpectedly and wouldn't stop.

Doctors had no explanation, and cold compresses were the only treatment. Perry can recall no joint bleeds during his early years. He was active in school, playing baseball and basketball with no difficulty aside from the nosebleeds.

When he finished school, Perry joined the army and served more than three years during World War II. He continued to suffer from nosebleeds, but the military doctors could find no explanation. In 1943 Perry married, and he and his wife Betty had two daughters. Returning to civilian life in 1946, he began working in the insurance industry.

For most of his life, Perry's undiagnosed hemophilia had presented few problems, but as he got older, things changed. In 1966, at age 43, Perry began to experience spontaneous bleeding into the thigh muscles of both legs. The bleeding kept him from working and led to a week-long hospital stay. Doctors still had no explanation and did not test Perry for hemophilia. Instead, they treated Perry with vitamin K injections. When the bleeding subsided two weeks later, doctors mistakenly credited vitamin K as an effective treatment.

In 1974, at age 51, Perry suffered a heart attack. After receiving an arteriogram, the arm used to insert the intravenous catheter developed a baseball-sized hematoma that wouldn't heal. Yet doctors still ran no tests to look for a bleeding disorder.

A year later, when Perry had a tooth extracted and bled for nearly a month, his physician suspected von Willebrand disease, and finally ordered a blood test. When the lab results came back, the diagnosis was hemophilia A.

Perry was lucky to finally have received a diagnosis, because in 1979 he needed all of his teeth extracted. The Veterans' Administration hospital in charge of the procedure called in two dental surgeons, recalls Perry, and "ordered a lot of bags of cryoprecipitate to prepare for any complications." The surgery was a success.

In 1992 Perry began bleeding into his knee joints. For the first time, he received factor VIII concentrate, and his recovery was short and successful.

Perry underwent a laser surgical procedure in 2005 to remove part of his prostate. Following the procedure, to treat his severe bleeding, Perry was transferred to a different hospital where he received factor VIII concentrate. When the bleeding began to subside, Perry was sent home.

During his recovery, Perry began bleeding again. His local hospital didn't carry factor concentrates and was unfamiliar with hemophilia treatment, so Perry was transported to the hemophilia treatment center (HTC) at Munson Medical Center in northern Michigan. But this time, factor VIII concentrate didn't stop the bleeding. A Bethesda Inhibitor Assay confirmed the hematologists' suspicions: Perry had an inhibitor! His treatment was switched to a bypassing agent, a specialized clotting factor product used in patients with inhibitors. Perry's bleeding was finally under control, and he went home with a follow-up treatment plan and home nursing regimen.

Today, Perry keeps his bypassing agent at home, and calls a home nurse if he needs treatment. But the inhibitor doesn't slow him down much, even at his age. Perry credits his survival and quality of life to a positive attitude,

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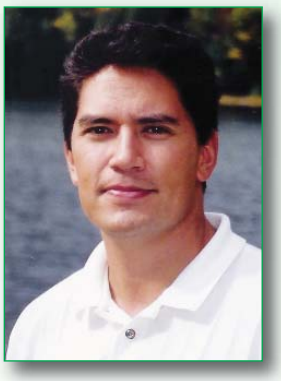

Kevin Correa

It's Not About Fashion: The Essential Medical IDs

If you suffer from an injury or illness and are unable to tell medical professionals that you have hemophilia, medical IDs will do it for you.

Medical IDs come in many forms, most commonly bracelets and pendants. For people with hemophilia, IDs are inscribed with the phone number of your emergency contact or hemophilia treatment center (HTC), and your factor deficiency. Subscription services link your medical ID to a 24/7 call center, which can access your medical records, helping ensure that you receive appropriate treatment. And many hemophilia foundations provide assistance to pay the membership fee.

Sounds great, right? Then why do so many young people with hemophilia go without a medical ID?

What's with the Bracelet?

The most common reason is the obvious one – it attracts unwanted questions.

"Adolescents don't like to feel different, and a medical ID is pretty obvious," says Ellen Kachalsky, a social worker at Henry Ford Hospital's Adult HTC. "When teens first transfer into our adult practice, only about half of them are wearing medical IDs."

"I never wanted to draw attention to myself," recalls Michael, 44, who has severe hemophilia. "The bracelet was so obvious. I just didn't want to answer all the questions."

Craig, who also has hemophilia, agrees. "I never wore mine as a kid. I was too ashamed to wear it, and I didn't want kids to see it."

Hiding Hemophilia beyond the Teenage Years

It isn't just transitioning teens and young men who choose not to wear their medical IDs.

"Many of my adult [hemophilia] patients – both men and women – don't wear them," says Dr. Danielle Nance, a hemostasis and thrombosis specialist. "They all have at least one or two necklaces or bracelets hanging around, but they never wear them to clinic."

Like Dr. Nance's patients, Michael had various bracelets and pendants, but didn't wear anything routinely until his mid-thirties.

The catalyst for Michael was his family. "I finally realized it's not just about me. I have a family, and thought, 'What if something happened to me and I wasn't wearing my bracelet?'"

Craig echoes this. "It was not until I was engaged to be married that I realized that I should wear the necklace. Looking back, I really should have

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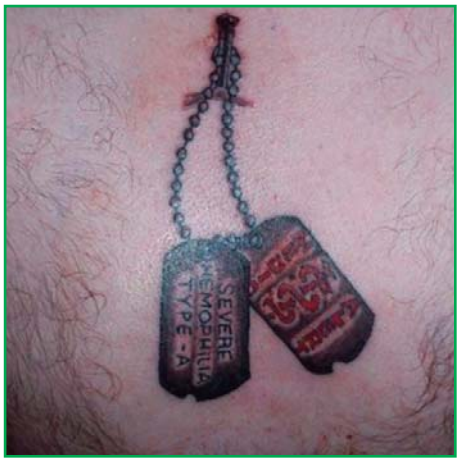
MedicAlert Foundation

For information on the MedicAlert 24/7 call center system, including jewelry and coverage options:
www.medicalert.org

ICE Cards

To learn about printing a free ICE card:
www.medids.com/free-id.php

Daniel Livolsi



No chance that Daniel will forget his medical ID at home! He had it tattooed on his chest.

project share

PROJECT SHARE

It's time to give back

Rachel Ruggles

Butterflies

Clark family

Bryan Clark and friend

Sometimes, even in the midst of sadness, an unexpected path can open to beauty. The Clark family's path was tragic, but canopied with butterflies.

Bryan D. A. Clark was born with hemophilia on May 15, 1973. At age 14, Bryan and his family learned that he was HIV positive. After a courageous battle, Bryan succumbed to pneumocystis pneumonia on June 1, 2009.

After the initial shock of Bryan's death, his grieving family began sorting through his personal items. They were concerned about his unused factor VIII and ancillary supplies. They knew the factor was valuable and didn't want it to go to waste, but they weren't sure where to send it. Someone at the hemophilia treatment center (HTC) at Maine Medical Center suggested Project SHARE.

When Dan emailed Project SHARE about his donation, he received an immediate reply from Laurie Kelley.

Laurie explained that in two days, she had planned to travel to the Dominican Republic (DR) to attend camp ¡Yo Sí Puedo! (Yes We Can!). But unfortunately, the original factor shipment promised to Project SHARE to support the camp had never arrived. So camp was to be cancelled. Laurie needed 70,000 IU for 50 campers – and Dan and Linda's donation totaled 73,000 IU. Out of the blue, the Dominican summer camp could now take place.

For so many of the Dominican children, this is their only week all year to be regular kids. Camp director and founder Haydée de García, president of Fundación Apoyo al Hemofílico (FAHEM), the national hemophilia nonprofit organization, called the donation "un milagro," a miracle, an answer to her prayer. She was stunned that the donation was exactly the amount needed. Bryan had saved the day for so many deserving children. His spirit channeled through the smiles and laughter of 50 Dominican campers. A special prayer was said for Bryan's soul, and for Dan and Linda.

When Laurie returned from the DR, she sent the Clarks a gift package from the campers. The theme of the camp

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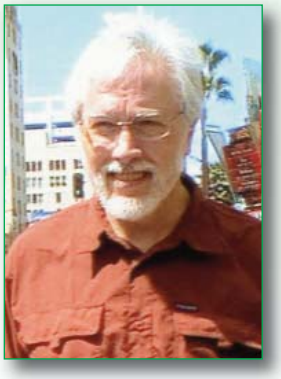
richard's review



Ann Woodruff

Richard J. Atwood

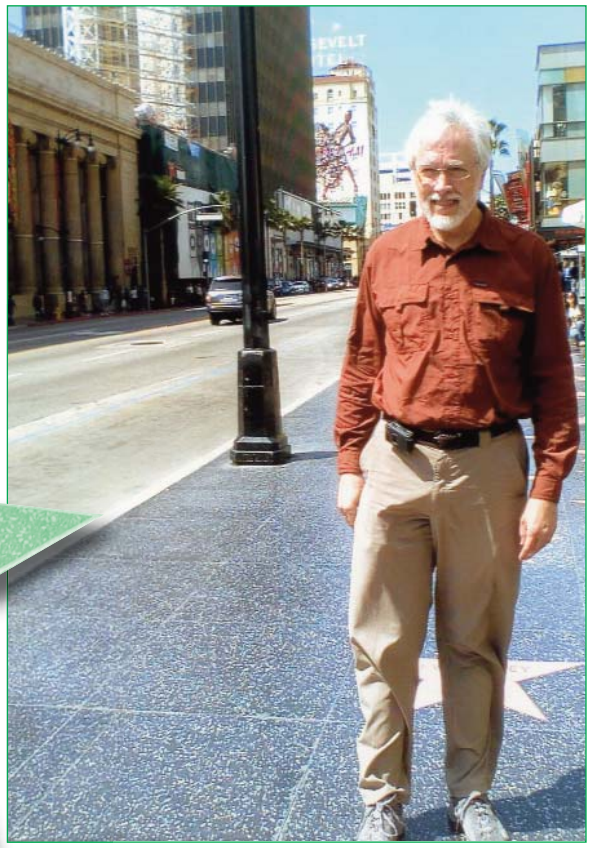
Sidewalk Star Shines for Hemophilia

If you happen to look down at the sidewalk in front of the Kodak Theater at 6801 Hollywood Boulevard, you'll spot the Hollywood star of award-winning actress Anita Louise. Though the two adjacent sidewalk stars for Kevin Spacey and Peter Frampton might be more recognizable, those celebrities are not connected to hemophilia – not like Anita Louise, who was a spokesperson for hemophilia in the 1960s. So what's the connection? I visited Hollywood to find out.

Anita Louise was born Anita Louise Fremault on January 9, 1915, in New York City. Her childhood acting career began on Broadway in 1921 and in silent pictures in 1922. She assumed the stage name Anita Louise in 1929. Her best-known screen roles are in movies made in the 1930s, including *A Midsummer Night's Dream* and *The Story of Louis Pasteur*. In 1938, Louise unsuccessfully screen tested for the role of Scarlett O'Hara in *Gone With the Wind*. During the 1940s, Louise appeared mainly in minor B-movie roles, but by the 1950s she was appearing on television. She may be best remembered as the mother Nell McLaughlin in the 1956–1958 series *My Friend Flicka*.

Louise was married to writer and producer Buddy Adler from 1940 until his death in 1960, and had two children. Her second marriage to businessman Henry L. Berger lasted from 1962 until her death. Louise suffered a stroke and died on April 25, 1970, in Los Angeles, and was interred at Forest Lawn Memorial Park in Glendale, California.

Anita Louise devoted her later years to both the Children's Asthma Research Center and the National Hemophilia Foundation. Despite my search, I found no information on her reasons for her involvement with hemophilia in the 1960s. Still, we can appreciate her commitment to the cause, and recognize her along with every other volunteer who speaks out for the bleeding disorder community.



Richard with Anita Louise's star on the Hollywood Walk of Fame

There is a vital need for all types of volunteers in our community because our member organizations are run by and dependent upon them. There are many altruistic reasons for volunteering, such as giving back to the community or helping others. Yet there are also personal reasons for volunteering, such as personal health benefits and just feeling good about yourself. Whatever your reason or motivation, there are definite benefits to being involved. Why not begin this spring? Every volunteer for hemophilia is important and deserves a sidewalk star.

Richard J. Atwood MA, MPH, lives in Winston-Salem, North Carolina, where he worked for 17 years at the Hemophilia Treatment Center at Wake Forest University. Currently he serves as president of Hemophilia of North Carolina.

How to Use the Web Wisely

The online bleeding disorder community is a great resource. To increase the odds that you'll find the answers you seek, start with a game plan.

1. Define the issue.
What information are you hoping to receive? Be as specific as possible.

2. Research the topic on the Internet.
Google is a good place to start. You don't need to be an expert on the topic. Your goal is to familiarize yourself enough to communicate effectively with others.

3. Investigate chat rooms and forums.
Many forums provide a search feature. Often you can find the information you're looking for by searching for keywords in the discussion threads.

4. Refine your search.
You haven't yet found the information you seek, but you're probably more educated on the topic. Use what you now know to narrow your search.

5. Post a question to a forum.
You need a firm understanding of what you're looking for in a reply. Take time to frame your question properly.

6. Consult your HTC.
Maybe you haven't yet found the answers you sought. That's okay. The process of searching for answers has brought you closer than you were when you started. And even if you think you have all the answers . . . always consult your HTC.

These are just general guidelines. You can always cut to the chase and call your HTC first, but it often helps to have some knowledge of the topic before you speak with your doctors.

tolerance induction (ITI). The Internet – and specifically the online bleeding disorder community – is a natural place to research and solicit opinions. But seeking advice and information on the Web has pitfalls.

A World of Information at Your Fingertips

There's no denying that the Internet is an incredibly valuable tool. With it, we can access a wealth of information and connect with people around the globe.

Before 1990, hemophilia information for parents was mostly limited to discussions with their doctors. If they lived in a metropolitan area, parents might be lucky enough to find other parents willing to share advice and experiences. Today, type "hemophilia" into Google and you'll receive over 1.5 *million* results.

The Internet has allowed the relatively small group of people affected by hemophilia to build a community of support and knowledge where no physical community before existed. But when Sarah tapped into this online community to find information specifically about hemophilia home birthing, the Internet became a mixed blessing.

Let's Agree to Disagree

"The subject of home birth even *without* hemophilia is controversial," Sarah admits. "I figured that about 90% of the responses I got would be against the idea, especially with hemophilia involved."

Home births in the US are rare, accounting for fewer than 1% of all births.* So it's understandable that people would form opinions that aren't necessarily based in fact. (Just think of the misconceptions people have about hemophilia!) For many, the term *home birth* conjures images of a tie-dye-clad mother burning incense as she prepares for her baby's arrival.

In reality, births attended by midwives are common in developed countries around the world. In the US, midwives are licensed professionals who must meet specific requirements set by the states.

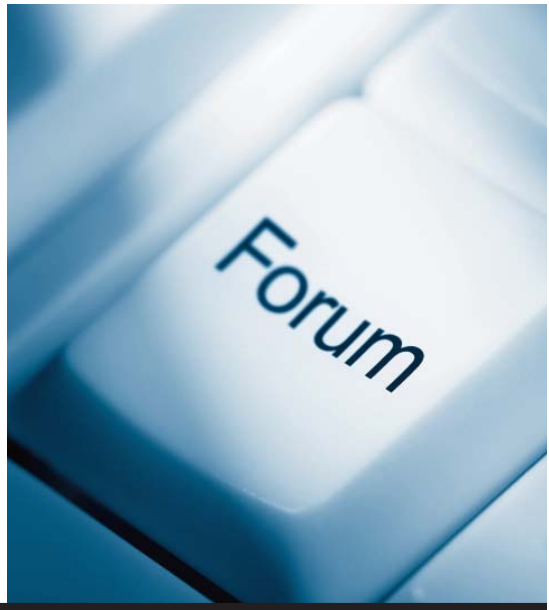
"When I was 18, I watched my nephew being born in a home birth environment, and I knew that's how I wanted to give birth," recalls Sarah. "I believe that home births are the safest way for a baby to be born."

Many people assume that a pregnant woman who opts for a home birth is simply looking out for herself, or setting up a personal challenge. Yet home-birth advocates emphasize the benefits for *both* mother and baby. In their view, when the mother is physically and psychologically comfortable, her own needs are only part of the equation. At home, there are fewer distractions preventing her from allowing her body to regulate the natural process of childbirth.

One of the main concerns of home-birth advocates is to avoid what they often consider unnecessary medical interventions, such as electronic fetal monitoring and cesarean sections. They firmly believe that a midwife-attended birth *at home* is safest, for both mother and baby.

But in a vaginal delivery when the baby may have hemophilia, there is risk of an intracranial hemorrhage (ICH) – a head bleed. An infant with undiagnosed ICH could suffer permanent brain damage or paralysis, or could even die.

Because of risks like ICH, any physician is likely to recommend a hospital birth for a potentially hemophilic baby. Hemostasis and thrombosis specialist Dr. Danielle Nance agrees. Not only is she a physician, but both she and her son have hemophilia.



* http://www.cdc.gov/nchs/data/nvsr/nvsr58/nvsr58_11.pdf

"When considering the most vulnerable moments in a newborn's life, we must be mindful of time," she says. "If the baby experiences bleeding or trauma . . . sometimes we only have seconds or minutes to act, and that can mean the difference [between] life, death or severe damage."

Dr. Nance also notes concern for the mother. "A woman who is a carrier of hemophilia often experiences bleeding as well," she says. "This bleeding can show up at any time. Delivering in the hospital ensures that if the mother bleeds [treatment can begin] immediately."

Though doctors may disagree, Sarah's personal experience with home births – including the birth of her hemophilic son – convinced her that a home birth was a viable option for a child with hemophilia. But she still sought confirmation from her peers, both in person and online.

Membership by Default

Your connection to the hemophilia community is unique. Consider some of the other communities you belong to: your neighborhood, your place of worship, your children's PTA, your book club, your professional association. You belong to all of these groups by choice, and you probably share several traits – socioeconomic status or religious beliefs, for instance – that play an integral role in how you look at the world.

With the bleeding disorder community, that isn't necessarily true. Certainly you may share some qualities or perspectives with others in the community, but the commonality that brought you together – a bleeding disorder – isn't something you willfully chose.

That's important when you consider the nature of online communication. You know relatively little about people you meet in bleeding disorder chat rooms and discussion forums. And this can lead to problems.

When you seek information or advice from others online, carefully consider how much weight to give their feedback. It probably shouldn't hold as much value as advice from medical professionals or people you know well – and who know *you* well.

Before Sarah sent out her email, she had done some research on hemophilia home births. She consulted with her hematologist, and she searched online. In the end, she says, she was left with little useful information.

"My hematologist pointed me to medical studies," says Sarah, "but none had exactly my circumstance." None of the studies considered home birth *and* hemophilia. From Sarah's perspective, no one had absolute answers.

When she eventually sent the email to LA Kelley Communications, Sarah explained, "I was just looking for *any* information on the outcomes of women who had births like mine." She wasn't interested simply in home births or hemophilia births; she sought information where both factors were present.

Of the people who responded to Sarah's email, most were complete strangers and knew nothing of her other than what she'd written.

Lost in Translation

The relative anonymity of online communication has its positives and negatives. On the one hand, people are often more willing to be honest because the Internet serves as a buffer. The flipside is that honesty can become *brutal* honesty if you switch off your "polite filter" because you're not facing the other person.

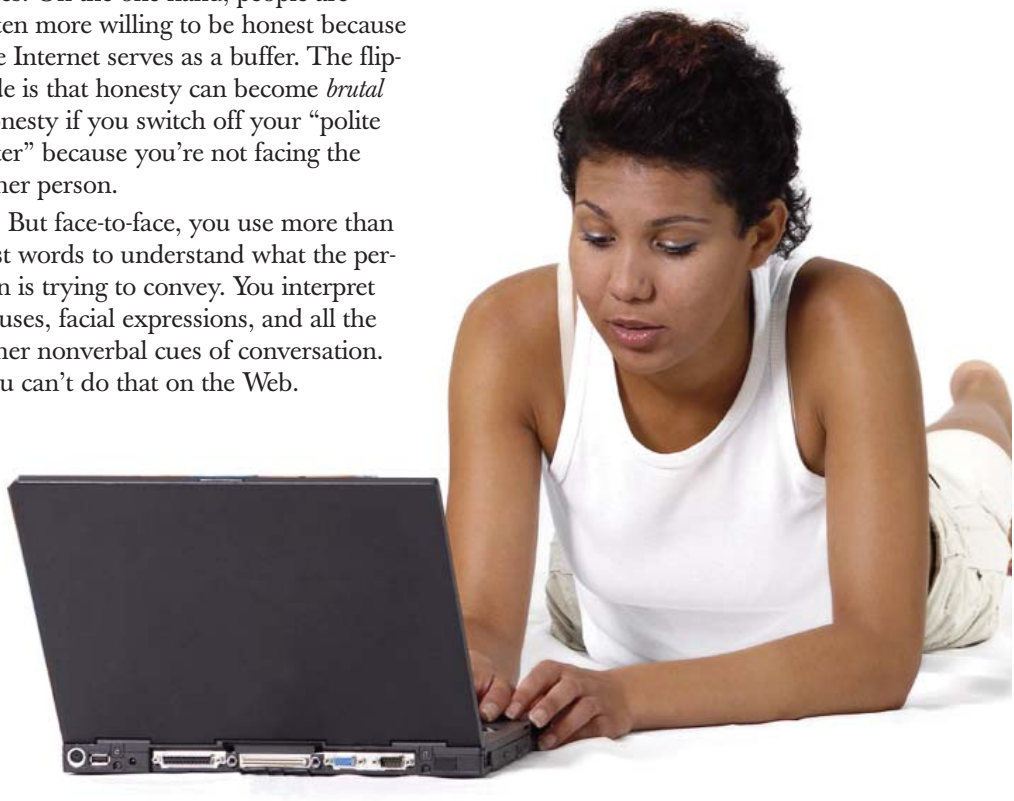
But face-to-face, you use more than just words to understand what the person is trying to convey. You interpret pauses, facial expressions, and all the other nonverbal cues of conversation. You can't do that on the Web.

As "Maggie," a hemophilia mom and online forum moderator, explains, "When you're sitting across the table from someone, you edit your words as you talk because you can read the person's body language and hear the tone in their voice."

Without these nonverbal cues, it's easy to misinterpret the words that pop up on your computer screen. Sometimes, what was intended as an innocuous comment ultimately offends the reader.

Consider one response that Sarah received:

> *Oh my, now is not the time to be some "natural home delivery" advocate. If there's a problem, you want to be at a hospital. Just think how you would feel if there was a problem that could not be solved at home & your baby bleeds to death and not being at a hospital was your decision. It's not about you, it's about what is best for the child.*
>
> *With your previous births you did not know hemophilia was an issue, now you do.*
>
> *PS: I'm assuming you live in the US and not some third world country.*



Does the tone of this email seem condescending? Perhaps. But was that the writer's intention? It's hard to say. One factor that often heats up online debates is the speed with which we communicate in cyberspace. Just because we *can* correspond almost instantaneously, doesn't mean we *have to*. The problem is that our polite filter often gets sacrificed as we try to make our point – quickly, and sometimes without waiting to consider what we're writing.

And as Maggie notes, "You can't take it back once you hit 'send.'"

The Heart of the Matter

As Sarah had anticipated, most of the responses she received did not encourage her to have a home birth when the baby might have hemophilia. Still, other than a few harsh emails, the community's support shone through. Most of the emails were considerate and helpful, regardless of her pending decision. And even in responses that shunned home birth, it's clear that *everyone* had the baby's best interest in mind.

Here are two typical examples:

> *I guess the question is IF injury or harm came to the infant due to home birth complications, would you or your husband be able to accept this knowing it could have possibly been prevented?*
>
> • • • • • •
>
> *I think the best answer is a question — could you live with yourself if you hadn't done everything possible to ensure your child's well being when he is being delivered and once he has arrived?*

And even in responses that did not agree with home birth, many were friendly:

> *As for home birth — I'll have to reserve my personal opinion and just say that professionally speaking things can go wrong and it's always good to have the medical backup right there if you should need it. Good luck with number four wherever you choose to deliver!*
>
> • • • • • •
>
> *My personal opinion is better be safe [than] sorry — have the delivery in a hospital where the baby can get immediate care if anything was to go wrong . . . Go with your heart, only you know what is right for you and your baby (with guidance from doctors too). God Bless.*

But there were some more pointed responses:

> *I understand my situation is very different from this mother's. Still, home delivery? To me, not worth the risk.*
>
> • • • • • •
>
> *Having a baby at home seems like an unnecessary risk to take when your baby's health may be at risk. What is the advantage to doing it at home? More comfortable for you? Is that worth risking your child's health?*

"At the time, I wished that the people who sent the really tough responses could understand what I was thinking," recalls Sarah, who insists, "I'd never put my child's life in jeopardy. When somebody thinks you don't care about the safety of your child, it's personal and insulting."

When online interactions turn ugly, often the best – and hardest – thing to

do is walk away. Don't respond. But if you choose to continue the interaction, calmly and thoughtfully defend yourself, keeping in mind that the worst thing you can do is return the barb. Be the bigger person.

Sarah took this approach. She did her best to distance herself from her emotions while peeling back the layers of negative emails for any valuable information. In doing this, Sarah recognized good intentions: "In several responses," she says, "I could tell that people really did care. And they helped highlight for me the benefits of giving birth in a hospital."

I'm Not a Doctor, But . . .

Remember that the advice both sought and offered in online bleeding disorder forums is often medical, and that most people respond based on their personal *experience*, not necessarily their medical knowledge.

Maggie warns forum users to be cautious, "because when you meet someone online, you don't know what their experience or knowledge is on a given subject."

Yet Maggie has noticed a positive trend over the past few years. More and more, she says, people are providing sources – including medical journal articles – to help substantiate their opinions.

The experiences of people who've "been there, done that" are valuable, but put them in the proper context: hemophilia, or any bleeding disorder, is a complex medical disorder. Treatment regimens and best practices are constantly changing as the field of medicine evolves.

And remember that in spite of people's best intentions, sometimes the advice they give is, at least from a medical perspective, *wrong*. For example, notes Paul Clement, PEN's science editor and father of a son with hemophilia, "Posting a question to a mailing list for advice on how to treat a mouth bleed will undoubtedly elicit many responses advising the use of Amicar – most of them forgetting to mention, or not knowing, that Amicar is only effective after a clot is in place. For those with severe hemophilia, this means *after* an infusion of factor."

Even when advice is suspect, there's a good chance you can find at least one other person online who agrees with it. *Does that make it sound advice?* If you have any doubts or questions, always consult your HTC hematologist.

You've Got Your Advice – Now What?

You've consulted your doctor. You've researched on the Web. You've sought assistance from the online community. So what's next?

Looking back at the responses she received, Sarah concludes, "It was clear that some people were less concerned about helping me than they were about expressing their views on home birth. But there were also several responses from people that I could tell did care. And those responses that provided solid information were the ones that meant the most to us."

Sarah and Matt had reached the point of preparing for the baby's arrival, which meant deciding whether to proceed with a home birth. Now, they had to weigh all of the feedback they'd received from doctors, the hemophilia community, family and friends.

So, recalls Sarah, "I took all of the information I'd gathered and said, 'How do I get this to work for us?'"

The Other 10%

As Sarah had expected, about 90% of the email responses were against a home birth. But within the 10% that supported the idea, Sarah found the exact person she had sought – a home-birthing hemophilia mom.

> *I am a carrier and a home-birthing mom. I had my first baby with hemophilia by c-section, not because of hemophilia, but because he was a twin. We had no history and didn't even know. My next baby, I decided to have at home. It was a girl, so I was not concerned. Then I was pregnant again and I knew it was a boy and that he had hemophilia. So, I made arrangements with our family doctor to run the cord blood for us. . . . He was born with a large, 14-inch head that had no swelling or [complications]. I think it's important to consider [the risk of complications like ICH in both a hospital and home setting]. I think it's also very important to be fully aware of what signs you are going to be looking for after the birth, and it's a very good idea to have your baby seen shortly after the birth. If I were to have another baby, I would again choose home birth without batting an eye.*
>
> *— Stacey Rainer, OB RN*

When Sarah read Stacey's response, she knew she wanted to use Stacey's story as a model for her own birthing plan. But at this point, Sarah was in week 38 of her pregnancy, and she and

Matt couldn't pull all of the pieces of the puzzle together in time. In the end, Sarah reached a compromise with her medical team. She would have a midwife-attended birth in a hospital.

Sarah refused intravenous fluids and had only intermittent monitoring. "Everything was so calm and quiet," Sarah recalls of the moment her new son Malakai was born. "It was the most gentle birth I've ever experienced."

Two hours later, Sarah and Matt learned that Malakai did not have hemophilia.

Lessons Learned

Into all of our interactions, we bring the experiences and beliefs that make us who we are. It's easy to latch onto an issue like home birth because it may fall outside the norm for us. But we can lose sight of the bigger picture: that an individual opened up, knowing she would receive some negative reaction, and turned to other members of the hemophilia community for advice and support.

Take the time to read Sarah's email again. She had exhausted her efforts to find information on hemophilia and home birth, and still sought the one source of information she most desired – a mother who chose a home birth with a potentially hemophilic baby.

This question was about home birth, but next time it could be about brand choice or home care companies, insurance or protective gear. In responding to an online forum or email, it's helpful to take a step back and try to read between the lines. *What exactly is this person asking? What does she or he need from me?* You may not be able to pinpoint someone's motivation, and that's not necessary. What's important is the simple act of putting yourself in someone else's shoes.

In some cases, the questioner may just need to know that there is an empathetic person reading somewhere in cyberspace.

"Periodically, people write something that is just an opportunity for them to emote," Maggie says of online posts. "The opportunity for cathartic release is crucial."

From time to time, you'll have a legitimate reason to disagree with someone online. But even if you disagree, you can do it in a civil, respectful way. The forums in the bleeding disorder community are invaluable resources, but only if people are confident that they can honestly express themselves in a supportive environment.

Maggie says that discussions can get heated and misunderstandings do happen. But she points out, "It's a very small downside to an incredibly valuable tool."

True to her optimistic character, Sarah views her entire experience positively. And now she has an entirely new perspective. Though she still feels that home is the safest place for a baby's birth, she believes that birth in a hospital can be safe – even beautiful – if the hospital staff is willing to listen and work with you.

"It worked out beautifully, and our little boy had a very gentle birth," says Sarah. "My motivation was always the safety of my baby. I am glad I sent my question to [the community] and received so much response from other hemophilia moms. Yes, some was just mean and judgmental, but a lot of it was very helpful. I would definitely use the public forum again."

Kevin Correa is PEN's Transitions columnist. He lives in Massachusetts with his wife Patty and three young children. He earned a degree in social anthropology from Harvard University. Kevin has been in his share of heated Internet debates — though mostly over the size of the fish he claims to have caught.

Sarah and Matt Reeves with their children (from left) Isaiah, Malakai, Ana, and Elijah

Karl Fielden

HemaBlog™

Sunday, April 4, 2010
www.kelleycom.com

Bringing Factor and Hope to Jamaica

Laurie Kelley

Jamaica: sunny beaches, rum drinks, dreadlocks, reggae, steel-drum bands. This beautiful Caribbean island was made famous by Port Royal, dubbed the "wickedest city in the world" and frequented by pirates in the 17th century – yes, there really were pirates of the Caribbean, and Jamaica was their favorite hangout.

And it's where I hung out for four days, to assess hemophilia care.

Why Jamaica? It needs help. In the past nine years, Project SHARE has received occasional requests from Jamaica for factor donations. Just a handful of patients. But in 2009 the number of requests jumped, so we took notice. Then last summer, two young men, ages 17 and 22, died. The younger, Kemar, had called me from his hospital bed to thank me for the factor donation he had received from SHARE. He died three days later.

That was the sad catalyst for my visit to Jamaica. I was pleased when longtime friend and colleague Derek Robertson decided to join me. Derek is a Jamaican living in Virginia who has worked with NHF, Gulf States Hemophilia Center, and Hemophilia Alliance.

Hemophilia in Jamaica

Derek and I made our first official visit to the National Blood Transfusion Services, to meet with hematologist Dr. Jennifer Thame. Dr. Thame explained that in Jamaica's healthcare system, most patients are treated at Kingston Public Hospital (which we did not tour), where care is free. Patients with insurance can go to University Hospital of the West Indies (UHWI).

Jamaica has about 290 patients with hemophilia, and almost all are registered. That's a plus. The big minus is that there is no factor.

Dr. Thame was eager to help the hemophilia patients and pledged to stay in touch. She helped us enormously by making a call to the Ministry of Health to get the $90,000 worth of factor I had brought with me released from customs.

That night we had a magical experience. It all began with one special lady, Kerry-Ann, a young Jamaican mother who had contacted me six months earlier to get factor for her little boy. Kerry-Ann and I had both been in touch with Kemar, the young man who died, and we felt it was time to bring the hemophilia patients together. So before I had even pledged to visit Jamaica, in Kerry-Ann I had found the leader I'd been seeking among patients.

Kerry-Ann and I invited some patients to the Pegasus Hotel for a buffet dinner and a discussion. Sometimes in developing countries, people want change; yet when it's time for commitment or action, they back away. Many citizens have learned over time that not much changes, or it takes too long, and they learn dependency and apathy. Not this crew.

Every single person we invited showed up! They were vocal, active, and determined. We met Lincoln, who had received the first factor we ever shipped to Jamaica. We also met Shirley, a single mom with four children, two with hemophilia. Her older son, Harris, desperately needs orthopedic surgery for his leg.

We met Tyrone and Damian, brothers with inhibitors, both in their twenties. Also attending were Beverly Parkinson and her husband, longtime beneficiaries of Project SHARE. Beverly and I have been in touch for many years to help her sons Kurt and Khaleel.

Dinner and discussion carried on far longer than planned. Out came frustration, anger, despair, and pleas for help. Wayne, a tall, fit man with hemophilia, declared that this was the first time any of the patients had ever been together in one room. Shirley hadn't even known there were other patients with hemophilia.

I told the families that in the 14 years I'd been doing this work, I had never seen a group so poised to make changes! With a wry smile, one of the moms told me that Jamaica was a stop on the African slave-trade route where the troublemakers had been dropped before arriving at Hispaniola. These active, lively people had founded her country!

Meeting the Prime Minister

We secured a meeting with the prime minister, thanks to the persistence of Juliet Hanlon, a goodwill ambassador with World of Hope International. Prime Minister Bruce Golding gave us 20 minutes, remarkable considering how extremely busy he is. He listened intently as we described hemophilia, its complications, and how we plan to help Jamaica. I showed photos of children from other developing countries, images you don't see in the US: grotesquely swollen joints, amputations, gangrene, disfigurement and pain. I'd brought a vial of factor, and Derek explained how much is needed as a child grows – and how much it costs.

» *page 17*

Jamaican families with hemophilia gather socially and strategically for the first time

headlines

manufacturer

FactorPlus:
Free Helixate® FS Trial Program

CSL Behring has launched a new free product trial program for Helixate FS, administered by Patient Services, Inc. (PSI). Depending on your physician's approval, you can try up to six doses of Helixate FS for free. PSI manages the program, so your confidentiality is assured. Why this matters: Not all factor products work equally well in all patients. Please discuss with your HTC staff before trying any new product.

For information:
www.FactorPlusprogram.com or 1-866-767-4883

global

WFH World Congress in July

July 10–14, Buenos Aires, Argentina

World Federation of Hemophilia's biannual congress welcomes doctors, scientists, healthcare workers, people with hemophilia, and hemophilia organizations from dozens of countries. Attendees learn about the latest developments in hemophilia treatment, and network within this global organization and community.

Contact: www.wfh.org

Paid Blood Donors:
Discrimination or Caution?

In March, presenters at Plasma Protein Therapeutics Association's 2010 International Plasma Protein Congress in Berlin urged an end to discrimination against high-quality plasma provided by donors who are compensated for their costs and inconvenience. Why this matters: The debate is ongoing: Is it ethical to pay donors for their donated blood? Is this a compensation or a fee for service? Does paying donors impact the quality and safety of donated blood? Learn more about this debate, especially if you use plasma-derived factor. Read opposing views at www.PPTA-global.org and www.COTT1.org

Source: IBPN, March 2010

nonprofit

HemAware Now Online!

NHF's bimonthly magazine *HemAware* is now available online. NHF created a new website for its flagship magazine to allow easier access and navigation. Why this matters: *HemAware* is full of great information for patients and clinicians, and the website offers instant access and social networking.

For information: www.hemaware.org

Inhibitor Education Summits 2010

August 5–8, Houston

August 19–22, Boston

NHF is now hosting the summits! People with hemophilia A or B with inhibitors, their families, and their caregivers can connect with expert healthcare professionals during a weekend of educational workshops and meetings. Travel and lodging assistance available for eligible patients and their caregiver(s).

To register: www.NHFinhibitorsummits.org or 877-560-5833
inhibitorsummits@hemophilia.org

First-Time Attendee Grants to NHF Annual Meeting

November 11–13, New Orleans

NHF offers Educational Participation Grants for first-time attendees of its 62nd annual meeting in New Orleans. Grants cover costs including airfare, hotel, expenses, and/or registration fees. Applications are due by mail, postmarked by Friday, June 25.

For information: sroger@hemophilia.org

advocacy

PACT Grant Winners

Administered by Hemophilia Association of New Jersey (HANJ) and funded by Baxter, the Partnership for Advocacy and Communications Training Grant provides financial assistance for a range of advocacy programs in the bleeding disorder community. Since 1995, Baxter has provided more than $985,000 for 33 state advocacy initiatives through PACT. The winners for 2009:

- Alaska Hemophilia Association
- Arizona Hemophilia Association
- Hemophilia Council of California
- Hemophilia Foundation of Michigan
- New England Hemophilia Association
- New York State Hemophilia Advocacy Coalition
- Ohio Bleeding Disorders Council
- Pennsylvania Chapters of NHF
- Virginia Hemophilia Foundation and Hemophilia Association of the Capital Area

RFP PACT Grant deadline: August 20, 2010
For information: www.hanj.org/services_pact.html

advocacy

New Healthcare Reform Legislation Passed

A historic moment occurred on Tuesday, March 23, 2010, when President Obama signed into law H.R. 3590, the Patient Protection and Affordable Care Act. The legislation is the climax of a long political struggle with many bitter exchanges between various stakeholders.

The act's most important provisions for the bleeding disorder community:

- Eliminates pre-existing condition exclusions for all Americans beginning in 2014, and prohibits health insurers from excluding coverage of pre-existing conditions for children, effective six months after enactment and applying to all new health plans.
- Provides $5 billion in immediate federal support for a new high-risk pool to provide affordable coverage to uninsured Americans with pre-existing conditions. This provision is effective 90 days after enactment, and will continue until 2014.
- Guarantees 50% price discounts on brand-name drugs and biologics purchased by low- and middle-income beneficiaries in the coverage gap, beginning July 1, 2010.
- Prohibits insurers from imposing lifetime limits on benefits. This provision takes effect six months after enactment and applies to all new health plans.
- Tightly restricts insurers' use of annual limits, effective six months after enactment for all new health plans.
- Allows dependent children to stay on their parents' health plans until age 26 instead of being dropped at age 19 to 24, or when they finish college.

Why this matters: Your child with hemophilia or VWD may never be denied insurance again as a result of exclusion for a chronic disorder or for reaching a lifetime cap. The act overturns decades of health discrimination for people with chronic disorders.

For information:
http://dpc.senate.gov/dpcdoc-sen_health_care_bill.cfm

Contact: www.hemophilia.org and www.hemophiliafed.org

science

Iran's First Transgenic Goats for Hemophilia

The Royan Institute announced that Iran's first transgenic goats were born on January 9, 2010, and contain factor IX in their milk. Transgenic goats, cows, sheep and pigs are already produced in many countries, including the US, UK, France, Japan, Denmark, Canada, Scotland, Netherlands and China. Iran hopes to mass-produce factor IX to increase affordability and decrease reliance on imported factor. The two goats, Royan TGF91 and Royan TGF92, are named Shangoul and Mangoul for two characters in a traditional Iranian children's story. Why this matters: If the products become commercially viable, transgenic animals may someday provide a source of inexpensive, abundant factor.

For information: www.yakhteh.org

New from LA Kelley Communications

Alex Lieber Memorial Scholarship

LA Kelley Communications announces two $1,000 scholarships for young adults with bleeding disorders, in memory of Alex Lieber of Texas. Alex was born on January 22, 1986, and diagnosed with severe hemophilia A. Intelligent and inquisitive, Alex was fascinated by electricity. As a teen, Alex filled his room with the remains of electronic toys he had disassembled for spare parts. Alex was the official sound and lighting engineer for his high school. He even renovated a 1963 Vespa scooter. Alex volunteered to become a camp counselor at Camp Ailihpomeh in Meridian, Texas, and was accepted into the camp's leadership program. But he never got the chance. On Saturday, December 13, 2003, Alex was diagnosed with bacterial meningitis, and he passed away suddenly on December 21, 2003. To honor Alex's legacy, the recipient of this scholarship for higher education must be a person with hemophilia or VWD who, like Alex, is committed to community service and can demonstrate this commitment. Why this matters: Alex's sudden death reminds us how fragile and brief life can be.

Through this scholarship, we hope that his inquisitive spirit and his tradition of caring will live on.

Deadline: June 1, 2010

For information: www.kelleycom.com

LA Kelley Communications is now on Facebook! Come see us and become a fan.

And visit our Project SHARE Facebook page to read about our donations sent around the world.

As I See It... from p. 3

But no publisher was interested: "No thanks, not my genre, but good luck!" So I saved my pennies and self-published.

One goal of my book was for medical staff, who go home after their shift *during a bleeding episode*, to read what happens after they leave. I wanted them to understand the consequences of waiting too long to treat a bleed. I wanted them to be with us as we endured a bleed that lasted days, weeks, or even a month.

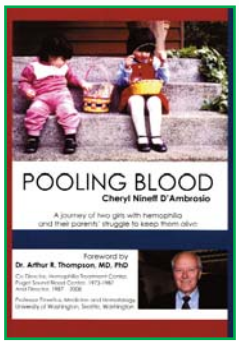
My second goal was to help parents, who sometimes need support when speaking up to the medical community. If nothing else, new parents could read my book and take steps to avoid the traps our family fell into.

My third goal was to help patients build confidence when advocating for their own healthcare. My message: It's time to stop feeling like you're all alone or a victim. The more you know about what others experience, the more you can stand up for yourself. Even though my book is about two girls with factor V deficiency, I believe that men and women with other bleeding disorders will find common themes.

Ultimately, my book *Pooling Blood* shows what I consider the keys to success in working with medical staff to get the best treatment:

1. Create a sense of urgency by letting others know that the bleed must be treated immediately.
2. Build a network of people you trust and who trust you. Your HTC is crucial in making sure your bleeding episode is managed expediently.

Do you notice that these two keys to success have to do with people, not technology or science? That's why I wrote my personal history of parenting two girls with a bleeding disorder.



Cheryl D'Ambrosio has been a process developer for Boeing Company for 25 years. She is the author of *Pooling Blood* and founder and director of MyGirlsBlood, a non-profit organization dedicated to providing awareness for girls and women with bleeding disorders. Cheryl, her husband Tony, and their two daughters live in the Pacific Northwest. *Pooling Blood* is available at amazon.com, Barnes & Noble, and iUniverse.

For information and to hear Cheryl's radio broadcast: www.poolingblood.com
For stories about girls and women with bleeding disorders worldwide: www.mygirlsblood.com

Insights... from p. 4

healthy eating, exercise – and of course, factor. "I don't let anything get me down!" he says. "If I've got to go somewhere, I go. If I can't go, I don't go!"

Today, Perry lives on beautiful Drummond Island, Michigan. Betty has passed away, so he now lives alone. But he enjoys spending time on his computer, visiting casinos, going on cruises, and staying with his daughter in Phoenix.

Perry told me how fortunate he feels to have escaped viral transmissions, considering the amount cryoprecipitate and blood that he received during his early years of treatment. And he's grateful that although his daughters are carriers, none of his grandchildren has inherited hemophilia.

Thanks to the evolution of HTCs during Perry's long lifetime, and advanced treatments with bypassing agents, Perry may just be the oldest living person with an inhibitor – an amazing accomplishment for an inspiring man.

Kerry Fatula is executive director of the Western Pennsylvania chapter of National Hemophilia Foundation. She is also the mother of four boys, three with severe hemophilia A and inhibitors.

Project SHARE... from p. 6

was Metamorphosis, to celebrate the camp's 10th anniversary. Just like butterflies, the campers had transformed from boys into young men, with teens now serving as counselors to new campers. Their spirits transformed too, as camp showed them their potential, a community that cares for them, and a future.

The Clarks' package included a custom-made photo album of camp, dedicated to Bryan and the Clarks; some locally made wooden butterflies to hang on the wall; and handmade letters, decorated with butterflies, each signed by several campers and translated. One read,

From all the children registered with the foundation, we want to thank you for donating factor . . . and we are sorry for the loss of your loved one. In the name of the Lord, we are all born for a purpose.

With all of our affection, we are very thankful by your magnificent, humanitarian kindness. May God bless you!

Henry, Diogenes, Angel, Jorge, Luis, Ronnie

Another read,

The reason for this letter is to tell you that we're sorry for the death of your son. We did not know him, but we know that he was a good son and we know that you, his parents, were by his side, fighting hemophilia.

Also, we want to thank you for the donation that we obtained on your behalf. Because of this donation we were able to enjoy camp, strong and healthy.

Luis, Isaac, Elian, Yoan, Manual, Bryan, David, Edward, Richard

Since summer 2009, when they made camp possible for the Dominican children, the Clarks have sent more donations to Project SHARE. Bryan's donations helped patients in the Philippines, Jamaica, and the DR.

Thanks to Bryan's family, children with hemophilia all over the world have had the good fortune to enjoy fun times at camp, to leave their hospital beds, or to celebrate their school graduations. We are honored that the Clarks chose to donate to Project SHARE in Bryan's memory. Thank you, Dan and Linda, and thank you Bryan, for these gifts.

Transitions... from p. 5

been wearing it the whole time for my parents' sake, to ease their fears." While medical IDs can certainly give loved ones some peace of mind, don't lose sight of the fact that you wear it for your own protection.

Naked Without It

Even people who don't wear their medical IDs won't deny their value. So how can transitioning teens and young adults be convinced to wear one?

One way is to get them into the habit. Kachalsky informs her new patients of the HTC's expectation that they will wear some form of medical ID. "We hope that they will get used to wearing a medical ID and feel naked without it," she explains. About half of her patients who did not routinely wear medical IDs when they first enrolled at the HTC do eventually wear them.

But persuasion goes beyond the jewelry's medical benefit. At the root is being comfortable with your hemophilia. The more comfortable you are, the more likely you will be to wear something that draws attention to it.

This was true with Michael. "I started wearing my bracelet when I'd gotten to a point in my life where I was more comfortable with myself and my health issues," he says insightfully.

A Decision with Consequences

Choosing to wear a medical ID or to carry an ICE (in case of emergency) card can be literally a life-or-death decision. "As a responder, it's critical to get the entire picture of a person's health condition at an emergency scene," emphasizes Albert Beardsley, a Massachusetts fire chief. "The first thing we look for – especially if there isn't a friend or next of kin available – is the medical ID or wallet ID card."

Beardsley adds, "If we see an alert bracelet, we can update responding paramedics. An important part of our protocols is to alert the next level of care what we have coming into their facility. In many instances this will give the emergency room advanced notice to have specialists in the ER upon the ambulance's arrival."

Recently a doctor was preparing to perform a colonoscopy on a hemophilic man who spoke only Spanish. The man assumed that the doctor had all of his medical information. Just before the procedure, the doctor noticed the medical ID bracelet, called the man's HTC, and postponed the procedure until they had factor on hand in case they needed to perform biopsies.

And what if you're *not* wearing it? At age 16, "James" wasn't wearing a medical ID when he was brutally assaulted in the company of a friend. When the ambulance arrived, James wasn't able to communicate clearly with paramedics, he had no medical ID, and his friend knew only that James had hemophilia. Finally, at the hospital, staff learned that James had severe hemophilia and an inhibitor, so he was transferred to his HTC for appropriate treatment. His condition was so critical that doctors wanted to use an air ambulance for transport, but the helicopter was in use, so they were forced to make the trip via highways, seriously delaying treatment.

James, now 34, knows that his treatment would have been different had he been wearing a medical ID. "I'm almost positive that if I had the medical card I carry now and the medical alert necklace I wear, I would have gone straight to [my HTC] and they would have had factor ready and waiting."

"The medic alert tag is there to save time," explains Dr. Nance. "And for people who are bleeding, a few minutes' heads-up for the doctor can mean the difference between getting factor first and getting factor eight hours later. Patients with bleeding disorders are very rare. Even experienced physicians may not know exactly how to treat them. With a medical ID, that knowledge is an easy phone call away."

Get Past Your Hangups

The bleeding disorder community faces a tough challenge in convincing everyone to wear a medical ID. Ironically, the toughest converts will be young adults in their "invincible" years, who are most likely to need a medical ID but least likely to wear it.

To make medical IDs more appealing, manufacturers constantly update their products with new styles. Styles range from the traditional to black leather to more customizable and discreet options, including watches from designers like Citizen. You can also find medical sports bands, dog tags, and other styles that teens and young adults don't mind wearing.

At the end of the day, your medical ID is not a fashion statement. It's an essential part of your hemophilia treatment plan.

Men like Michael, Craig and James can have a huge impact on younger people in the community. They've been through the pressures of the young adult years. They know what it's like when people ask the unwelcome, awkward questions.

To the young people not wearing their medical IDs, Michael says, "You have to get past your hangups and vanity. A bracelet is all you really have as a backup if you get hurt and can't talk."

HemaBlog... from p. 13

I asked only one favor of the prime minister: a meeting with patients on April 17, 2011, World Hemophilia Day. Mr. Golding happily agreed!

Next stop: UHWI. Derek, Kerry-Ann and I met with Dr. Wharfe, head of the Jamaica Hemophilia Committee. Dr. Wharfe, an extremely kind and caring hematologist, faces tough challenges. She is frustrated by the lack of factor and lack of patient involvement. But sensing that all this is about to change, we discussed how to move forward to improve care.

Later that afternoon, Derek, his mother Rita, and I took a trip to Port Royal. In the scorching sun, we walked among abandoned forts where cannons once fired on enemy ships, and we could almost hear the pirates and buccaneers. We ate a delicious seafood dinner before returning home.

Derek and I had a positive trip that inspired hope in a group of isolated patients. My next step will be to hammer out a strategy to bring these determined patients and dedicated physicians together as a team. Above all, we don't want to lose the energetic momentum we have gained.

Inbox... from p. 2

Last fall, LA Kelley Communications learned of a young boy with hemophilia in a Chinese orphanage. Although Chinese adoptions can take years, this one took only months, with the help of Delin Kong of Hemophilia Home of China. When we sent a plea to all PEN readers, we raised $17,000 in 48 hours for the Luckeys, a family with hemophilia.

OUR FAMILY CAN NEVER THANK YOU ALL enough for your generous donations for our adoption of Lu Feng. The hemophilia community showed so much compassion and concern. The success of the fundraiser was overwhelming: we had enough funds to pay the rest of our adoption fees and to cover most of the costs of travel to China.

We left for China on January 20 and received custody of Lu Feng on January 25. Two days later, Lu Feng had a knee bleed. We couldn't get factor concentrate, so we treated his pain and iced. We borrowed a wheelchair during our time in China. Lu Feng had never been in a wheelchair before and loved the new sense of freedom. Previously, he was confined to bed when he had a bleed. We stayed in China for two weeks, for legal processing of documentation. Two days before leaving China, Lu Feng had had enough of the terrible job we did pronouncing his name. We asked him what he thought of the name Luke. He loved it, and we have called him Luke ever since.

We arrived home on February 7 and were so happy to be reunited with our other three children. Luke is settling in nicely. He started school the week after he arrived home and is in third grade. He loves school and looks forward to it. He's learning English very quickly. We make an effort to continue exposing him to Mandarin speakers to keep his native language abilities intact.

We have had several doctors' appointments, and Luke has started physical therapy to increase overall strength and range of motion in his right knee. He's also getting up to date on his immunizations. He's already gained five pounds, which is great because he is quite underweight.

We are so happy that Luke is here in America. Here, he is a son, a little brother, a grandson, a nephew, and a cousin. Here, he will get the best medical care available for his bleeding disorder. Here, he will never feel hungry. Here, he can continue to be a part of the Chinese culture. He has already introduced his new family to many new foods, and he teaches us new Mandarin words each day. We are excited to blend the Chinese and American cultures in our home.

Luckey family
Michigan

I JUST WANT TO SAY THANK YOU FOR writing such a great book [*Raising a Child With Hemophilia*]. I am reading it now, and it is helping me more than anything else I have read. My son is a month old and has severe hemophilia A. Finding this book has been so helpful. Thank you again for everything you are doing for the hemophilia community.

Katrina Piche
Florida

OUR FAMILY HAS BEEN READING PEN since our son Robert, who has severe factor VIII deficiency, was very young. He is now 16, and I am trying to encourage him to read the articles as this information is really made for him. I want you to be encouraged that your publication is always a wealth of information and is an invaluable resource to the bleeding disorder community. I noticed in the February PEN that you add the phrase "Why this matters" in Headlines. This shows the reader the importance of the articles and the impact it has on them. What a great idea.

Thank you for the time and care you and your staff put into this magazine. Thank you also for keeping us up to date on health insurance, inhibitors, new treatment horizons, and Project SHARE. Quite often we tend to focus on our own situations and issues, forgetting that there are children in this world without the benefits of medication, medical equipment, or basic everyday necessities.

John and June Wulf
New York

LOVED THE LAST PEN. YOU NAILED IT!

Ray Dataolli
Texas Central Hemophilia Association

THANK YOU FOR THE PACKAGE OF BOOKS! I can't believe I got them for free! I love your book *Raising a Child With Hemophilia*. It's really helped me understand and learn a lot about hemophilia. It's a wonderful guide book. It's something I can always go back and read over again for tips.

Chiemi Trevnaya
Saipan

Project SHARE

THANK YOU SO MUCH FOR SHARING your experiences with us. It was one of the most heart-wrenching and inspiring inservices I have ever sat in. Thank you for all you do every day in these underdeveloped countries. Having grown up in South Africa, I had experienced some of this, but as you said, no child should be without appropriate medical care to live life to the fullest.

Lara Tucci
ASD Healthcare
Texas

We collected the factor already, and thank God and thank you all for brightening Christmas for us. From our family to your family and the people at Project SHARE, keep up the wonderful work. God bless you all!

Laurence and Lloyd Bakhsh
Guyana

I thank you from the bottom of my heart. I can't express how pleased I am knowing that you will supply us with factor. I find your organization very efficient and supportive. I can't tell you how impressed I am with your participation to help humanity.

Ashraf Moussa
Egypt

We are very thankful for your support for our son Denol Encarnación for his factor, and we thank you also for your gracious heart in extending the life of our son. We hope that you are always there to support us and others who need you. God bless!

Mr. & Mrs. Encarnación
Philippines

I have received the factor VIII donation. I once again thank you and your team for saving our lives. May God bless you.

Moses Mwanja
Uganda

Thank you for all your help to make my brother's surgery a success! He received the donation letters and all vials of NovoSeven. His doctor performed a successful surgery on his leg. They gave him six to eight vials of NovoSeven every two hours during the operation. Project SHARE's donation of the medicine has made the surgery possible and saved my brother's life. I really appreciate your help and hard work. Your compassion and efficiency is inspiring and very much appreciated!

Nongji Zhang
China

I can't thank you enough for the von Willebrand factor you sent to my daughter Star. At least now we can rest knowing that when she bleeds again, we can infuse her right away. She's been back to school a day after she was released from the hospital last week, and we will be attending the family love day in her school on Saturday. Life is back to normal. Thank you to Project SHARE! God bless!

Andrea H. Trinidad-Echavez
Philippines

Greetings from the Philippines. I hope to meet you some day to personally thank you and your noble organization for your invaluable humanitarian service. Ron David Torres and his family are forever grateful to you and Project SHARE for sharing with him the lifesaving factor IX that saved their child's life on more than one occasion. My prayer and hope is that you will continue to help him and the many more with hemophilia around the world. We are forever grateful.

Carlos M. Salazar
Philippines

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ABIGAIL VAN BUREN

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