

PEN

## inside

- 3 **As I See It:** A Path to Success
- 4 **Inhibitor Insights:** Rethinking Career Choices
- 5 **Richard's Review:** Preparing for the Future
- 6 **Project SHARE:** Making History in Romania

# The *Jobs* Journal

## Working with Hemophilia

### Part 2

*Sara P. Evangelos*

Paths to employment—or happiness, or true love, or anything else worth having—are never straight. Often, the truly interesting paths in life are downright crooked.

In Part 1 of the Jobs Journal (Nov. 2012), we profiled men with hemophilia whose paths to employment were fairly straight. This time, we follow four slightly crooked paths forged by four men with hemophilia who all found rewarding work in unique ways. But despite all the twists and turns—disclosing hemophilia, finding insurance, testing limitations—a single signpost marks each man's path: *motivation*. These are stories from different eras in hemophilia care, and they focus on different types of employment; yet each man profiled here found a way to do what he wanted to do, and not let his hemophilia stop him.

»» *page 7*



# welcome

Laurie Kelley

I suppose that, as in generations past, those of my own generation (born in the late 1950s) are fond of saying, “When I was their age...” Fill in the blanks: people went without, worked harder, were willing to sacrifice, finished college; and didn’t eat out, have cell phones, drive cars with computer chips, or play hours-long video games.

The so-called millennial generation—in their 20s and often just out of college, graduate school, or the military—sure is different. But it’s a different time, economy, and culture. Even so, conditions today are similar to when my generation was looking for work: the economy was sinking fast, with high inflation, high unemployment, high gas prices, and Middle East conflict escalation.

And today, our kids are searching for employment while trying to manage a bleeding disorder. The unemployment rate for 18- to 29-year-olds seems stuck in double digits (compared to 7.8% for overall unemployment), with about 63% of that age range settling for jobs in service or retail instead of a preferred career. The job market has been tough for almost everyone seeking work in the past few years, but experts say it has been especially difficult for millennials.

That’s one reason to read the inspirational stories in this issue of PEN. Meet several men with hemophilia who have managed to overcome challenges to find work doing what they love, while providing valuable services to their communities. Our feature story may help motivate you to reach your personal career goals. ☺

## inbox

THE HEMOPHILIA COMMUNITY SHOULD BE GRATEFUL to Laurie Kelley and Paul Clement for the superb article on new concentrates in PEN [Aug. 2013]. This is a confusing scene, and Paul explained it beautifully. Those tables are priceless! I shall put copies up on the wall of my office for reference.

Carol Kasper, MD  
*Emerita Professor of Medicine*  
UNIVERSITY OF SOUTHERN CALIFORNIA

KEEP UP YOUR GOOD WORK. THE COMMUNITY WILL always need good people like you. Thank you for everything you’ve done over many years. I received the latest issue of PEN and was very pleased to see the variety of current factor products and the new products that are yet to become available. The list was educational, informative, and a necessity to all of us in the community. Thank you for your time and effort in producing it.

Tom Albright  
ARKANSAS



## PARENT EMPOWERMENT NEWSLETTER NOVEMBER 2013

EDITOR-IN-CHIEF Laureen A. Kelley

SCIENCE EDITOR Paul Clement

CONTRIBUTING WRITERS Richard J. Atwood • Sara P. Evangelos

MANAGING EDITOR Sara P. Evangelos

LAYOUT DESIGNER Tracy Brody

DIRECTOR, PROJECT SHARE Zoraida Rosado

PEN is a newsletter for families and patients affected by bleeding disorders. PEN is published by LA Kelley Communications, Inc., a worldwide provider of groundbreaking educational resources for the bleeding disorder community since 1990.

PEN respects the privacy of all subscribers and registered patients and families with bleeding disorders. Personal information (PI), including but not limited to names, addresses, phone numbers, and email addresses, is kept confidential and secure by the LA Kelley Communications editorial staff in accordance with our privacy policies, which can be viewed in entirety on our website. PEN publishes information with written consent only. Full names are used unless otherwise specified.

PEN is funded by corporate grants or advertisements. Sponsors and advertisers have no rights to production, content, or distribution, and no access to files. The views of our guest writers are their own and do not necessarily reflect the views of LA Kelley Communications, Inc., or its sponsors.

PEN is in no way a substitute for medical care or personal insurance responsibility. Parents or patients who question a particular symptom or treatment should contact a qualified medical specialist. Parents or patients with personal insurance questions should contact their employer’s human resource department, Medicaid or Medicare caseworker, payer representative, or HTC social worker.

Articles may be reprinted from PEN only with express written permission from the editor, and with proper citation. PEN and/or its articles may not be published, copied, placed on websites, or in any way distributed without express written permission.



37-39 West Main Street, #8  
Georgetown, MA 01833 USA

978-352-7657 • fax: 978-352-6254

info@kelleycom.com • www.kelleycom.com

Credit for the photos in this issue, unless otherwise noted: Copyright © 2013 LA Kelley Communications, Inc. and its licensors. All rights reserved.



as i see it

Stephen Choate Place

## Mild Hemophilia: A Path to Success

I have always liked to work with my hands. Even when I was very young, my dad and I were always fixing things. Repair technicians did not come to my house. We fixed everything that needed repairing ourselves. We took on many large projects, such as renovating the kitchen and bathroom, building a boat in our basement, electrical and plumbing repairs, and anything that Mom asked us to do. Dad taught me that if we thought about something and asked questions, just about anything could be accomplished—with great results—even if it was way beyond our knowledge and skill level.

As a child in the 1950s and 1960s, my mild hemophilia presented many challenges and heartbreaks, and also some victories. I felt terrible when I couldn't join in some activities like "normal" kids. Contact sports were definitely out, especially when Mom was watching. Dad, however, often let me do things that were, let's say, at the edge of safety for someone with hemophilia. I participated in pickup basketball games, flag football, ice skating, and good old

rough horseplay. There were bruises, cuts, incapacitating swellings, and missed opportunities due to bleeds. But there was ice, *lots of ice*, lots of idle time sitting, and life went on. Victories were found as I gained self-confidence and education.

I received a bachelor's degree in business administration and thought I was all set. I spent 30 years in the building materials industry, managing and selling. This led to other opportunities in print media sales, and in life insurance. Then, I realized, sales was not my passion. What to do? How to support my family? What was my path to success and happiness?

I once heard someone say, "If you get a job doing something you love to do, you'll never work a day in your life." Well, I haven't worked a day for the past two years. That's because I started my own professional handyman business at age 56. I love fixing and repairing



Carole and Stephen Place

things. Every day I decide what I want to do. As a perfectionist, I can do every job well, and my customers appreciate my skills. I don't advertise, yet I always have work to do. I also work for a local professional caregiver franchise as a paid caregiver for elderly and disabled people. The rewards are phenomenal!

Now, understand, I have every power tool and sharp instrument imaginable, and I work in situations where many others with hemophilia would not dare. I know my limits, but I sometimes go beyond my own safety zone. Believe it or not, my bleeds most often occur *off* the job. Go figure.

At about age 14, after a very bad head injury, I made a conscious decision to always respect my disorder, *but never be afraid* of it. That decision has helped me through 44 more years of living. Today, I am a very happy and secure man—just ask my wife of 34 years and my two adult children.

My advice to others with hemophilia is to figure out what you love to do, get some training, and do it. Do it for yourself—not for your parents or for someone who advised you out of ignorance. Life is too short, and filling it with a job you hate is wrong. Wrong for you and for those you love. Don't be afraid of your disorder; use it to your advantage. And most of all, have fun! ☺

*Stephen Choate Place is a professional handyman who lives on Cape Cod in Massachusetts with his wife, Carole, and daughters Meredith and Stephanie. He has mild hemophilia A.*



## Rethinking Career Choices for Young People with Inhibitors

If you want your teen to grow into an independent adult, you need to think seriously and early about his career choices. As a person with hemophilia and an inhibitor, your young adult will need a job that provides good medical insurance, or one that will support buying medical insurance. But with the advent of the Affordable Care Act (ACA), it's possible that he can rethink the idea that he *must* to go to college to prepare for a traditional job that will most likely offer a good insurance option.

ACA makes it possible for anyone without insurance to browse websites, called Marketplaces, to compare and eventually choose insurance. Yes, health insurance premiums will always seem expensive to a young adult, but the "affordable" in Affordable Care Act means that most Americans should be able to pay the premiums. This may allow our children to consider jobs other than just college-generated jobs—and college, with its super-high price tag these days, is no guarantee of a well-paying job.

In thinking about employment, a

young adult should consider his interests and skills, job satisfaction, and general happiness. Job satisfaction is based on enjoyment, challenge, competence, and contribution—not just security, financial reward, or even access to health insurance. Introduce your teen to a variety of activities to uncover his skills and passions: chemistry, music, art, medicine, writing, engineering, travel, acting—the list is endless! Ask if your HTC team can refer him to a vocational or educational counselor.

### Career and Healthcare Coverage

Career choice, of course, can directly affect health insurance coverage. Working for the government provides excellent coverage. Large companies, banks, and hospitals normally offer a wide range of coverage. Private companies, self-employment, and small firms may provide less coverage. When possible, young adults should get a copy of a prospective employer's insurance policy before accepting a job, and should have it examined by a social worker who is familiar with insurance as it applies to hemophilia.

The decision to attend, postpone, or drop out of college no longer has the serious consequences it did before ACA, if you as a parent have insurance. Whether he attends college or drops out, your child will be covered by your employer's plan. All children are covered until age 26 by their parent's plan, even when they are married or not living with a parent!

Still, a solid education can be the foundation of many opportunities, including job satisfaction, job choice,

and excellent health insurance. Overall, the bleeding disorder community still recommends that your child stay in high school and at least consider college. It doesn't even have to be a four-year college; local community colleges have excellent programs, including certification programs such as radiology and phlebotomy.

### Alternatives to College

Not all young adults want to attend college or can afford it. There are many alternatives: family businesses, clerical positions, trade schools. Scholarship programs exist just for students with hemophilia attending college or trade school. Consult your child's high school to find volunteer or summer jobs that offer career experience: working in an office or store, coaching sports, being a camp counselor, and applying for professional internships can all open doors to a bright future.

Some high schoolers take a "gap year" after they graduate: a year off for travel, work, or public service before making a decision about going on to higher education. Young people can do things like being employed overseas, doing mission work in developing countries, volunteering with local social service organizations for the poor or elderly, working with animals or with forestry services, or working as camp counselors.

When your young adult finds an appropriate job with good medical coverage, he'll need to decide what to tell his employer. If hemophilia affects his job performance, through absences or inability to do heavy labor, he should consider informing his employer about his medical condition. If his job is flexi-







## Preparing for the Future as Viewed from the Past

**H**ow realistic are the stories told by novelists and screenwriters? Should we believe in them, especially when their fictional characters with hemophilia provide advice about growing up? A young adult novel and a teen movie, both classics from over 30 years ago, are favorites of mine for showing how teenagers once coped with their bleeding disorders and also prepared to enter the workforce. To me, both the movie and the novel are fairly realistic and factual, at least for their descriptions of hemophilia.



### *Senior Trip*

1981 (2006), New Star Video

Writer and Director: Kenneth Johnson

Cast: Scott Baio, Faye Grant, Jason Alexander, Mickey Rooney

As a rite of passage in this comedic coming-of-age teenage flick, a busload full of high school seniors, chaperoned by three adults, travels from Ohio to New York City. These young men and women are following their dreams for adulthood. Surprisingly, the teens are unsupervised when they tour the Big Apple. Hormones rampant, the characters awkwardly and unsuccessfully search for initial sexual experiences. They also behave like adolescents: shaving cream and water balloon fights, plus sneaking a horse into the hotel room. Roger Ellis (played by teenage heartthrob Scott Baio) attempts to bolster his father's engineering business with a presentation to an electronics company. Roger strives harder than the other teens, possibly to compensate for his hemophilia—though my impression is that he would strive harder in any case.

As proof of his condition, when his arm is cut by glass, Roger's peers watch him infuse; fortunately, he carries factor concentrate and syringes in his briefcase and toiletry kit so he can treat himself. In one scene, we see the factor concentrate box and the very large syringes used in the early 1980s. Yet Roger does not want to be treated differently in school; he wants to be rewarded based on merit rather than on hemophilia. He feels there is nothing in life that he cannot do.

*A note about the movie's cast:* Older readers of Richard's Review may be interested to know that Mickey Rooney was still acting in 1981. Younger readers might realize that yes, this is Jason Alexander—before Seinfeld. Some readers may even reflect, “Did I really have a crush on Scott Baio?” And of course, the youngest may say, “Who?”



### *Starring Peter and Leigh*

Susan Beth Pfeffer

1979, Delacorte Press

This young adult novel tackles the adolescent dilemmas of being different and striving for normalcy. One teen protagonist deals with her celebrity status as an actor, and the other copes with his medical condition of hemophilia. Both teens must adapt to a reconfigured family because of divorce and remarriage. Leigh Thorpe is a 16-year-old professional actor in Los Angeles when her mother remarries and moves to Long Island, New York. Her new family includes Peter Sanders, a 17-year-old stepbrother with hemophilia. Peter is often bedridden, so he is tutored at home. Leigh just wants to be a normal teenager, but she doesn't know how. Peter teaches Leigh how to fit into her new high school so he can vicariously attend school. Peter endures painful, but necessary physical therapy to avoid using a wheelchair or crutches for mobility, yet he still limps. His physician even makes house calls to treat his swollen knees with transfusions. Peter plans to attend an expensive therapy clinic in California and then attend college in North Carolina. Unfortunately, Peter is described as being a “cripple” and an “invalid,” terms that are certainly no longer appropriate.

I enjoy these two fictional examples of hemophilia from three decades ago. The movie and the novel may not be based on real people or events—or even that good in their respective genres—but the condition of hemophilia is insightfully (and melodramatically) described in both. In fact, they offer us a measurement of the advancement of hemophilia treatment over the past 30 years if we compare the treatment then with the safer, purer, wider choices for concentrates of today. They also supply a glimpse into the adolescent angst of preparing for the future, an emotional rite of passage that seems to be timeless. Though most novels and movies are better suited for entertainment, fortunately they can also provide some realistic descriptions of human behavior. ☺





PROJECT  
SHARE

It's time to give back.

Laurie Kelley

## Making History in Romania

Daniel Maruta, 35, lives in Tirgu Jiu, Romania, a southwestern city renowned for its outdoor sculptures by artist Constantin Brâncuși. Brâncuși lived here as a boy, and later was commissioned to create a memorial monument to World War I soldiers, located on the Avenue of the Heroes. Brâncuși's large, outdoor sculptures are now World Heritage sites: *The Table of Silence*, *The Gate of the Kiss*, *Chairs' Alley*, and *The Endless Column*—when you sit at its base and look up, the column appears to go up forever.

Endlessness is something familiar to Daniel, who has severe hemophilia A and grew up in Romania. Seemingly endless pain and hospital waits have been a way of life for him. And if having hemophilia weren't bad enough, Daniel has long suffered from collapsing veins. With repeated infusions, his veins weakened and became scarred; over time, the veins collapsed. As a child, he had received infusions of factor in his head, sometimes the only place where accessible veins were found. As Daniel grew, he had fewer and fewer usable veins; it was getting harder and harder to get factor into him.

Adriana Henderson, president of

S.T.A.R. (Start Thinking About Romanian) Children Relief, a US-based nonprofit that helps Romanian children with cancer or chronic disorders such as hemophilia, visited Romania last year and met with Daniel. He tentatively asked about having surgery to implant a port. A port is a medical device consisting of a small stainless steel reservoir with a quarter-sized silicone *septum* (partition or covering) on top. The port is connected to a vein by a tube called a *catheter*. Ports, commonly inserted into the chest wall, allow drugs to be infused without having to puncture a vein: the needle is inserted through the skin of the chest into the port's septum, directly beneath the skin. Drugs infused into the port find their way to a vein via the catheter attached to the port.

Adriana, who was born in Romania, hesitated to answer Daniel. No one with hemophilia in Romania had ever had port surgery. In fact, no one with hemophilia in Romania had a port. Not wanting to raise Daniel's hopes, Adriana didn't promise him anything at first. She told him that such a surgery required a lot of factor—about 50,000 IU, which

would cost a fortune in Romania. Because of insufficient supplies, any available factor is rationed and used primarily to help with emergency bleeds: an elective surgery like getting a port would be very low on the priority list for Romanian doctors. Still, Daniel was very excited. "He was so desperate for help," recalls Adriana.

Adriana contacted Project SHARE in April 2013. Over 12 years earlier, Adriana had also contacted us, when she met Nicusor, a crippled Romanian child with hemophilia. Nicusor had been promised factor to cover the surgery needed to correct his joint damage, but he had been let down repeatedly in the past when factor was not found. Project SHARE donated enough factor for his operation, but not until the factor was in her hands did Adriana let Nicusor know it had arrived. His operation was a success!

Hopeful again, Adriana turned to us to help Daniel obtain enough factor for his operation. Incredibly, a donation of factor was made to Project SHARE at the very same time that Adriana made her request. SHARE often runs out of factor, because the waiting list is long and worldwide, and the needs seem endless. But Daniel got lucky.

This summer, Daniel became the first Romanian hemophilia patient to have a port implanted. Though he is unable to work because of his disabilities, and he lives with his parents, Daniel now can give himself factor without trouble, thanks to his new port. And, in the process, he's also made hemophilia history in Romania! ☺



Daniel Maruta: First Romanian hemophilia patient to get a port







## Vaughn Ripley

Age 46

Maryland (home);

Virginia (work)

Chief Information Officer

Hemophilia A, mild

"I dig computers. I mean on another, out-of-this-world level." It's as simple as that for Vaughn Ripley.

In 1985, Vaughn was attending community college and planning to major in computer information services at a four-year school. Then, a skateboard

accident that resulted in a serious hip bleed forced him to withdraw for a semester. But, he recalls, "I was an adult now—even though my parents were being helpful, they weren't paying for everything. So I needed *something*, and I started working." Through a recruitment firm, Vaughn was hired by IBM as a temporary worker. The money was good, he was working with computers, and he had bills to pay.

At about the same time, Vaughn learned that he was HIV positive. "It devastated me, because I was nineteen," he says, "and the doctor told us that I had fewer than two years to live." So Vaughn's college plans faded. He thought, "Well, first off, I'm working, and I need this income. Secondly, if I have only two years to live, what the heck am I going to college for?"

Vaughn credits his love of computers with helping him move forward. He has worked for various companies since then, in health insurance, data processing, telecommunications, and consulting, each for about five years. "I knew, especially without my college background, I needed to stay at these places and establish myself, but also I was really into the work that I was doing." His perseverance and motivation served him well. "I managed to just kind of claw my way up the ladder without a college degree," eventually discovering that, for him, "experience is tenfold more important than the college."

Vaughn's customer at one of his jobs was the US Department of Justice. "I was raised in a military family," he says, "and I would have been in the military, too." But Vaughn's hemophilia had stopped him from enlisting. Then, the Justice Department offered him a job. "It was a win-win," says Vaughn. "Obviously it's work, and that's good, and it was also something where I could give back to the government, to the country that I'm thankful for being a part of...just in a different way than my brothers and dad did." He worked for Justice for five years.

Vaughn even started his own company at one point, but then closed it in the economic wake of 9/11. For about the past four years, he's been with Emergent, LLC, a value-added reseller for software and hardware companies, selling primarily to the federal government.

Now, even considering his own background, when Vaughn interviews prospective young employees, he admits that he looks for college students. "It's an easy measuring stick," he explains, "because I know that this is a person who follows through." Vaughn avoids the one- or two-year "bouncers,"





because “I know that they’re going to continue that pattern.” What they don’t realize, he notes, is that “every time you change jobs and move somewhere else, *you* go with you.”

But basically, regardless of education, what Vaughn looks for in an employee is inspiration, motivation, and diligence—the same qualities he possesses. “I think college is important when you’re trying to just get your wheels off the ground, but once you’re already flying, I think it becomes less and less.” And personally, he adds, “I’m a huge go-getter, and just because I see that statement ‘needs college,’ that’s not going to stop me.”

Vaughn’s work day is filled with meetings, conference calls, customers, partners, and vendors. In the evening, at home with his wife and two children, “I pop open my laptop and do a final run-through of the day and tomorrow’s agenda...then, it’s family time!”

Vaughn freely discloses his disorder to co-workers. But in the mid-1980s, Vaughn kept his hemophilia and HIV secret “because we were afraid. We got death threats...I was terrified to tell anyone.” Eventually, he decided to write a book about his experiences, “letting out something that I’d kept in for 20 years.”

Hemophilia didn’t determine Vaughn’s choice of jobs, but “it sort of shaped me.” He speculates, “Maybe that’s why I’m so into computers, because when I was being raised, I wasn’t allowed to do organized sports, to participate.” Perhaps he got

involved with computers, he says, because “I was always afraid of being overly physical.”

Growing up with hemophilia also shaped Vaughn’s character. When he was young, he was very shy. “I was the guy in the corner; I was reading a book or playing chess, or working on my computer.” Now, he laughs, “It’s funny, because I’m actually the opposite: I’m an extrovert.”

As a child, Vaughn’s doctors advised him to avoid most sports except swimming—no cycling, no running, no weightlifting. He admits, “They were kind of right, because if I did run or ride a bike, I’d end up with bleeds in my knees or ankles.” But as an adult, influenced by his “fitness fanatic” friends, Vaughn started working out and weightlifting. Now, he believes that “lifting as an older guy is the single strongest reason I have fewer bleeds!”

Vaughn’s left knee is his target joint. But after he began lifting, and without pushing himself to extremes, he realized he was strengthening the muscles and tendons around his knee joint, and “no longer getting the pains, no longer getting the bleeds.” Now, he says happily, “I can do any of the things that I used to dread—like running and biking—without any problems because my knees are strong.” He also notes that cross-training, plus a full-body workout routine, help build “stabilizer muscles” that strengthen his elbows, shoulders, and hips.

Besides his computer job, Vaughn is also a certified personal trainer. He advises consulting a physician before beginning any workout routine, hemophilia or not. “We should all have that kind of investment in our lives, where we check with somebody—because everybody’s a little bit different.” The flip side: “But don’t be disgruntled because a physician just says ‘No,’” he stresses. “Listen to them, but at the same time, use your own brain, because you know more about your body than anybody.”

Insurance? Absolutely a factor in Vaughn’s job choices. He has several types of insurance, but his PPO is sufficient for his hemophilia. “I’ve been fortunate and always had good health insurance, but because of the HIV even more so than hemophilia.” His monthly medicines average \$2,000, so he has needed to “make sure that there would be good coverage and the right kind of coverage that would work for me.”

Vaughn is active with Hemophilia Foundation of Maryland. As a triathlete and avid cyclist, he rides in the annual Gears for Good Ride and the Chesapeake & Ohio Canal ride sponsored by Hemophilia Federation of America. Still, he says, “I don’t think I do enough. I’m so busy and just barely got back into the community. I have a goal of doing more and being an advocate!”

Vaughn’s advice for young people with bleeding disorders? “I want the younger generation to realize that there is some excitement and happiness in life. You don’t lose hope just because you have hemophilia. There’s so much that we can do and accomplish despite having these ailments.”

And how does Vaughn view his still-meandering employment path? “It’s been an amazing adventure.”

Vaughn’s blog: [healthywealthytribe.com](http://healthywealthytribe.com)

Vaughn’s self-published book: *Survivor: One Man’s Battle with HIV, Hemophilia, and Hepatitis C*





## Mike Ravan

South Carolina  
Nonprofit Executive  
Director  
Age 60  
Hemophilia A, mild

"I remember the first mission trip I went on in 1985," recalls Mike Ravan. "My doctor was so upset, first of all, that I would be in construction." But to top it off, Mike was traveling to Brazil for his church to do things like building orphanages, drilling wells, and organizing construction teams.

Wise move for a man with hemophilia in the mid-1980s?

Mike's hemophilia wasn't diagnosed until he was 13, in the mid-1960s. Before that, if he fell on his bike and got hurt, the medical judgment was, "He bruises easily and is possibly a 'free bleeder.'" And treatment then consisted of whole blood or cryoprecipitate. But Mike's hemophilia didn't slow him down much. "I've been one to work all my life," he remarks. "Worked on the farm as a kid around equipment, and also as a teenager, and then all through college, I worked in manufacturing."

In high school, Mike was placed in a vocational rehabilitation program, with the goal of learning a trade that would be safe, given his health issues. "In our area, textiles were a large part of the industry, and industrial engineering was well thought of and paid well," he explains. So on the advice of the voc rehab program, he went off to college, graduating in 1973 with an industrial engineering degree. "But that's not what I loved to do," he admits. So his path began meandering.

Mike was hired at a manufacturing plant as an industrial engineer, but he ended up working in management. He says simply, "That's because my spiritual gift is administration." So Mike returned to school at night, and got a degree in industrial management in 1977. He worked for several years in automobile battery manufacturing, but when the plant closed down, he was asked to relocate. "At that point," he relates, "we didn't feel we wanted to move. We'd just had a new baby." So Mike took a job managing the parts department in an automobile dealership. "A manager's dream," he laughs, "to have millions of dollars of inventory and just keep up with how it turns, and what you need and what you don't need, and what's selling."

In 1978 Mike had again returned to school, this time to get his builder's license. "I took agriculture in school and learned how to build things, and I just had that desire." He started off small, building one house a year. By 1980 he was building two houses a year, and then worked his way up to as many as seven houses. All the while, he continued managing in the automotive dealership. But his path wasn't done twisting.

In 1985, after Mike returned from that first mission trip, his church organized Carpenters for Christ, now a 501(c)3 nonprofit. Carpenters for Christ works in the US and worldwide to complete construction projects for communities in need.

And now—you guessed it. "I did all *three* jobs," says Mike: "residential home building, managing a multimillion dollar automotive parts industry at new car dealerships, and Carpenters for Christ." In 2007, he stopped doing residential construction and went full-time with Carpenters for Christ. In 2010, he was ordained into the ministry, and he finally quit his automotive job.

The Carpenters are basically mission consultants, Mike explains. "We put together construction teams, medical teams; we feed children, build orphanages, drill wells." The organization recently raised \$60,000 for a well-drilling machine in Guatemala, where, Mike reports, "the children's mortality rate is pretty high, primarily because of contaminated water." This year, Carpenters for Christ took a team of 99 to Guatemala. "Most people would be shaking in their boots to take just three or four people," Mike laughs.

Since that first trip in 1985, Mike has led mission trips all over the world, including to developing nations that lack adequate hemophilia care.

As nondenominational, self-supported missionaries, explains Mike, "We take folks whether they're involved with the church or not, whether it's the humanities side or the religious side. And we take folks from any walk of life, not necessarily construction. They can be mail carriers to nurses to manufacturing workers to farmers." Mike stresses that the organization is more interested in people's "availability" than in



their “ability.” There’s always a way to serve.

In his early days as a missionary, Mike didn’t take much on his trips in the way of hemophilia treatment. When he was in Honduras, he recalls, “We were redoing a government building and converting it into an orphanage. This required some sewer lines to be dug, and we were hand-digging those. I was going alongside, and fell in one of the sewer holes, right down on my fanny.” At the time, Mike had a DDAVP inhaler only (used to treat mild hemophilia only), so he treated with that. Now, Mike carries medical papers that outline his hemophilia treatment needs if he is injured.

Today, Mike serves as chaplain for a local large construction company, which provides him with his health insurance. “But it’s still a high deductible,” he notes.

Mike and his wife of 40 years have two children: a son and daughter, who are both teachers. They also have two grandchildren, and a third due in November. Mike’s 11-year-old grandson has hemophilia, though his other grandson does not. Having hemophilia in the younger generation has prompted Mike to become involved with lobbying for legislation at the local and state level. And he looks forward to traveling someday to lobby in Washington, DC. His special focus, because of his own experiences with county hospitals, is the need for hospitals nationwide to be capable of caring efficiently for patients with bleeding disorders. His vision for the future is to establish action plans: “I think that every county ought to have one hospital that has an action plan in place if someone with hemophilia is involved in a serious accident, rather

than saying ‘We’re not set up to treat him.’”

That’s something Mike is pushing for, especially because of his grandson.

“See, I didn’t care about all this when I was a teenager,”

he admits. “I didn’t care about this when I was 50 years old.

But when I turned 51 and had my first grandchild, and he had hemophilia...when that grandson came along, I had an all-new perspective on hemophilia.”

When the path changes, perspectives change too—and that’s a good thing for the community and the world.

Carpenters for Christ:  
[carpentersforchrist.org](http://carpentersforchrist.org)



## Brian Heffler

Age 35

Lighting Designer; Independent

Energy Consultant

Pennsylvania

Hemophilia A, severe

“I’ve tried, and failed, at many things,” Brian Heffler is the first to admit. “I tried modeling, financial services, a catering business, selling gasoline additives to improve gas mileage, health product-based businesses...” Almost all were

failures, he doesn’t mind saying, but “I believe that you truly can’t appreciate success without failure.”

Brian attended a two-year college and earned an associate’s degree in computer-aided drafting. Then he began working as an electrical designer of power and lighting layouts for commercial businesses. “It used to be a lot of fun,” he recalls. “It paid well, you had lots of time to do jobs, there was always money in the budget, and it was neat to go out and see the jobs where I had helped contribute designs.” But the work atmosphere changed with the changing economy, and now, Brian states simply, “the engineering is just not fun anymore.” As he puts it, “People expect you to design the Taj Mahal for two thousand dollars in two weeks, with no mistakes. It’s unrealistic.”

So, disillusioned with his design work, Brian started his own part-time energy consulting business in May 2011, partnering with a Texas company. “I’ve always been kind of ambitious,” he explains. “Never enjoyed being an employee. I realized that the key to wealth was owning your own business.” Now, working from home in the evenings, Brian “helps people save money on their natural gas and electric bills,” and enjoys training and mentoring them to achieve their goals.

But at the same time, he’s also still employed as an electrical designer. So for Brian, his energy consulting work is his second job. Two jobs, a family of five, and hemophilia. How does that work? “I do my regular job until 3:30 or 4:00,” Brian explains, “and then in the evening I make some phone calls and some new contacts through networking.” Two nights a week, Brian also conducts business presentations. And after our interview, he was heading to Texas on business.

How does Brian’s busy schedule mesh with his hemophilia? “To say that it’s not in the back of my head that I’m going to have some leg pain and foot pain would just be dishonest,” he says about his active life, which includes lots and lots of walking. “It’s always in the back of your mind, but one thing I’ve never done is let that deter me. You shouldn’t let the fact that you have hemophilia deter you from doing *anything*.”

Brian has always been a maverick. “There’s a running joke up at my hemophilia center,” he laughs. “The hematologist in charge says, ‘I never apply any of the rules about hemophilia to you because you just seem to break them all.’”



Exercise is a big part of Brian's life. He goes to the gym three or four times a week, and has taught indoor cycle and spin classes twice a week. "I'm definitely not easy on my body," he admits. "And I think there's an advantage there, because I've always been a firm believer in exercise." In fact, he says, "I've had less problems when I stay active versus when I don't."

As a young man, Brian was advised not to do a physical job, or one that would keep him on his feet all day. "Did I heed that advice initially?" he asks. "Absolutely not. Have I now? Yes." Today, Brian has limited range of motion in his right knee, so standing or walking for extended periods isn't comfortable. Still, he says, "There are so many things for people like us to do out there. Our health conditions cannot limit us."

Brian receives his health insurance through his wife's employer. This made the most sense for the family. "My insurance at my job isn't the greatest," he explains, and "I'm always looking at health insurance policies because I have to be a little more aware than the average person."

Currently, Brian is involved in his third long-term study of a new factor product. "I get my factor for free, and they get to follow me and read my data." He vigilantly logs all his bleeds, his treatments, and his responses, which is time-consuming. But, he notes, given "the long-term benefits for when a product finally hits the market—that's a minor inconvenience."

Future plans? Brian looks forward to participating more with the hemophilia community, through his south central Pennsylvania chapter. On the home front, he wants to "continue to have strong relations with my children, and just continue to do good things."

And Brian has also committed himself to one huge goal: he plans to retire from his electrical design job to devote himself to full-time energy consulting. He's even picked the date: June 20, 2014. Let's check back with him then!

Brian's webpage: [www.hefflerenergy.energy526.com](http://www.hefflerenergy.energy526.com)



## Jim Casey

Age 65

Pilot

Alaska

Hemophilia A, severe

No excuses for Jim Casey. "Once you use one, you'll never quit using them."

Jim was born in Alaska, and diagnosed with hemophilia as a baby. When he was 14, Jim knew he wanted to become a pilot like his father. Did hemo-

philia affect his decision? "No, I never gave it a second thought."

But for Jim to become a student pilot, he needed to pass a medical exam. The examining doctor knew about Jim's hemophilia and warned him, "You probably want to spend your life flying airplanes, but don't count on it because you're not going to live to be a commercial pilot." Even so, the doctor passed him. "That was my very first flight medical," recalls Jim, "and it went through! I don't know that he kind of glossed over certain aspects of it. I have no idea—all I know is he passed it." In the mid-1960s, having hemophilia might have disqualified Jim as a pilot.

So Jim flew in Alaska until he graduated from high school in 1965. He needed 200 flight hours before he could return to the Midwest, to the same flight school his father had attended, and obtain his commercial license. But first, he needed to pass *another* medical exam. "I'll never forget the doctor," Jim laughs. "He started asking all the right questions. Then he said, 'Now, you listen to me. I'm going to give you one medical [approval], but don't you ever come back here again. I said, 'Don't worry, sir, I'm going home to Alaska.'" And Jim passed his exam. "How they did it, I don't know—probably by not saying too much."

Not saying too much was the rule for Jim in the 1960s. No one, except his family and a few doctors, knew about his hemophilia then. But his family was supportive. "I was encouraged, 'If that's what you want to do, we'll give you all the help you want.'" Jim couldn't let anyone know about his hemophilia because he wouldn't have been allowed to fly. "So I didn't say anything. I just went ahead and did what I wanted to do."

Jim didn't accept anyone's limits, though at the time, he had few limits—and few treatments. "I didn't get cryo until I was almost 30," he recalls. "Until then, you just bled." For him, the toughest were the intensely painful kidney bleeds, but he manages to put a positive spin even on those. "The only good thing about those bleeds is that I never had one really, really bad when I was flying."

Jim also had joint bleeds. "I must have gone through 10,000 Ace bandages," he recalls. "I'd wrap it so tight that my toes would turn blue, and I'd go to school." But, he says, "Not once did I get a pair of crutches. I would not give anybody the chance to knock those crutches out from underneath me. I've never used them to this day."



# Tips from the Guys



- Do what you're passionate about.
- Everyone's path is different.
- Don't be afraid to make a change and pursue your dreams.
- Nurture your interests—they can help you when times are tough.
- Listen to doctors, and listen to your own body.
- Don't let hemophilia (or anything else) hold you back.
- Don't "bounce" jobs—show a prospective employer that you can follow through.
- Exercise and keep fit to protect your joints.

When his sister's sons were diagnosed with hemophilia, the memory of Jim's experiences helped her cope. "She says it served her pretty well watching me grow up—because I had *nothing*." Living as he did, with little treatment, Jim learned that life is "*exactly* the way you make it." But he emphasizes, "I didn't do anything extraordinary; I just did what I wanted... There's no secret to it—if you want to go ride your motorcycle, you go ride your motorcycle. If you want to go deer hunting, you go deer hunting. If you want to learn how to fly, you learn how to fly."

Jim credits his active life for keeping him healthy and flying. "I've had several doctors tell me that I stayed in good shape because it's a physical job. It wasn't that I was going to the gym and working out three times a week—all I did was get up in the morning and go fly an airplane and lift a lot of freight."

Jim has never focused much on his hemophilia. In fact, he really doesn't want to discuss it. "That's the last thing I want to talk about," he laughs. Instead, "Let's play football. Let's go flying. Let's go fishing."

Jim says his hemophilia doesn't affect his job as a pilot; he flies seven days a week. He began flying for his father in 1966, and then for another outfit beginning in 1973. Now he runs his own flying business. He spent much of his life without insurance, but in 1993, he joined a state program for uninsured Alaskans. Now he's on Medicare.

A typical work day? Pretty simple. "People call us up and tell us where they want to go and when they want to go, and we take them—usually with a ton of crap," Jim laughs. "And you can quote me."

Jim's business has a website, but "around the state of Alaska, the little airplane doesn't have to sell itself," he asserts. "Just unlock the door in the morning and put on the coffee pot, and *here they come*." In a state with few roads, that's the way to get around. "People still have to travel, so small airplanes and little boats do all the traveling."

Clients who book flights with Jim include business people, tourists, and those who have lodges or live in the bush, or want to hunt or fish. "Just like the rest of Alaska, just like Canada,"



# headlines

## PHARMA

### The Human Factor

Octapharma, a Swiss pharmaceutical company, has submitted a marketing authorization application (MAA) to the European Medicines Agency (EMA) for its human cell line-based recombinant factor VIII product, Human-cl rhFVIII. The Octapharma product is the first to use a human embryonic kidney cell line. **Why this matters:** This product was developed with the belief that a human cell line may do a better job building the protein than hamster cell lines currently used for recombinant factor production, potentially reducing the risk of inhibitor development in hemophilia A patients.

Source: *IBPN* July 2013

## Long Time

A phase I/II clinical trial (called Prolong-9FP) of CSL Behring's investigational factor IX product has documented the clinical efficacy of a once-weekly dosing regimen in hemophilia B patients. The new product, rIX-FP, extends the half-life of factor IX by fusing it with human albumin, which has a naturally long half-life. The new recombinant fusion has a half-life of 94 hours, as compared to factor IX's typical 18-hour half-life. **Why this matters:** Albumin has been shown to be an ideal genetic fusion partner for recombinant factor because of its inherently long half-life and good tolerability profile. This product would allow once-weekly dosing for prophylaxis, as opposed to the current two to three times a week.

Source: *IBPN* July 2013

### New Online Game for the Hemophilia Community

Allies Quest, created by Baxter, is an exciting and fun way for the hemophilia community to interact online and build stronger community relationships. Players can sign up and play on behalf of their local chapters. Players band together as Allies to complete in-game and real-world challenges to reach a common goal: restoring the Allies' Shield. The Shield, which is the Allies' source of power, has been stolen and must be

recovered to restore peace. The game also has an educational component about annual bleed rate (ABR). A winning chapter and individual player will be named based on rankings at the conclusion of the game. **Why this matters:** Online games are a great way to engage young people with hemophilia, who often drift away from the bleeding disorder community.

For info: [www.AlliesQuest.com](http://www.AlliesQuest.com)



## WORLD

### Road to Independence

The Somar Group, one of Mexico's largest pharmaceutical firms, has recently invested \$51.2 million to create GenBio, a state-of-the-art plasma fractionation plant. This plant will produce a range of plasma therapeutics, including albumin and coagulation factors VIII and IX, all treated by solvent detergent and nanofiltration. **Why this matters:** Though this plant will produce only a small amount of factor concentrate, the plant will increase Mexico's ability to treat its people with hemophilia.

Source: *IBPN*

### China and India Tops in Donating Blood

Ten countries account for 65% of global blood collections. In descending order of amount collected, they are the US, China, India, Japan, Germany, Russia, Italy, France, South Korea, and the UK.

Because of their large populations, China and India also have the highest numbers of people with hemophilia in the world. **Why this matters:** Blood collection is vitally important in developing countries, which sometimes rely on plasma and cryoprecipitate to treat bleeding disorders.

For info: [www.who.int/bloodsafety](http://www.who.int/bloodsafety)



### Numbers Matter

The recently developed National Hemophilia Registry of China now includes 10,652 patients: 9,055 (85%) with hemophilia A; 1,298 (12.2%) with hemophilia B; 54 (0.5%) with von Willebrand disease; and 245 with rare bleeding disorders. Although these numbers are triple what they were several years ago, the latest registry tally of people with bleeding disorders is only a fraction of the estimated 100,000 people with hemophilia in China.

**Why this matters:** National registries are fundamental tools to gain government support for buying clotting factors.

Source: *IBPN*



## Pulse *on the Road* Visited 5 States in 2013

Pulse on the Road (POTR) is a comprehensive, hands-on insurance symposium and workshop that has traveled the US for the past four years to educate the bleeding disorder community about changes in health insurance coverage and the Affordable Care Act (ACA). POTR's last stop for 2013 was Oregon, in September, where much of the focus was on ACA's Health Insurance Marketplace, a web-based program that allows consumers to compare different insurance plans. POTR is funded by Baxter Healthcare Corporation and run in cooperation with NHF. **Why this matters:** Bleeding disorder patients need to know how their individual state will manage the Health Insurance Marketplace.

For info: Zoraida Rosado, LA Kelley Communications, 978-352-7657



### *Inhibitor Insights... from p. 4*


ble, he might be able to make up hours outside his regular shift. It's a difficult decision. He may risk discrimination if he reveals his disorder too early. He may face resentment if he reveals it too late, after many job absences.

Prophylaxis has a tremendously positive influence on securing and keeping jobs. If your child must stop prophylaxis because of inadequate or limited insurance coverage, he may still be in excellent condition for work because his joints will be preserved. If he can continue prophylaxis, then his range of job opportunities widens because his bleeds are prevented.

The bleeding disorder community itself may be an excellent place to seek employment. Nonprofit organizations, home care companies, even pharmaceutical companies are all looking to recruit people with bleeding disorders into their ranks. Why? You can be skeptical, and assume that the revenue your child generates from his factor usage will provide income to the home care company that hires him (if he uses that company as his factor provider). Or you can think positively: a young employee who lives with the disorder has tremendous experience to share, and may connect well with other families and patients. Employing a person with a bleeding disorder could result in healthcare coverage plus a great job, without a college degree.

Penn State professor Kenneth Gray, quoting US Bureau of Labor Statistics, predicts that as few as 12% of all jobs will require a college degree in the future. Most of the work world will require a high school diploma and perhaps an additional year or two of training.

More important than answering the question *What will I major in?* may be to answer these questions: Can you list your strengths, talents, aptitudes, and abilities? Can you name a few jobs that you are drawn to, and can realistically aspire to, given your hemophilia and inhibitor? Can you describe where you want to go and what you want to do in life?

And finally, ask yourself this: Do you really need college to get where you want to go? 



## Having issues with co-pays or gaps in coverage for your **hemophilia A** treatment ???

### **We may be able to help.**

Bayer offers a range of programs that can help you **navigate insurance questions about your hemophilia A treatment**. If you're having issues with co-pays or gaps in coverage, we may be able to offer assistance. Speak with one of our case specialists to find out more.

Call 1-800-288-8374 and press 1 to speak to a trained **insurance specialist!**

Bayer and the Bayer Cross are registered trademarks of Bayer.  
© 2013 Bayer HealthCare Pharmaceuticals Inc. All rights reserved. 04/13 KNI0000213C



he believes, “the little airplane will be forever.”

Regrets? One—maybe. In 1966, Jim returned home to Alaska from flight school as a newly licensed commercial pilot. A letter was waiting for him from Alaska Airlines. “They wanted to hire me as a flight engineer on a C-130, to fly the slope,” he recalls, explaining that the oil boom on Alaska’s North Slope was just starting. So he discussed the job with his father, who agreed that this was a great offer, but advised Jim to stop and think about whether it was the best choice. “If you want to fly,” Jim’s father told him, “there’s lots of ways to fly. You don’t *have* to do it that way.” If he’d taken that job, Jim says, “Right now, I would [already] be retired six years, and I would have made—oh, the money!”

But looking back, Jim believes his father was right. He describes the likely scenario of flying a jet in 1966: “Well, you’re cruising along in your C-130, and all of a sudden you get a nosebleed, and you’re on a

seven-hour trip”—with other crew members. “You can’t hide that.” If the company had discovered Jim’s hemophilia, “they would have bounced me right out of there.”

Jim sums up his own complex journey with hemophilia: “What I did was follow my passion. I wanted to fly, and so that’s what I did.” He advises young men, “There’s got to be something out there you *can* do...Find what you want to do, and pursue it. And if there are stumbling blocks in front of you, or someone tells you that you *can’t*, then find out how you can work around that.”

Work around obstacles in a twisting path. Do what you love. Stay active. Get stronger. Never give up. Sounds like good advice. ☺

*Sara P. Evangelos is a writer and editor who has worked with LA Kelley Communications for more than 15 years. She is co-founder of JAS Group Writing and Editorial Services, at [www.jasgrouponline.com](http://www.jasgrouponline.com).*

**CORRECTION:** In the feature article “New Factor Concentrates: The Future is Now!” (PEN, Aug. 2013) we incorrectly listed Pfizer’s BeneFIX as a second-generation recombinant FIX product, but it is a third-generation product, making Baxter’s new rFIX product, Rixubis, the second third-generation rFIX product to hit the market. Pfizer/Catalyst Biosciences’ new rFVIIa product uses a hamster cell line, not a human cell line. Finally, Baxter’s Recombinate is a first-generation recombinant product, not a plasma-derived product, as listed in Table 1. These errors have been corrected in the PDF version of PEN, available online at [www.kelleycom.com](http://www.kelleycom.com).

## Parenting Moment

We may not be able to prepare  
the future for our children,  
but we can at least prepare  
our children for the future.

— Franklin D. Roosevelt

With the changing economy, no  
one has lifetime employment.  
But community colleges  
provide lifetime employability.

— Barack Obama

## OUR DEEPEST THANKS TO PEN’S CORPORATE SPONSORS

### Baxter

800-423-2862

[www.thereforyou.com](http://www.thereforyou.com)

Baxter is a registered trademark  
of Baxter International Inc

### CSL Behring

888-508-6978

[www.cslbehring.com](http://www.cslbehring.com)

  
novo nordisk®

800-727-6500

[www.novonordisk-us.com/  
biopharm](http://www.novonordisk-us.com/biopharm)

  
Pfizer

888-999-2349

[www.hemophiliavillage.com](http://www.hemophiliavillage.com)



37-39 West Main Street, #8  
Georgetown, MA 01833 USA  
[www.kelleycom.com](http://www.kelleycom.com)

*Visit Your HTC Annually!*

biogen idec  
HEMOPHILIA

The real value  
of listening is  
proof that you've  
been **heard.**

Discover [BiogenIdecHemophilia.com](http://BiogenIdecHemophilia.com)

 [facebook.com/BiogenIdecHemophiliaCoRes](https://facebook.com/BiogenIdecHemophiliaCoRes)

© 2013 Biogen Idec. All rights reserved. Printed in U.S.A. 10/13  
HEM-1001424