

PEN



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CT Scans for Head Bumps: Always the Best Choice?

Paul Clement



New x-ray backscatter scanners were introduced to airports last year, sparking a debate about the dangers of radiation from these machines. Americans were indignant about privacy, and worried about health and safety. As a parent of a child with hemophilia, you may face the same health worry each time your child has a head bump: will your doctor order a CT scan? Computer axial tomography (CT or CAT scans) can emit 10,000 to over 200,000 times the radiation of an airport scanner. Should you be concerned about your child's exposure?

Of all the developmental milestones in your child's life, perhaps none is quite as exciting as your baby's first steps. Yet, for parents of children with hemophilia, this excitement is often tempered with apprehension: baby's first steps bring many falls—and often, a bump to the head.

Head bumps can cause head bleeds. Head bleeds may have no outward signs, may progress rapidly, and can cause

long-term neurological damage or even death. To compound the problem, babies can't describe their symptoms in words. When you bring your baby to the emergency room for a head bump, most ER physicians will order a CT scan of his head, regardless of the severity of the fall, absence of signs of a head bleed, and whether he is on prophylaxis. This sounds like the medically responsible thing to do.

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welcome



Laurie Kelley

When 10-month-old Tommy was learning to walk, I remember how terrified I felt that he would fall and hit his head. In the days before prophylaxis was common, all parents of children with hemophilia feared head bleeds especially. Our nurse, Jocelyn Bessette, of Children's Hospital Boston, told us to always

bring Tommy to the ER when he hit his head, even if he had no symptoms. We didn't know how to home infuse, and our life was tethered to the hospital. At 18 months, the inevitable happened: he hit his head hard when I dropped him on the daycare driveway, after slipping on some mulch while wearing three-inch heels (it was the 1980s, after all).

I spent all morning at the ER, and the medical team couldn't decide whether to x-ray Tommy or get a CT scan. I waited and waited patiently as I watched several doctors huddled while discussing this. Meanwhile, Tommy, in a diaper, was scampering up and down the halls, laughing.

I was confused: why didn't they just order the CT scan and get it over with? Tommy seemed fine. Eventually, I made the decision to go home without the scan. After signing a mountain of liability releases, I took Tommy home and vigilantly watched him day and night for symptoms of a head bleed, staying in close contact with the hospital. Nothing. He was fine!

I have a better appreciation now of what our doctors were

anguishing over. Did the head bump warrant exposing this baby to radiation? I had no such worries or concerns. I was blissfully ignorant.

Parents, you don't have to be as ignorant as I was. In our feature article, Paul Clement, parent of a child with hemophilia, explains the risks of radiation when our children are exposed to CT scans. What should you know before you agree to a scan? How might it affect your child? Read carefully, and you'll be well equipped to speak to any doctor, in the ER or HTC examining room, about the wisest steps following a head bump. This article will be one of the best tools in your child's health advocacy toolbox. And please don't wear stilettos while carrying your child with hemophilia! ☺



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EDITOR-IN-CHIEF Laureen A. Kelley | SCIENCE EDITOR Paul Clement
CONTRIBUTING WRITERS | Richard J. Atwood • Kevin Correa
MANAGING EDITOR Sara P. Evangelos | LAYOUT DESIGNER Tracy Brody
DIRECTOR, PROJECT SHARESM Kathryn Ondek
MANAGER, PROJECTS & PRODUCTION Zoraida Rosado

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65 Central Street
Georgetown MA 01833 USA
978-352-7657 • fax: 978-352-6254
info@kelleycom.com • www.kelleycom.com

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inbox

CONGRATULATIONS ON 20 YEARS OF OPEN, HONEST communication and on the *Communiqué*: informing, educating, and empowering individuals in the hemophilia and the bleeding disorder community. You have been a "voice" of the people and for the people. You have instilled a sense of dignity and self-worth to a minority of individuals who often felt discounted. You have brought us to our feet, standing tall on our own, advocating for us and others. In the darkest of days, you have been our inspiration for action. Ralph Waldo Emerson said, "When it is dark enough, you can see the stars." Thank you for having the vision to "walk through the storm" and champion so many causes on our behalf. We joyfully celebrate your 20 years of service!

John Jarratt, MEd, LPC

Program and Education Specialist, Accredo's Hemophilia Health Services Tennessee

YOUR BOOK *RAISING A CHILD WITH HEMOPHILIA HELPED US* out so much when our son was first diagnosed with hemophilia. I don't know what we would have done without it!

Kelcee Anderson Christensen
Idaho

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Chris Healey

When Is Clotting Factor Safe Enough?

The definition of clotting factor safety continues to evolve. In the 1980s and 1990s, safety meant free of HIV, hepatitis, and most other viruses. In the late 1990s, it meant making sure there was adequate supply during times of recombinant product shortages. More recently, at a November 2003 inhibitor workshop, Jay Epstein, MD, director of the Office of Blood Research and Review at the US Food and Drug Administration (FDA), said this:

“Today, with HIV and other viral contaminants under control, inhibitor formation presents itself as the chief adverse event associated with the use of antihemophilic factor.”

Of course, the fact that HIV and other viral contaminants may be “under control” doesn’t mean that manufacturers, healthcare providers, or consumers can ignore previous safety concerns. To the contrary, as the focus of safety continues to evolve, we must broaden our view and still maintain vigilance across all aspects of safety. This is no small feat.

The safety of clotting factor is a shared responsibility. You may ask, “How can that be? Consumers don’t make the products.” That’s true, but consumers, through their advocacy efforts, play a huge role in clotting factor safety.

Many of the safeguards in place today for plasma-derived clotting factor are part of the International Quality Plasma Program (IQPP). This set of

industry standards is in addition to FDA requirements, and creates extra layers of product safety. Here are some of the IQPP standards that apply to source plasma:¹

- Only plasma from repeat or “qualified” donors is accepted; plasma from a one-time donor is never used.
- Every plasma donation must be held in inventory for a minimum of 60 days: if blood tests disqualify the donor, prior donations can be recovered and destroyed.
- Every donation must be tested using special DNA techniques called nucleic acid testing (NAT) for HIV, HBV, and HCV.
- Every donor center must maintain strict criteria concerning the health and safety of the types of people they attract as donors.

Although many of these IQPP standards have been in place since the mid-1990s, they too continue to evolve and improve. And consumer advocates have been at the forefront of many of the discussions involving such improvements.

More recent concerns have been the identification of viruses such as H1N1 (a subtype of influenza A) and XMRV.² When manufacturers learn of these possible threats, they immediately challenge and check their manufacturing processes and viral inactivation methods to assure product safety. This safety work is often done in collaboration

with other companies and regulatory authorities such as FDA, to provide a common level of understanding and knowledge. One critical element of this work is outreach to the consumer community—even as the work is progressing, and before all the answers are known.

For consumers, the first step to maintaining product safety is to *understand* it. Direct communication with manufacturers and regulators about safety concerns is an essential part of consumers’ understanding. That’s why many companies invite community members to tour their donor centers and manufacturing facilities to learn about current safeguards and standards. Grifols is one such company that offers educational tours. Participants in Grifols’ educational tours walk away with a firsthand look at all the safety measures in place—from donor to consumer.

When is clotting factor safe enough? I don’t think there will ever be an answer to that question. But one thing is for sure: the more educated consumers become and the more questions they ask, the safer their products will be. ☺

Chris Healey is vice president of public affairs at Grifols, Inc. Contact him at chris.healey@grifols.com. Learn more by watching a brief plasma safety video at www.grifolsusa.com.

1. Source plasma is plasma donated through plasmapheresis solely for the manufacture of blood products such as factor concentrate. Recovered plasma is the liquid portion of a blood donation that is separated from the blood and used for the production of blood products. Recovered plasma is not subject to IQPP standards. 2. Xenotropic murine leukemia virus-related virus (XMRV) may not be an infectious virus but the result of contamination of clinical specimens or laboratory reagents with mouse retroviruses or related nucleic acids.

Healthcare Reform and Inhibitors

Treating an acute bleed in a child with inhibitors usually involves infusions with a bypassing agent such as FEIBA VH or NovoSeven RT. And immune tolerance therapy to eliminate the inhibitor may require thousands of IU of factor per day or week for a year or more. These treatments can get prohibitively expensive. Families with inhibitors have always worried about exceeding their insurance lifetime maximums (caps) or being prevented from purchasing an insurance policy because of the high cost of their treatment.

That's why healthcare reform, enacted in March 2010 as the Patient Protection and Affordable Care Act (PPACA), was a landmark piece of legislation for the bleeding disorder community. Now called ACA, the act eliminates lifetime caps and prohibits discrimination against preexisting conditions. An insurance company can't cut you off because you've exhausted your insurance money, and can't reject you from insurance because you have hemophilia. Great news, especially for people with inhibitors.

Kerry Fatula's family benefitted immediately from ACA. Kerry is executive director of the Western Pennsylvania Chapter of National Hemophilia Foundation (NHF) and mother of four sons—three with hemophilia and inhibitors. Two of her sons had capped or aged out of their insurance before ACA. "Paul went almost a year with no coverage," notes Kerry. "He was on Medicaid until age 18, then aged out. Medicaid still covered him while we appealed. Nathan also was not covered for a short time. But he relied on the factor we had in stock, and also used manufacturer programs to get more bypassing product." With the passage of ACA, the two Fatula boys returned to the family's policy.

Now that expensive patients like Paul and Nathan can't be rejected or terminated as customers, will this affect what they pay for insurance? Out-of-pocket costs are a major concern for the bleeding disorder community: many worry that insurance companies—now unable to reject high-cost patients by using lifetime caps or refusing them a policy—will raise premiums. This would encourage

employers to shift more costs to consumers. How? Perhaps by offering policies with higher out-of-pocket costs.

What Are Out-of-Pocket Costs?

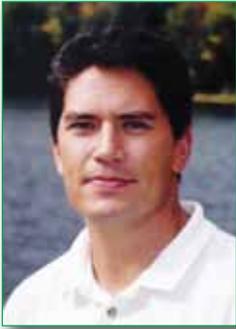
Out-of-pocket costs are the portion of your medical bills that you must pay. Here are some examples of costs that you may incur.

- **Deductible:** The annual amount of money you must pay first, before your insurance policy's coverage begins.
- **Coinsurance:** The amount (usually a percentage of costs) you must pay before your insurance policy will cover the rest of the cost of a medical service or prescription.
- **Copayment:** The dollar amount you must pay for a medical service or prescription.
- **Out-of-pocket maximum:** The annual maximum amount that you pay directly for health-care services and drugs under your medical benefit, including copays, coinsurance, and deductibles. After you reach this maximum, your insurance company will pay 100% of the costs.
- **Annual policy insurance premium:** The actual cost of the insurance policy, usually paid monthly, quarterly, or annually.

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Kevin Correa



Achieving a Healthy Balance in Your 30s and 40s



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As they reach their 30th birthdays, hemophilic men are well aware of the important role of diet and exercise in managing their hemophilia. Yet many men—even after maintaining a healthy lifestyle for years—struggle with fitness at this stage.

The transition into the 30s is often marked by increased personal and professional demands. Long hours at work and business trips, kids' soccer practice and dance recitals can all make it difficult to find the time and motivation to exercise and eat right—difficult, but not impossible.

Escape from Alcatraz

Matt Radvansky, 38, has severe hemophilia. While in college, Matt was a competitive cyclist. After graduating, he expanded his athletic pursuits and began competing in triathlons, including the Escape from Alcatraz Triathlon. As you may have guessed, this race includes a grueling 1.5-mile swim from the island prison to shore. Achieving that level of fitness takes lots of time and a firm commitment.

In spite of Matt's obvious drive, he was not immune to the pressures of life. He married in his late 20s and now has two children. Along with family demands, he's faced growing responsibilities in his career. Not surprisingly, over the years Matt has found it increasingly difficult to budget the time to work out.

"The biggest obstacle to exercising is finding the right balance between work and life," Matt says, as his mounting obligations "killed the routine."

With so much of life in the 30s and

40s dictated by what you need to do for others, it's easy to let your own needs take a back seat. Now that he doesn't have time for the strenuous training needed for triathlons, Matt exercises when he can.

"I'll walk the dog in the morning, and if I have the time, I'll try to run at lunch on a workday." Matt adds, "You can always come up with a reason not to work out." The key to avoiding the excuses and maintaining a routine, he believes, is to schedule time to exercise.

It's Your Choice: Cary Grant or Wilford Brimley?

Dwayne Whitis, 43, has severe hemophilia, and he echoes Matt's sentiment. "It's 2011, everyone's busy. But that doesn't mean you can neglect self-care."

Unlike Matt, Dwayne hasn't been a model of fitness since his teens. He admits to living a generally unhealthy lifestyle in his early 20s. He smoked, ate and drank too much, and exercise wasn't atop his list of priorities.

But his story illustrates that it's never too late to start taking care of your body. Today, Dwayne is in the best shape of his life, thanks largely to a multidisciplinary exercise regimen called Crossfit. Dwayne didn't simply jump into this intense fitness program; he began exercising literally one step at a time—by walking.

That first step toward fitness is often the hardest, especially for people whose hemophilia has limited their mobility. As Dwayne says, "It takes a genuine decision and concerted effort."

Dwayne approaches his health guided by the philosophy that life is pre-

cious and limited, and that we all have the ability to choose how our lives will play out. He looks down the road and asks himself, *What's my quality of life going to be in the years ahead?*

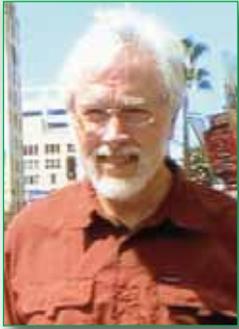
With a touch of humor, Dwayne explains that one of his motivations to stay fit comes from the silver screen. "What do Cary Grant in *To Catch a Thief* and Wilford Brimley in *Cocoon* have in common?" he asks. "They were both 51 when they starred in those movies. Personally, at 51, I'd rather be like Cary Grant, running around the French Riviera with Grace Kelly, than Wilford Brimley, hanging out in a retirement home with Don Ameche."

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Dwayne Whitis built his fitness program beginning with daily walks.



Richard J. Atwood



Looking Back on X-Rays and Hemophilic Arthropathy

Doctors and patients have always been curious about the painful, swollen joints associated with hemophilia. Their cause and cure were subjects of medical speculation before an effective treatment for hemophilia became available. Doctors of the 19th and early 20th centuries heeded the advice never to operate on a hemophilic joint because fatal consequences were documented, even for aspiration of a joint. So any examination was external—and limited—because manipulation of the swollen joint was also known to cause more internal bleeding.

Pathologists of the 19th century were limited to examining the swollen joints of people with hemophilia at autopsy. Some of the best examples of joints were even kept in hospital museum collections.

Yet physicians wanted to know what happened inside a joint during an active bleed; they debated what caused the swelling because the symptoms resembled the consequences of rheumatism and gout. As early as 1832, Dr. James Hughes noted that the obstinate hemorrhage in a patient with hemophilia was associated with rheumatism in the joint. The notion that *blood* caused joint swelling was proposed by French physician E. Dubois in 1838, but he had no proof, so the debate continued for the rest of the century, despite growing evidence that blood was the cause.

The technology for x-ray (*roentgen ray*) examination was developed by Wilhelm Konrad von Röntgen, a German physicist, and introduced in 1895. In 1897, English physician J. E. Shaw was first to use x-rays to investigate swollen joints in a patient with hemophilia. The 30-year-old patient had experienced many bleeds in his larger joints since childhood. X-rays of his knee and elbow showed changes

similar to those in rheumatoid arthritis: reduced cartilage size, and obvious changes in bone shape—some flattened, and others with enlarged ends and lipped edges. We now know these as the eroding effects of having blood in the joints, a condition known as *hemophilic arthropathy*.

Today, the use of diagnostic x-rays continues to provide medical evidence of changes in the joint tissue due to bleeds, even documenting the benefits of prophylaxis.

When x-rays were first used, the dangers of irradiation were unknown, and few precautions were taken. The new technology was quickly accepted and applied in a wide variety of experiments. Shortly after 1900, some researchers experimenting with x-rays found that small—but not large—doses of irradiation stimulated the production of blood cells. Now, x-ray technology could also be used for treatment.

In 1916, two California physicians irradiated the long bones (whose marrow produces red blood cells, platelets, and most white blood cells) of five patients with hemophilia, and found that x-rays did not speed blood clotting. In 1935, physicians in Massachusetts found that x-ray exposure of the pituitary gland in a patient with hemophilia had harmful effects and did not improve blood clotting. But in 1946, Maryland physicians Marcus Ostro and David Macht reported on the therapeutic use of x-rays over the spleen areas of two patients with hemophilia: the patients' clotting times were reduced, but they suffered from radiation sickness. From the 1940s through

1990s, x-ray irradiation was a popular treatment for pseudotumors, a complication of hemophilia, but with variable success. There are fewer pseudotumors in developed countries today because effective treatments, such as clotting factor concentrates, usually prevent their formation.

The diagnostic benefits of x-ray technology for hemophilic arthropathy were obvious from the start, though it took a while to comprehend some of the dangerous side effects of exposure. In the search for new treatments, patients with hemophilia were involved in a variety of experimental clinical studies of therapeutic x-rays.

Increasingly, x-ray technology has played a vital role in the history of hemophilia medical care, beginning with a courageous 30-year-old man with hemophilia and swollen joints who, in 1897, was willing to be the first to undergo an x-ray examination. ☺

For more information on the history of x-rays and hemophilia, or for a list of references used in this article, please contact Richard at info@kelleycom.com or visit www.kelleycom.com/newsletters.html



www.old-picture.com/american-legacy/001/Machine-Xray-Old.htm

a project share story

Kathryn Ondek



**PROJECT
SHARE**

It's time to give back

Nothing's Impossible at Hemophilia Camp

Rajkot Hemophilia Chapter in India held a National Youth Group Camp, "Bye Bye 2010," December 23–27, with 46 hemophilia patients and 24 volunteers from several areas of India. Project SHARE donated factor for all the patients.

Camp started with a traditional lighting of an oil lamp by Mr. Balvantbhai Desai, executive secretary of Ashok Gondhia Memorial Trust. Mr. Taksh Mishra held meditation with music, allowing campers to enjoy peace of mind and relax. Then Dr. Asha Satasiya gave guidance on yoga and physiotherapy by demonstrating different types of exercises; these sessions were held every day during camp. And Mr. Kiran Avasia, secretary of the Rajkot Hemophilia Chapter, screened the motivational film "Nothing Impossible with Hemophilia."

The campers took a quiz to test and improve their understanding and awareness of hemophilia. Then came the laughter and fun, as campers played games such as balloon-blowing, cricket, chess, and charades. At night, everyone gathered by the campfire to talk and sing songs.

On December 24, several doctors

spoke about self-infusion, an essential aspect of camp. With the help of Usha Parthasarathy, liaison to Project SHARE, the campers were supplied with donated factor VIII and factor IX for any current bleeds. Later that night, an exciting Christmas celebration featured singing, dancing, and cake-cutting, helping campers forget about the pain and suffering they feel most days.

The next morning, campers took a picnic trip to historic Somnath Temple. They also visited the Asiatic lion sanctuary Gir-Sasan, and viewed lions, deer, leopards, blackbucks, and monkeys.

On December 26, popular writer and columnist Mr. Jay Vasavada, of Gujarat, India, gave a motivational speech on the topic "When the going gets tough, the tough get going."

On December 27, camp ended with awards and gifts to all campers. As they said goodbye to 2010, these wonderful young men with hemophilia shared special time relaxing, having fun, and learning about their disorders. Project SHARE was proud to support such an enriching camp experience for so many young adults with hemophilia. ☺

**"Since our childhood, Mr. Kiran Avasia
has guided us to be independent."**

—Pradip Thoriya

Project SHARE

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Campers attend a physiotherapy demonstration.



An early morning physiotherapy session begins the day.



Camp Bye Bye 2010



Older peers with hemophilia train and mentor younger campers: Kiran Avasia (left) supervises Pradip Thoriya (right) as he explains self-infusion to Anil Dabhi (center).

But CT scans carry risks, and medical staff rarely explain these risks to parents. In fact, physicians often are unaware of the risks of repeated CT scans. Or, believing the risks to be miniscule, doctors may think they aren't worth mentioning, especially in an emergency.

Is a CT scan always necessary every time your child with hemophilia bumps his head? Should you agree to one? What are the real risks?

What Exactly Is a Head Bleed?

The term *head bleed* can mean more than one thing. Not all bleeds are the same. Some are more serious than others, and some are more easily treated.

Head bleeds are classified into two broad groups:

- *Extracranial hemorrhage (ECH)*: a bleed outside the skull (cranium).
- *Intracranial hemorrhage (ICH)*: a bleed inside the skull, which houses the brain. To physicians, the term head bleed usually refers to an ICH.

An EHC in babies with hemophilia is relatively rare—except in childbirth, where more than 90% are caused by the use of vacuum extraction or forceps. The vacuum device actually pulls the scalp away from the skull slightly during delivery. This can be life threatening because more than half of the baby's blood volume can bleed into the space between the scalp and the skull. Obstetricians know not to use instruments when delivering a child suspected of having hemophilia.

In children with hemophilia, ICH is usually caused by trauma—when a baby bumps his head on the coffee table while learning to walk, or a child falls off his bike or playground equipment. An ICH can also occur spontaneously, for no known reason. There are several kinds of ICH, named for the location where the blood tends to pool, usually between one of the three layers of connective tissue between the brain and the skull:

1. *Epidural hematoma*: a bleed between the *dura mater* and the skull. The *dura mater* is a tough, fibrous layer just beneath the skull that protects the brain and anchors it to the skull. On a CT scan, this kind of bleed often

resembles a well-defined, football-shaped mass against the skull. It's the easiest ICH to treat when caught early.

2. *Subdural hematoma*: a bleed between the *dura mater* and the *arachnoid mater*. The *arachnoid mater*, a network of fibers laced with blood vessels, lies below the *dura mater*. It contains the cerebrospinal fluid that helps protect and minimize damage to the brain from impacts to the skull. On a CT scan, these bleeds often appear crescent shaped.
3. *Subarachnoid hemorrhage*: a bleed between the *arachnoid mater* and the *pia mater*. The *pia mater* is the innermost layer of thin connective tissue covering the brain. This type of bleed is often accompanied by a sudden massive headache called a "thunderclap."

A fourth kind of bleed can occur within the brain itself—an *intracerebral hemorrhage*.¹ Intracerebral bleeds are the most difficult to treat, because the bleeding is occurring within the brain itself.

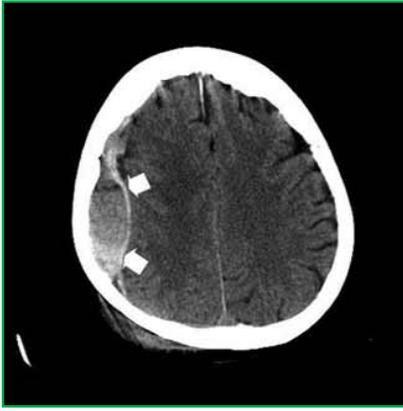
Frequency and Diagnosis of ICH

Luckily, ICH is uncommon, and prophylaxis may also help to reduce the risk. Children with severe hemophilia and on prophylaxis have a 1% to 2% risk of ICH.² One retrospective study found that patients with severe hemophilia on prophylaxis, who were HIV negative and had no inhibitor, experienced a 50% risk reduction for ICH.³ But not all head bleeds can be prevented: about 60% of ICH cases in children are caused by trauma, and 40% are spontaneous with no apparent cause.

If your child bumps his head or has symptoms of a head bleed, you'll want



1. There are several subtypes of intracerebral bleeds that we will not discuss in this article. 2. Intracranial hemorrhaging in someone with severe hemophilia is the most common cause of death related to bleeding. For those with severe hemophilia who have an ICH, the risk of dying from the bleed is more than 20%, and ICH is responsible for 30% to 50% of all hemophilia deaths as a result of hemorrhage. 3. Witmer, Char, MD, et al. "Disorders of Coagulation or Fibrinolysis" Poster III. 50th American Society of Hematology Annual Meeting and Exposition, San Francisco, CA, 8 Dec. 2008.



The two white arrows point to a football-shaped epidural hematoma on the left side of the brain.

to get him diagnosed as soon as possible. But diagnosis isn't easy. Bleeding is usually hidden, with some symptoms resembling those of less serious conditions, such as the flu. And almost half of newborns with ICH show no signs or symptoms.

Most ER physicians do an initial evaluation, which includes checking pupil response, and a quick neurologic evaluation using the Glasgow Coma Scale (GCS). GCS scores range from 3 (severe brain injury) to 15 (no brain injury). If the physician suspects a bleed, he or she will often repeat neurologic evaluations of your child while in the ER.

A child without hemophilia who has bumped his head, but has a normal GCS score and no signs or symptoms of a head bleed, is usually sent home without a CT scan. But your child with hemophilia is much more likely to have a CT scan after a head bump—even if he is asymptomatic—because ER physicians will consider him at high risk of ICH. Still, it's rare that a CT will find any signs of a head bleed in children who have bumped their heads but have normal neurological function and no signs or symptoms of ICH. Dr. Ellis Neufeld, Associate Chief, Division of Hematology/Oncology at Children's Hospital Boston, recommends head CT for all severe head trauma (for example, loss of consciousness, hit in the temple with a pitched baseball, motor vehicle accident, or symptoms without such trauma). He says, "We try really hard not to automatically do head CT at the mild end of trauma, but sometimes the tricky part is to determine what is 'mild.'"

What Is a CT Scanner?

A CT scanner is a large machine with a tunnel in the center. The patient lies on a narrow table that slides in and out of the tunnel. A CT scanner uses *x-rays* and *digital x-ray detectors* to collect the data

used to make three-dimensional images of the body. The data collected by the x-ray detectors is fed into a computer, which creates many cross-sectional images of the area being scanned.

There are several generations of CT scanners, and each new generation incorporates technological advances. With each generation, the scanner can make more images, at a faster speed, with better image quality. Newer *multi-slice helical* or *spiral* CT scanners are rated by the number of "slices" of tissue scanned without moving the table. Fast, 64-slice CT scanners can produce images of the head in a few seconds. But there are also 128-slice, 256-slice, and now the 320-slice scanner, currently the fastest, which scans the head in a fraction of a second. Because of their cost, fast scanners may not be available in all areas or at all hospitals. Fast scanners not only take pictures faster, they also deliver less radiation: compared to a 64-slice scanner, a 256-slice scanner delivers 80% less radiation.

Radiation Risks

CT scanners use x-rays, a type of electromagnetic energy. Radio waves, microwaves, heat, light, ultraviolet light, x-rays, and gamma rays are all kinds of electromagnetic energy. X-rays and

Signs & Symptoms of ICH

Contact your HTC *immediately* if your child shows any of the following signs or complains of any of the following symptoms of ICH—with or without head trauma. Often, children exhibit several symptoms when having an ICH.

- sudden severe headache or headache that worsens
- seizures with no previous history
- weakness in an arm or leg
- vomiting more than twice, with or without nausea
- decreased alertness; lethargy; trouble waking up or staying awake
- changes in vision, such as double vision, blind spots or blurred vision
- dilated or unequal pupils; eyes not moving together
- dislike of bright light
- tingling or numbness in extremities
- difficulty speaking or understanding speech
- difficulty swallowing
- difficulty writing or reading
- loss of fine motor skills; hand tremors
- loss of balance; difficulty walking; stumbling or falling
- abnormal sense of taste
- stiff neck or back
- extreme or persistent crying in babies
- excessive irritability in babies
- loss of consciousness, even for a few seconds

gamma rays carry more energy than do other forms of electromagnetic energy; their higher energy and shorter wavelength allows them to travel through your body and out the other side. This is what makes these rays useful for taking pictures of your internal anatomy.

But what makes them useful also makes them dangerous. The higher energy of x-rays and gamma rays is capable of breaking chemical bonds that hold atoms together in compounds. As the rays pass through your body, they can strip electrons away from atoms. Atoms that lose or gain electrons become charged, and are called *ions* or *free radicals*. Energy that can produce ions is called *ionizing* radiation. Because ions are charged, they are chemically unstable atoms. Ions rapidly enter into chemical reactions with other atoms around them, often forming unwanted compounds. These reactions can cause changes in the DNA.

Changes in the DNA are often repaired correctly by the cell. But some-

times the cell can't repair the damaged DNA correctly, and this results in a *mutation*. Mutations may cause the cell to die, or may cause an inherited disorder. Sometimes, a mutation causes the cell to grow out of control, resulting in cancer. Ionizing radiation is now a well-known cause of cancer, especially leukemia.⁴

What We Know about the Risk of Cancer from X-Rays

The exact risk of developing cancer from exposure to ionizing radiation such as x-rays is not known, though it's generally believed to be low. But so far, there have been no published large-scale studies of the relationship between low-dose medical use of ionizing radiation and cancer risk. Why?

It's a tough relationship to study. First, no immediate cause and effect can be observed—after someone is exposed to low-dose ionizing radiation, a cancer may take 10 to 30 years to appear. Second, cancer is a common disease,

caused by many different things. Over a lifetime, 40% to 50% of us will develop cancer. It's hard to tease out the effect of a small dose of ionizing radiation on the many people who will develop cancer. Finally, radiation is in and around us, all the time, and there's no way to point to a cancerous cell and say that it was caused by exposure to radiation on a specific day.

We do know that the greater your exposure to ionizing radiation, the greater your risk of developing cancer, particularly leukemia, and that the radiation dose is cumulative over a lifetime. We also know that risk of cancer is different for different types of CT scans and different for various organs. The good news is that compared to the abdominal organs, the brain is two to three times less sensitive to the effects of ionizing radiation—so the overall risk of brain cancer from a head CT scan is lower.⁵

And we know that babies and young children are at greatest risk of developing cancer as a result of exposure to ionizing radiation. Why? Babies and young children, because of their small size, absorb more radiation than do adults for the same type of scan. Also, babies and young children are growing rapidly, so their cells are dividing rapidly—and dividing cells are more susceptible to genetic damage. Compared to adults, children are two to ten times more sensitive to the effects of ionizing radiation.

Is Your CT Scan Really Necessary?

The risk of cancer from CT scans is now being scrutinized because their use continues to skyrocket—from 3 million scans a year in 1980 to more than 72 million in 2007. And most alarming, the number of CT scans performed on children in pediatric ERs rose from 330,000 in 1995 to 1.65 million in 2008.⁶

Overuse of CT scans is especially worrisome for children with hemophilia. One study found that hemophilic children under age two were *42 times* more likely to have a head CT than children with the same symptoms but no hemo-



4. Leukemia is a cancer of the blood or bone marrow, resulting in overproduction of white blood cells. 5. A head CT also exposes to indirect radiation the thyroid gland, located near the Adam's apple in the neck. Although the thyroid gland receives only a fraction of the radiation the brain receives in a head CT, it's more susceptible to the effects of the radiation. 6. Radiological Society of North America. "Emergency Department CT Exams of Children Have Increased Substantially." News Release, 5 April 2011.

philia.⁷ Remember that more scans can increase the cumulative risk of cancer.⁸

Are hospitals and physicians aware of these studies and risks? Many are, but most are not. One study found that 75% of radiologists and ER physicians underestimated the radiation dose from a CT scan. And 53% of radiologists—along with a whopping 91% of ER physicians—did not believe that CT scans increase lifetime cancer risk.⁹

Besides the increasing number of scans, children are often exposed to higher radiation levels than previously thought. Some children are exposed to radiation levels 10 to 20 times higher than necessary. Even though the US Food and Drug Administration (FDA) is working on dosing guidelines for CT scanners, they aren't expected for a few years. From one hospital to another, radiation doses from CT scans have been found to be as much as 13 times different for the same test on the same-sized patient. At some hospitals, pediatric CT scans are routinely done using higher, adult dose settings. And some radiology technicians routinely use higher doses to increase the sharpness of the image, when multiple studies have found that lower doses are often equally effective.

Unbelievably,
no FDA dosing
guidelines exist for
the use of
CT scanners.

Perhaps most disturbing is that CT scans are often done unnecessarily. It's been estimated that as many as one-third of all CT scans are not justified by medical need, and perhaps 1 million children per year in the US are being irradiated needlessly.¹⁰



Why would a physician order a CT scan without good reason? Some parents believe that any head bump warrants a CT scan, and physicians may order a scan just to placate them. More commonly, physicians order tests as a means of avoiding a lawsuit—a practice called defensive medicine.

Reduce Your Child's Radiation Exposure

You can help avoid defensive medicine and limit your child's exposure to ionizing radiation by questioning each scan to ensure that it is medically necessary. You should also track your child's exposure to ionizing radiation. California has already taken a lead, with a landmark law in 2010 requiring that radiation dosage levels from CT scans and radiation therapy be recorded on the scanned image and in a patient's health records. The law also requires that radiation overdoses be reported to the patient, the treating physician, and the California Department of Public Health. And it requires that all facilities performing CT scans be accredited by July 2013.

If you don't live in California, you can still make sure your child is exposed to the smallest amount of radiation possible. Try the following:

- Don't demand a head CT scan if your child has no signs or symptoms and your hematologist considers it unnecessary.
- Ask if radiation dose will be adjusted based on your child's size.
- Request lead shielding for parts of the body not being scanned.
- Keep records—date, time, location, type of scan, and if possible, dose—for all CT scans and x-rays.
- Ask if the radiology lab can give you information about the "effective dose" (in millisieverts, or mSv) that your child will receive from the scan (this must be calculated by a radiologist, and may not be readily available).
- Ask how long the CT scan will take, and if your child will need sedation. If a head CT takes two seconds or less, your child won't need sedation.
- Ask if the scan is a duplicate. If your child already had the same kind of scan at a different hospital or at an earlier time for the same suspected bleed, you can use images from the earlier scan instead of having the scan repeated.
- To help avoid rescans, bring a flash drive with you (CT scans

7. Lee, Lois K., et al. "Intracranial Hemorrhage after Blunt Head Trauma in Children with Bleeding Disorders." *Journal of Pediatrics*, 14 Jan. 2011. 8. An estimated 29,000 future cancers could be related to the 70 million CT scans performed in the US in 2007. See Berrington de González, Amy, DPhil, et al. "Projected Cancer Risks From Computed Tomographic Scans Performed in the United States in 2007." *Archives of Internal Medicine*, 169.22 (2009): 2071–77. 9. Lee, C. I., et al. "Diagnostic CT scans: Assessment of Patient, Physician, and Radiologist Awareness of Radiation Dose and Possible Risks." *Radiology* 231.2 (2004): 393–98. 10. Brenner, David J. PhD, DSc, and Eric J. Hall, DPhil, DSc. "Computed Tomography—An Increasing Source of Radiation Exposure." *New England Journal of Medicine* 357 (Nov. 29, 2007): 2277–84.

are digital). Ask the technician to copy the images onto the drive or a CD, especially if your child is being transferred to another hospital.

- Ask if the radiology lab follows ALARA (As Low as Reasonably Achievable) guidelines. ALARA keeps radiation doses and releases of radioactive materials to the environment as low as possible, based on technologic and economic considerations.
- After hours or on a weekend, ask if a board-certified radiologist or pediatric radiologist will interpret the images. Most physicians have minimal training in reading CT scans, and small hospitals may not have a radiologist on duty 24/7.
- Ask how having the scan will change your child's treatment options.

The Alliance for Radiation Safety in Pediatric Imaging,¹¹ as part of its Image Gently campaign, recommends that physicians and radiologists follow these guidelines when possible:

- Use the lowest effective radiation dose when imaging pediatric patients.
- Image only when there is a clear medical benefit.
- Image only the indicated area.
- Use alternative diagnostic studies (such as ultrasound or MRI).

How will you know if your hospital follows these guidelines? Check it out before you get a scan. Search for hospitals and clinics that are accredited by the American College of Radiology at [acr.org/accreditation/accreditedfacilitysearch](http://www.acr.org/accreditation/accreditedfacilitysearch). Accredited facilities are most likely to have qualified staff who are aware of the risks of ionizing radiation to pediatric patients, and are most likely to use the safest scanning procedures.

Making CT Scan Decisions with Your HTC

Do you know your HTC's policy on CT scans? Now is the time to find out—before your child is considered for a CT scan. Physicians, especially ER physi-

cians, are likely to order a CT scan when your child has bumped his head, especially if they are practicing defensive medicine. But this doesn't mean that a CT scan should be automatic. As your child's parent and advocate, speak up! Work with the medical team to make the best decision. Anytime a CT scan is ordered, weigh the risks and benefits, and consider how the information would change your child's treatment. Keep in mind that if your child has inhibitors or has had a prior ICH, your medical team is more likely to order a CT scan because your child is at higher risk for ICH.

Ideally, your HTC follows a protocol similar to the one used at Children's Hospital Boston, where CT scans for a mild head trauma are *not* automatic. Before deciding whether to order a CT scan, physicians at this hospital try to determine the severity of the head bump, while taking into account other risk factors. They also try to assess the degree of severity by phone before patients leave home for the ER.

Even if your HTC follows a different policy, there's still good news. Even though the brain receives high doses of radiation during a head CT scan, the risk of cancer from a head CT scan is

very low. Still, work with your HTC and ER to limit your child's exposure to ionizing radiation. Explain that CT scans for a mild head bump without signs or symptoms of ICH are usually unnecessary. Don't automatically authorize a scan, but make sure one is ordered when your child has known head trauma, or when he shows symptoms of a head bleed—even when you don't know whether he bumped his head.

Head bumps *will* happen. Your child with hemophilia *will* experience them, and you may want to have his head scanned. But now you can approach the ER physician or your child's hematologist armed with confidence, with valid questions about CT scans and radiation risks, to ensure your child's lifelong safety as much as possible. ☺

Paul Clement is a high school science teacher who has written extensively for the hemophilia community. For the past decade, he has been PEN's science editor. Paul holds a bachelor's degree in biology and a master's in science education from California State Polytechnic University. He and his wife Linda have two children: 26 year-old Erika and 24-year-old Brett, who has severe hemophilia A.

Cranfill family



11. The Alliance for Radiation Safety in Pediatric Imaging (www.acr.org) consists of several radiological organizations and manufacturers of CT scanners.

headlines

manufacturer

Easier Infusions

Pfizer now has a new dual-chamber syringe that eliminates the diluent transfer step in Xyntha®, its recombinant plasma/albumin-free factor VIII concentrate. The “all-in-one” prefilled syringe comes in a 3,000 IU dose, 4 mL reconstitution volume. Other dosages in the prefilled dual-chamber syringe will be introduced in 2011. **Why this matters:** Easier infusion may mean better compliance with treatment regimen.

For info: www.xyntha.com



New Fourth-Generation Products Underway

To create a new generation of products, Octapharma has begun clinical studies of the first recombinant factor VIII derived from a human cell line (Human-clrhFVIII). Researchers are investigating the cell line to assess pharmacokinetics, efficacy, safety, and immunogenicity for previously treated patients with severe hemophilia A. **Why this matters:** Products made from a human cell line might reduce the chance of inhibitor development.

For info: www.clinicaltrials.gov

The Spanish Acquisition

Grifols, Spanish manufacturer of plasma-based factor VIII and IX products, has offered \$3.4 billion in a bid to acquire Talecris Biotherapeutics, US manufacturer of a plasma-based factor VIII product. According to Reuters, talks between Grifols and the US Federal Trade Commission are ongoing, and the two companies may be working on a compromise designed to make the deal acceptable to regulators. Grifols first announced an agreement to acquire Talecris in June 2010. **Why this matters:** An acquisition reduces competition in the marketplace, strengthens the purchasing company, and may affect choices in treatment options.

For info: www.grifolsusa.com

First Mobile App to Help Diagnose Bleeding Disorders

Coags Uncomplicated is the first mobile application to assist in the diagnosis of bleeding disorders. It features a Lab Value Analyzer that enables physicians to input test results and receive a list of potential diagnoses, including a description of each bleeding disorder and typical lab values. The app also provides step-by-step suggestions for appropriate lab tests to narrow possible diagnoses. Created by Novo Nordisk with guidance and input from Dr. Craig Kessler of Georgetown University. **Why this matters:** Specialists who see abnormal blood clotting in patients often focus on the location of the bleed rather than the cause.

For info: free download at www.coagsuncomplicated.com



manufacturer



The First Factor XIII Concentrate

CSL Behring was granted FDA approval for Corifact™, a plasma-derived factor XIII

concentrate, to treat congenital factor XIII deficiency, a rare bleeding disorder caused by the body's inability to form stable blood clots. Factor XIII deficiency affects 1 in 2 million, or about 150 people in the US. Corifact is already available in 12 countries worldwide under the trade name Fibrogammin®- P. **Why this matters:** This is the first and only US-approved treatment for factor XIII deficiency.

For info: www.corifact.com



Inspirational Videos on Social Networks

Baxter Healthcare Corporation's new series of inspirational videos, "More to Life Than Hemophilia," should reassure new parents that their children will live healthy lives by properly using factor replacement therapy and visiting their HTC annually. **Why this matters:** Some people are visual learners; and for many young people, social networking is a primary source of learning.

For info: www.youtube.com/morethanhemophilia or www.facebook.com/morethanhemophilia

advocacy

Update with a Great Blog!

Hemophilia Federation of America has a diverse, interesting blog to keep bleeding disorder patients up-to-date on healthcare reform. **Why this matters:** Healthcare reform is changing daily as the nation grapples with dwindling budgets and the new healthcare reform act.

For info: hemophiliafed.org/advocacy/blogs

Bob Massie Runs for Senator



Democrat Bob Massie, son of Robert and Suzanne Massie, authors of *Journey*, is running for senator in Massachusetts to unseat Republican Scott Brown, who suc-

ceeded the late Ted Kennedy in a surprising electoral outcome. Massie's life story was told by his parents in *Journey*, and he was also featured in the recent documentary *Bad Blood: A Cautionary Tale*. **Why this matters:** Massie, who was born with hemophilia and contracted HIV, may be poised to champion the chronically ill on Capitol Hill.

For info: bobmassie.org





First American with Hemophilia to Climb Kilimanjaro?

Chris Bombardier may be the first! Chris, 25, has severe hemophilia B and lives in Colorado. He is climbing 19,340-foot Kilimanjaro in May 2011,

after visiting the clinics and patients in Kenya. All donations raised for his climb go to the African programs of Save One Life. **Why this matters:** Increasingly, patients with hemophilia show that frequent infusions, exercise, and training can allow them to reach new heights.

For info: www.SaveOneLife.net



Into Thin Air

More climbers are headed to Kilimanjaro! A team of ten, including LA Kelley Communications president Laurie Kelley, will travel to Kenya on July 29, 2011, to meet with hemophilia patients and clinics. Then on August 5, the team will go to Kilimanjaro in Tanzania to start the climb on August 6. The team hopes to raise \$30,000 for the African programs of Save One Life, a nonprofit dedicated to helping hemophilia families, one at a time. **Why this matters:** You can help change the life of a child with hemophilia in a developing country through Save One Life.

For info: www.saveonelife.net/donate_now.php



NHF Annual Meeting: First-Timers May Receive Grants

National Hemophilia Foundation offers a limited number of Educational Participant Grants to individuals or families with bleeding disorders attending the annual meeting for the first time. Special consideration will be given for difficult personal obstacles or financial need. Grants may be used to cover airfare, mileage, and/or hotel, for a maximum of three nights and four days. **Why this matters:** Grants give newcomers a chance to attend an NHF meeting to learn more about bleeding disorders and to network.

Deadline for applications: June 24, 2011

For info: sroger@hemophilia.org



NATIONAL HEMOPHILIA FOUNDATION

for all bleeding and clotting disorders

2011 Inhibitor Education Summits

May 20–22 (Spanish-speaking only), Miami

June 16–19, Miami

July 14–17, San Francisco

NHF presents three inhibitor summits, one in Spanish only. Inhibitor patients and their families can interact with expert healthcare professionals and share experiences with other inhibitor families. **Why this matters:** Living with hemophilia A or B and inhibitors can be isolating; summits help bring community members together for support.

To register: www.nhfinhibitorsummits.org or 877-560-5833





First Hemophilia Song for Children!

“My First Factor Song” is the first educational song for children with hemophilia. Lyricist Carri Nease, mother of twins with hemophilia, helps toddlers learn what to do when they get a “boo-boo.” Sing the song to your child each time he needs an infusion, each time you apply ice, and whenever he needs to rest. Part of the *My First Factor* series of books that introduce toddlers to hemophilia situations, words, and concepts. Sponsored by Baxter Healthcare Corporation. **Why this matters:** Children learn terms and concepts easily when they are accompanied by music.

Download: lyrics and song at www.thereforu.com after June 1

international

Independent Iran

Iran has become self-sufficient in collecting human plasma to meet its domestic needs for fresh-frozen plasma and plasma-derived biotherapeutics. This achievement reportedly can save Iran an estimated \$200 million annually in therapeutics costs. Iran has traditionally shipped plasma to fractionators in Europe for further manufacture. **Why this matters:** Iran could provide a hemophilia model for other developing nations to help alleviate patients' suffering.

For info: shirinravanbod@hemophilia.org.ir

The World of Hemophilia

According to the 2009 Annual Global Survey, the World Federation of Hemophilia (WFH) reports that 105 countries, covering approximately 92% of the world population, have identified 115,204 people with hemophilia A; 24,038 with hemophilia B; and 62,158 with von Willebrand disease.

In 2009, about 7.3 billion IU of factor VIII and 956.7 million IU of factor IX were used worldwide. **Why this matters:** It's usually estimated that 400,000 have hemophilia worldwide; knowing how many are identified shows how many more patients need to be found.

For info: www.wfh.org



medical

World's First Blood Test for vCJD



The world's first accurate blood test for variant Creutzfeldt-Jakob brain disease has been developed by Medical Research Council scientists in the UK. The prototype test is 100,000 times more sensitive than any previous attempt, and could transform diagnosis and screening. vCJD, the human form of BSE (“mad cow disease”), was suspected of infiltrating the UK blood supply before 2001. **Why this matters:** A widely available, accurate blood test would allow earlier diagnosis and could also help identify carriers of vCJD to prevent its spread.

For info: www.mrc.ac.uk/Newspublications/News/MRC007683

Prophylaxis Takes a Hit

Despite the recommendation of NHF's Medical and Scientific Advisory Council (MASAC) that people with severe hemophilia A or B should receive three prophylactic infusions of factor per week to prevent bleeding, a survey of US HTC's found that more than half do not follow those guidelines. Only about 25% of HTC's reported starting prophylaxis after a single bleed, and 56 of 62 centers reported starting prophylaxis after one or more bleeds. **Why this matters:** Risks of infection, high treatment costs, and hospitalizations to implant and maintain venous access devices might hinder a patient's adherence to prophylaxis and create risk of joint damage.

Source: *International Blood/Plasma News*

For info: 52nd Annual Meeting of the American Academy of Hematology

These are potentially high costs to pay from your pocket. What you pay depends on your insurance policy or your medical needs, but with inhibitors, you'll usually generate higher medical bills than the average hemophilia patient pays.

Fighting Back Tiers

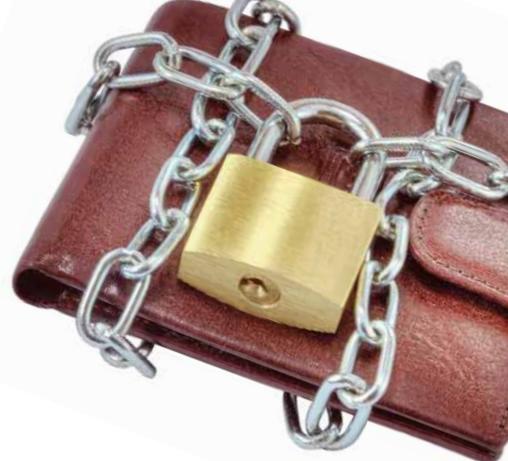
Kerry's chapter recently held a meeting to discuss insurance reform with an expert who focused on *specialty tiering*. A tier is a classification of a drug. Insurance companies assign tiers to each drug as a way to control drug cost reimbursement by creating an incentive for customers to use lower-cost drugs. There are four tiers.

- Tier 1: generics; the cheapest drugs
- Tiers 2 and 3: brand-name drugs; usually more expensive
- Tier 4: the most expensive drugs, including biological drugs (such as factor concentrate) and injectible drugs

"Specialty tiering seems a likely target by insurance companies now, aimed at controlling hemophilia costs," comments Kerry. "Everyone is concerned about it."

The problem with tier 4: Insurance companies can charge coinsurance, a *percentage* of total costs, instead of a flat copay on drugs that cost more than \$500. "The more expensive your drug, the larger your percentage of out-of-pocket costs," Kerry explains. "A 10% deductible for someone with hemophilia is almost undoable. And we're looking at much higher cost than that." For someone with an inhibitor, costs could be astronomical.

"People give mixed reviews about healthcare reform," Kerry continues. "Some think it's great, but most people don't realize that there could be additional charges."



Safeguard Your Budget

To make sure you can afford your out-of-pocket costs, be your own best advocate. Be proactive about questioning prices and procedures.

Know your cost per unit of factor. This is your highest single cost. Inhibitor patients have few choices in which product to use, so be sure to compare what different factor providers charge.

Examine your Explanation of Benefits (EOBs) carefully. Request itemized hospital and home care bills. Watch for mistakes in services or amount of factor ordered, and for duplicate charges.

Question healthcare services. Ask in advance why a procedure or device is being ordered and how much it will cost.

Explore home- or self-infusion. Visiting the ER for an infusion is expensive. Have a nurse come to your home, or learn how to infuse your child.

Coordinate multiple insurance policy benefits. If your spouse has an insurance plan, you might be able to submit your out-of-pocket costs to that plan for reimbursement.

"Right now there are a lot more questions than anything else," admits Kerry. "You've got to look at your policy. A lot of hemophilia families aren't aware of copays or specialty tiering, and aren't even sure what they are looking for. Nobody seems to know what's going on and what will happen. As a community, we need to talk to payers now. We should continue to speak to legislators, but our future lies with speaking to and understanding payers, and having them understand our needs." ☺

How to Estimate Out-of-Pocket Costs

1. **Know your policy requirements.** Are you required to pay \$10 or \$20 for a doctor's office visit?
2. **Estimate known costs.** Some costs, such as emergency surgery, are unpredictable. Other costs, such as clinic visits, prophylaxis, and even specific bleeding patterns, are predictable.
3. **Keep accurate records.** Keep a copy of your insurance policy, and save your receipts and EOBs. Always keep records of infusions, office visits, and medical procedures, including dates.

Out-of-Pocket Help is Here

- **Your HTC social worker.** This expert should always be your first stop for insurance help.
- **Reimbursement programs.** Many home care and pharmaceutical companies offer help if you can prove financial hardship. They may waive fees or portions of the bill, or even provide free product. Visit your factor manufacturer's website and look for the reimbursement help section.
- **Bleeding Disorder Legal Information Hotline.** Call with insurance questions: 800-520-6154.
- **Patient Services, Inc.** PSI may be able to help you meet the out-of-pocket costs you can no longer pay.



Bad Blood: A Cautionary Tale

I HIGHLY RECOMMEND THE BOOK

April Fool's Day, by best-selling Australian author Bryce Courtenay. It's the hauntingly beautiful story of Damon, Bryce's son, born in 1967 with severe hemophilia A. This is an extraordinary love story, but it also describes the archaic and often barbaric methods used at that time in Australia to treat severe hemophilia. Damon contracted HIV from tainted blood products. The Courtenay family lost Damon on April 1, 1991.

Though tremendously difficult to read, this became one of my five favorite books. I felt as if I were a friend of Damon's. I was furious at the stupidity of the doctors, and cried when I read of the horrors this little boy had to endure. Damon became such a part of my life, I actually could not read the last couple of chapters. As long as I never finished the book, I felt that Damon could live forever in my heart.

As the mother of a 16-year-old boy with severe hemophilia B, my heart goes out to all the families who lost their sons and loved ones to AIDS: your special child will live forever in your hearts.

Susan Philips
Arizona

I RECENTLY LEARNED YOU HAVE WRITTEN another book on inhibitors. You are a godsend to our community. My son Forrest has hemophilia, and has had three brain surgeries. He is doing remarkably well. He's in grade 6 and loves to paint; he is a gifted artist. Last night, we were invited to see the film *Bad Blood*, a must-see. Thanks for all the work you are doing on behalf of all children with bleeding disorders.

Edna Stone
Ohio



Project SHARE

I'M ELATED TO INFORM YOU THAT BIRU has recovered and can walk with crutches. Thank you for all the support bestowed on Biru. Without your aid, it would

have been very hard to sustain Biru's treatment. Thank you once again, and God bless you.



Mukesh Garodia
Guwahati Chapter, India

I WAS OPERATED ON MARCH 11 TO remove a big hematoma, which had developed in my stomach. The operation was successful. The medicine sent by Project SHARE helped in my treatment to a great extent, and I am thankful for this.

Ravi Vaishna
India

Alex Lieber Memorial Scholarship

TODAY I RECEIVED THE ANNOUNCEMENT for the Alex Lieber Memorial Scholarship Award. I commend you for offering

these important and valuable funds to deserving students. I sit on the BioRx/Hemophilia of North Carolina Educational Scholarship committee, and I find this to be one of the most rewarding duties that I perform for the chapter. I am amazed at how academically qualified our youth are, and am intrigued by their personal stories. I also feel optimistic for the future because these students are quite capable of assuming important roles in their careers, and hopefully in our volunteer organizations. I only wish that there were more scholarships to distribute, because the number of scholarships, though continually growing over the years, is still limited. Thanks for all you do.

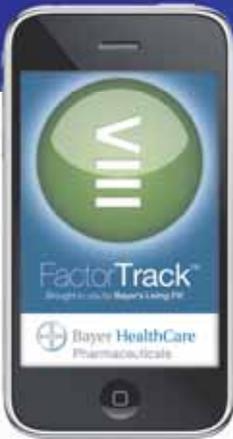
Richard Atwood
President, Hemophilia of North Carolina





FREE

ANYTIME, ANYWHERE:
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The first **FREE**, customizable mobile app designed to help you track and record your hemophilia A Factor VIII infusions:

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- ▶▶ If you infuse on-demand, the app records your bleeds and infusions.

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FactorTrack™ is part of Living Fit! A Joint Effort™.

**Please note that an internet connection is required to receive infusion reminders.*

This app is not intended to offer or replace professional medical advice. Speak to your nurse or physician if you have any health concerns. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.



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Dwayne knows that although it certainly takes effort to exercise, the reward is living a more fulfilling life.

Do What You Enjoy

To get into—or back into—shape, the first step is to consult the team at your hemophilia treatment center (HTC). The doctors and physical therapists will probably recommend exercises for you, but remember that if you don't begin with an activity you enjoy, you're unlikely to stick with it.

Dwayne agrees. "If your doctor tells you to try swimming, and you don't like swimming, it's not going to work out." Instead, he suggests finding an activity that excites you. "One of my friends is an avid golfer," says Dwayne. "So much of his exercise revolves around golf."

But whatever you choose, once you've found an exercise activity that you enjoy, the next step is to make exercising a priority, or you'll risk slipping back into a sedentary lifestyle. Matt offers some tips to help you avoid those excuses that inevitably pop into your head and threaten to derail your ambitions.



Find a workout buddy. It's easy to convince yourself to hit the snooze button and forget about that early-morning walk or jog, but if a friend is waiting outside for you, you're less likely to crawl back under the covers. Plus, it's nice to have company.



Set goals. It can be hard to stay focused and stick with a routine if you're not working toward something. Your goal doesn't have to be running a marathon. Maybe you'd just like to walk your kids to school without feeling like you ran a marathon.



Go at your own pace. When you're just starting out, take it easy and let your body adjust to the new routine. Particularly if you're trying to lose weight, don't expect instant results, and don't get discouraged if the weight doesn't simply fall off.

No Free Passes

Okay, fast-forward several months. You've been exercising long enough that it's

become routine. You're feeling good about yourself, and maybe you've shed a few pounds. But your recent success doesn't mean you can cut corners in other areas of health management.

Healthy diet is an essential component of overall health. Your HTC can point you in the right direction, but as with exercise, the key to success is finding a nutritional plan that you can live with.

Most men cringe at the idea of eating right. They envision themselves weighing food on a postal scale or trying to figure out how much three ounces of pasta is. Dwayne finds practical eating tips in the pages of *Men's Health* magazine, in a feature called "Eat This, Not That." Like Dwayne, experiment until you determine the program that works best for you.

Along with eating right, keep up with all of your appointments. If you feel healthier than you have in years, you may be tempted to skip visits to the doctor or dentist. Don't.

As you reach the goals that you set out to achieve, don't forget to reward yourself. And for those monumental accomplishments—the ones that seemed impossible at the outset—celebrate with something big...perhaps a trip to the French Riviera. ☺

Correction

In PEN's Biennial Bleeding Disorder Resource Guide, we printed the incorrect contact information for BioRX, providers of the programs *BioBuddies Workshop* and *A Day in the Life*; and publications *The Great Inhibinator*, *I Am Nate!*, and *Quest for Infusion: Nate Goes to Camp*. Here is the correct information:

BioRX
10828 Kenwood Road
Cincinnati, OH 45242
www.biorx.net
513-382-5409

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www.hemophiliavillage.com



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the
hemophilia newsletter
by families
& for families

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Parenting Moment

*By profession I am a soldier and take pride in that fact,
but I am prouder—infinately prouder—to be a father.*

GENERAL DOUGLAS MACARTHUR

*Don't worry that children never listen to you;
worry that they are always watching you.*

ROBERT FULGHUM

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LA Kelley Communications, Inc.

65 Central Street • Georgetown MA 01833 USA
978-352-7657 • fax: 978-352-6254 • info@kelleycom.com

www.kelleycom.com