

PEN



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Just A Snip?

The Circumcision Decision

Paul Clement

Preparing for the birth of a baby boy is a time of many decisions. Along with choosing a doctor, a car seat and a stroller, setting up the nursery, buying baby clothes, arranging for childcare and a hundred other things, you must make this important decision: Should you circumcise your child with hemophilia?

Neonatal circumcision, or surgical removal of the foreskin of the penis of a newborn, is the most commonly performed neonatal surgery in the US. It's also the focus of spirited debate over ethics and medical necessity. Is circumcision beneficial, necessary, or harmful? How do you decide what's best for your son?

Circumcision in the US

This may surprise you, but most of the world's males are uncircumcised, about 70%. Of the 30% who are circumcised, 70% are circumcised as part of a religious ritual of Islam and 1% of Judaism. Aside from the US, most of the developed world does not perform routine neonatal circumcisions for nonreligious purposes.

In the US, circumcision for nonreligious reasons dates back only to 1870, when Dr. Lewis Sayre, an eminent New York physician, campaigned for the procedure as a treatment for myriad diseases and disorders. Sayre advocated circumcision for both sexes to "prevent" masturbation. In Victorian times,



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Gotta love Facebook. Where else can the hemophilia community discuss helmets, bruises, factor levels, factor brands, immune tolerance induction, choice of furniture and flooring to prevent bleeds, birth control, babysitters, port infections...all in one day?

Recently the subject of circumcision appeared: to circ or not? Oh my, what a discussion. Unlike flooring choices, this subject was hot and personal. Participants had very strong

opinions. And I noticed, not surprisingly, some misinformation. Facebook is great for widening the net of opinions, but when it comes to important medical decisions, it's really best to do more in-depth research.

We've provided that in this issue of PEN. Paul Clement's feature on circumcision, a reboot of one he did back in the 1990s, will answer many of your questions about whether it's necessary or safe for a child with hemophilia to have a circumcision. I confess I knew nothing about circumcision when my own son was born, and my obstetrician asked me about it for the first time after the C-section, while I was on the operating table. Not good! Now you can gather information on circumcision in a flash on the Internet, and even watch the operation on YouTube. But here, you'll get a thoughtful, well-researched article about one of the most important surgical decisions for your son with hemophilia. Read, think about it, and choose wisely.

See you back on Facebook! ☺

inbox

MY FAMILY AND I HAVE READ AND USED YOUR PUBLICATIONS FOR nearly eight years. Thanks for the many years of effort you have spent educating and advocating for hemophilia! I'm a firm believer that my children have better care today because of the work you and others like you have done in the past.

Hope Fairchild Thacker
Texas

THANK YOU FOR SENDING US YOUR BOOK AND CHILDREN'S books [*My First Factor*] that Amichai and Oz can't put down—even when getting their factor. We just celebrated Shavuot, a holiday where we celebrate Moses receiving the Torah at Mt. Sinai, and we celebrated the receiving of the holy hemophilia kids' books too! It's even more special that we received your books in time for this holiday. I have shared them with friends who live in my community, parents who know what we are going through, and other children. Thank you for having the initiative to create and provide these books, and to give such a beautiful and positive outlook with every word.

Molly Livingstone
Israel



Livingstone family

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PARENT EMPOWERMENT NEWSLETTER | AUGUST 2015

Editor-in-Chief Laureen A. Kelley
Science Editor Paul Clement

Contributing Writers Richard J. Atwood • Paul Clement
Managing Editor Sara P. Evangelos
Layout Designer Tracy Brody
Director, Project SHARE Zoraida Rosado

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

978-352-7657 • fax: 978-352-6254

info@kelleycom.com • www.kelleycom.com

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as i see it

Don't Fear Heights— or Hemophilia

Elizaveta Temidis

It is not the mountain we conquer, but ourselves.

—*Sir Edmund Hillary*

My son John and I are avid hikers, and we love a good dose of adventure. John is 15, a sophomore at Wallkill High School, New York, and has severe hemophilia A. He keeps busy on the school's Nordic ski team, playing piano and French horn, and reading.

But last summer, John literally rose to new heights: he summited Mt. Whitney, the highest mountain in the contiguous US. Mt. Whitney is 14,509 feet above sea level, in the Sierra Nevada Range in California. A one-day permit means completing the 11-mile ascent and return hike—with an elevation gain and loss of 6,145 feet—in 24 hours.

Driving to the West Coast from New York in the family car was an adventure in itself! We departed July 30, a beautiful summer morning, with Ramen noodles, factor, and audiobooks.

The American West is beautiful and fascinating. Dust devils wander aimlessly on the Utah and Nevada plains. In Nebraska, a gigantic gate on Rt. 80 welcomes everybody to the Wild West! Carbon County in Wyoming proudly holds a Cow Plop annual event. Mustangs still roam free in Utah. Warnings about rattlesnakes are mundanely posted on garbage cans at rest stops. American pronghorn antelopes are the second fastest land animals after cheetahs. Our car can outrun a Nevada sandstorm.

After a four-day drive through 11 states, we arrived in California on August 3 and pitched our tent at a campground 8,000 feet above sea level, to get acclimated to the altitude and explore before the big hike. We protected ourselves against black bears that roam the campground at night, gawked at the amazing beauty of magnificent mountain ranges, and chopped enough firewood for evening campfires.

On August 7, we packed up and moved to Whitney Portal campground.



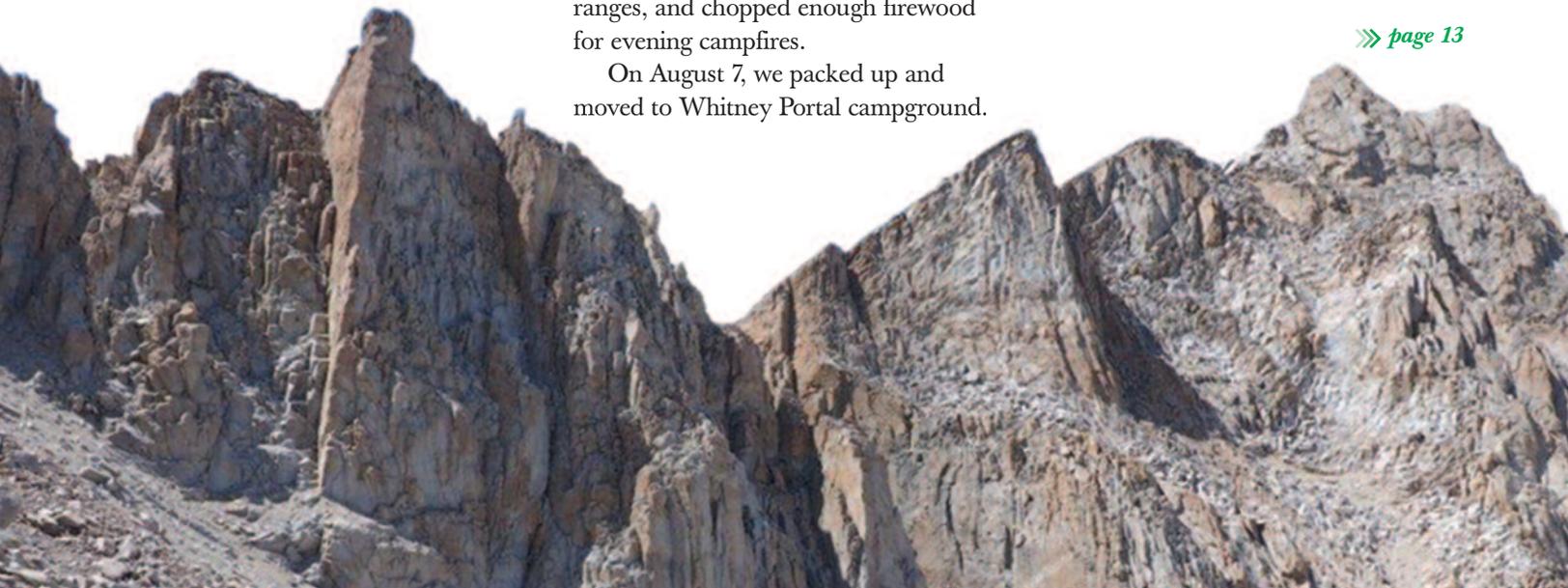
Temidis Family

On top of the world: Elizaveta and John Temidis summit Mt. Whitney

We set up our tent, gathered our supplies, replenished our drinking water, and went to bed around 6:00 pm. We awoke four hours later, John infused his factor, and we set off on our grand new adventure at 11:45 pm.

Faraway flashlights moving on the side of the dark mountain assured us we were not alone. We stopped every hour for a snack and every 15 minutes for a gulp of water, watching for signs of altitude sickness. The last two hours before

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Help is Here!

Resources for People with Inhibitors

Laurie Kelley

In 2005, when I first sat with families with inhibitors and listened—really listened—to their challenges, I was blown away. First, by how much they struggle: standard factor doesn’t work to clot the blood, different treatment protocols sometimes fail, children are on prescription painkillers, with ports and surgeries. Second, by how separated they were from the rest of the community, shunned almost. “No one understands our challenges,” one mother told me, “and when we share, they back away.” Hemophilia with inhibitors was almost like a separate disorder. Third, I was amazed by how stoic and strong these families are! And even more amazed by the lack of resources for them.

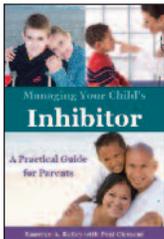
I’m happy to say so much has changed since 2005. We now have inhibitor summits, financial aid programs, books, and even a camp! All for families with inhibitors. At long last,

our hemophilia community has embraced the inhibitor families, and we’ve united.

When I learned about the struggles of inhibitor families, I vowed to write a comprehensive guide to dealing with and living with inhibitors—and I did! From the interviews for *Managing Your Child’s Inhibitor* emerged the need for a summer camp. A colleague took that idea and eventually did just that. What will knowing the needs of the inhibitor community lead you to do?

Begin by ordering these free resources and enrolling in the patient assistance programs. Having inhibitors is tough enough, but knowing there are colleagues and professionals waiting to help you will ease the path forward. I hope our paths cross at a hemophilia or inhibitor event. I look forward to knowing your story.

BOOKS



Managing Your Child’s Inhibitor

Laureen A. Kelley and Paul Clement

2009

Written by parents of children with hemophilia, this comprehensive resource is the first and only book about inhibitors in the world. From the parents’ and patients’ point of view, it extensively covers topics such as pain management, surgery, family life, products,

and treatment regimens. Published by LA Kelley Communications, Inc. with funding by an unrestricted grant from Novo Nordisk.

To order: www.kelleycom.com



The Great Inhibinator!

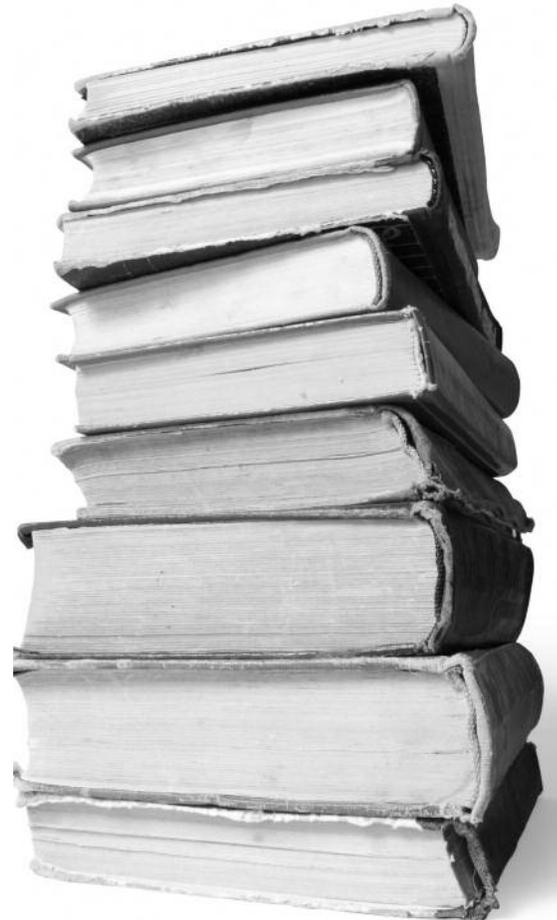
Chris Perretti Barnes

2006

This richly illustrated storybook introduces a preschool boy with hemophilia and an inhibitor. He manages his feelings by becoming a Halloween

superhero called the Great Inhibinator. Written by the mother of a child with hemophilia and inhibitors. For ages 4–7. Sponsored by Bayer HealthCare and BioRX.

To order: www.biorx.net



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Richard J. Atwood



A Mummy with Hemophilia? The Strange Case of Ahmose I

What if I told you an Egyptian pharaoh had hemophilia? And that recent medical examinations of his mummy, involving proof of his intact foreskin, provide the diagnosis? Would you believe me?

Ahmose I reigned from 1549 to 1524 BC, the first Egyptian pharaoh in the 18th dynasty. Notable accomplishments during his reign include expelling the Hyksos (a mixed group of Asiatic invaders) and then uniting Upper and Lower Egypt. Ahmose appeared to be in poor health. X-rays of his mummy show osteoarthritis in his back and both knees, probably causing painful movement. A pelvic x-ray shows his intact foreskin; unlike his father and brothers, he was not circumcised.

Circumcision was practiced in Egypt as early as 3,000 BC. It was performed as a ritual initiation into adulthood. At age 16 or 17, a young man would cut his long hair, have his foreskin removed, and start wearing a loincloth. Circumcision was common but not universal. A bas-relief from the 6th dynasty (2350–2190 BC) depicts ritual circumcision, and the hieroglyphic sign for phallus lacks a foreskin. The ancient Egyptians progressed from using sharpened stones, such as obsidian, for the circumcision surgery to using metal scalpels, lancets, and knives, possibly with some form of anesthesia.

Mummification in Egypt began in the Old Kingdom over 4,500 years ago. The techniques for preserving corpses improved significantly beginning with the 18th dynasty, and the dry climate aided preservation. Ahmose I was well preserved due to the elaborate procedures reserved for the upper classes. During the 70 days after a death, priests and specialized embalmers carried the body across the Nile, and washed and dyed it; removed the brain through the nose; eviscerated the abdomen of organs except the heart, and stored them in jars; dehydrated the body; and washed the body with an oily liquid. Then over two weeks, they wrapped the body in bandages coated with wax and gum. Lastly, the mummy was placed in a coffin and buried in a royal monument or burial tomb.

Modern medical investigation of mummies began with dissection in 1820 and progressed to autopsies in 1886. Use of radiography or x-ray began in 1896, allowing examination without destruction of the mummies. Paleopathology¹ became

a medical discipline in 1920. More advanced technologies were also applied to mummies beginning with computerized axial tomography (CAT scan) in 1977. Recent advances allow the creation of 3-D color pictures to reveal even more detail. DNA analysis of mummies began in 1985. Modern medicine has a long history of poking and prodding mummies in the name of science, so we now know a lot more about the health of ancient Egyptians.

In 1912, English anatomist Grafton Elliot Smith examined the unwrapped mummy of Ahmose I but did not x-ray it. Beginning in 1966, the Michigan Expeditions to Egypt—a group of dentists, physicians, scientists, and scholars from the University of Michigan, University of Alexandria, and Egyptian Museum—performed complete body x-rays on the museum's extensive collection of royal and upper-class mummies. As part of this collection, the mummy of Ahmose I was x-rayed in 1970.

The leaders of the Michigan Expeditions, James Harris and Kent Weeks, summarize the findings in their book *X-Raying the Pharaohs*. About the discovery that Ahmose I was not circumcised, the authors write, "It is tempting to suggest that this pharaoh was in ill health—perhaps even a hemophiliac or 'bleeder.'"² The authors continue, "Why this was so is not known, but one cannot help wondering if this is not further confirmation of a foreign origin of the late Seventeenth-Dynasty rulers, or a confirmation of a physical disorder, perhaps inherited—hemophilia, for example—which the Egyptians realized would have made such an operation fatal."³

Harris and Weeks offer several explanations for the intact



Medical examinations of mummies began in 1820, fueling the public's endless fascination with mummies like this one

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1. A medical specialty created to study disease in mummies. 2. James Harris and Kent Weeks, *X-Raying the Pharaohs* (New York: Scribner, 1973), 30, caption accompanying pelvic x-ray. 3. *X-Raying the Pharaohs*, 127.

No Matter How You Cut It...

Laurie Kelley



If you received YOU magazine recently, you'll know that we are starting this new column with YOU in mind. It's all about personalized healthcare (PHC). PHC means a healthcare approach tailored to each patient. The goal of PHC is to improve your quality of life as a patient with a specific disease or disorder, by taking into account your individual needs, beliefs, and lifestyle, and then tailoring a treatment plan. How does that happen? It's a collaborative process involving you and your medical team.

PEN's feature article by Paul Clement goes into detail about circumcision and what you need to know technically to make a decision. Here, we explore how your beliefs and feelings as parents help you decide about this very common but controversial surgery.

There seem to be three approaches to the circumcision decision:

The Ambushed: usually don't know that hemophilia even runs in the family, and now they have a child and with hemophilia, and must make a decision fast.

The Absolutists: have already made up their minds to circ or not, thank you very much.

The Seekers: have not made up their minds, and solicit information and new ideas about circumcising.

Let's look at these three perspectives in detail.

Ambushed!

This would be me, September 1987. Two weeks overdue, truly suffering after gaining 50% of my body weight, I begged for a C-section after 10 horrible hours of induced labor. Lying on the operating table, I was asked by my ob/gyn as he was sewing me up, "What about circumcision?"

Crickets.

We hadn't even talked about circumcision in our many visits to the ob/gyn over six months. My husband and I blurted out, "Yes, make him look like the other males in the family." There was no discussion. A mere 24 hours later, our son was bleeding effusively. That's how we learned he had hemophilia.

Because PHC is a collaborative effort between you and your medical team, being ambushed, especially by your physician, is not good, not safe, and not effective. It puts pressure on the family already under pressure; and if things turn out badly, parents may forever second-guess themselves, wondering if they did the right thing to circumcise. Especially when the infant has hemophilia.

Kristin Webster learned about her first son's hemophilia when he was circumcised shortly after birth.

When she was pregnant with her second, her HTC doctor told her not to have him circumcised. So she followed the doctor's advice, but now regrets it. "Had I known we could have [circumcised him] and just treated him [with factor], I would have."

Even without PHC, some parents would have done nothing differently. "My son's circumcision was our first indication something was wrong," recalls

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masturbation was considered a vile habit and, because the origins of most diseases were unknown, many were attributed to masturbation. Circumcision was thought to prevent or cure a host of disorders including alcoholism, epilepsy, asthma, headaches, impotence, and even suicide.

As advances in medicine began to uncover the real origins of disease, new justifications for circumcision appeared. During the 1930s, the erroneous fear that foreskins cause penile cancer helped champion circumcision as a prophylactic procedure.

The practice of circumcision was given a boost during World War I by the US military, which led a strong effort to circumcise soldiers and sailors because it was believed this would make them less susceptible to venereal disease. By the onset of World War II, the US had circumcision rates of 40% to 50%, and Britain 30% to 40%. The US rate of neonatal circumcision continued to climb after the war, peaking in the early 1960s at 85% to 90%.

Since 1981, the number of neonatal circumcisions in the US has slowly decreased; in 2009 approximately 55% of US newborns were circumcised.^{1,2} The incidence of circumcision varies widely from one part of the country to another. The West has the lowest rate at about 25%, followed by the South at about 56%, the Northeast at 67%, and the Midwest with the highest, about 75%. Among nations, the US has the highest rate of neonatal circumcision for nonreligious purposes in the developed world.

After World War II, a dramatic split occurred in the practice of circumcision in the US and Britain. In 1949, British pediatrician Douglas Gairdner published an exhaustive study of circumcision in the *British Medical Journal* that significantly changed circumcision in Great Britain. Dr. Gairdner described the foreskin as normal, healthy tissue that serves the important function of protecting the head of the penis from feces and urine. After Gairdner's study, the British National Health Service dropped circumcision from its list of covered services, and the rate of circumcision plummeted, as it did in most other English-speaking countries.

Anatomy of the Penis

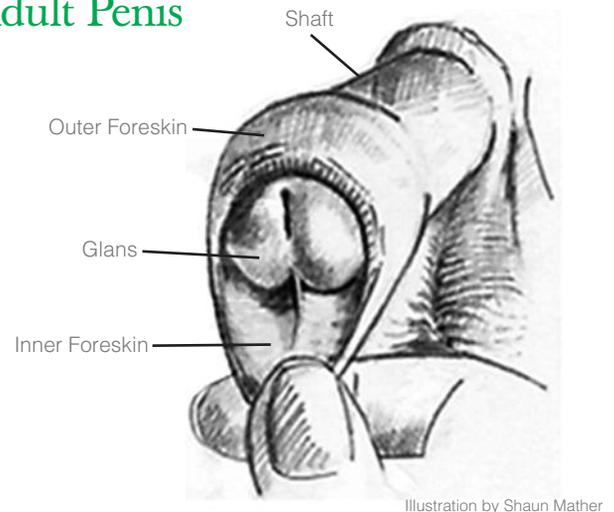
Let's begin by understanding the basic anatomy of the penis, a topic that is rarely included in books and educational materials for expectant parents.

The penis consists of a cylindrical *shaft*, loosely covered with skin that is rich in nerves and blood vessels. At the tip of the shaft is a rounded end called the *glans* (Latin for "acorn"). The glans does not have its own protective layer of skin: like the eye, it is kept moist and supple by secretions from a specialized double-layered fold of skin called the *foreskin*.

The foreskin has two layers: the *outer foreskin* and *inner foreskin*. The outer foreskin is a continuation of the skin of the shaft of the penis. The end of the outer foreskin folds in on itself (imagine pushing in the tip of a rubber glove), and is attached to the shaft at the base of the glans. The inner foreskin is not actually skin but a mucous membrane, like the inside of the eyelid or mouth. It is supplied with complex, specialized sensory nerve tissue, and is very sensitive to touch.

The length of the foreskin can vary greatly from one man to the next. The foreskin represents 30% to 80% of the skin surface area of the penis. In most cases, the erect penis of *intact* (uncircumcised) and circumcised men looks very similar: the main difference is that the skin on the shaft of a circumcised man is typically tight due to the lack of a foreskin, and in an intact man the skin is looser.

Adult Penis



Separation of the Foreskin: A Normal Process

At birth, the foreskin is *nonretractable*—it can't be rolled back to expose the glans. This is because the foreskin is fused to the glans in almost all boys at birth, and the opening of the

1. From the latest report by the Agency for Healthcare Research and Quality (HCUP), a division of the US Department of Health and Human Services: J. Maeda, R. Chari, and A. Elixhauser, "Circumcisions in U.S. Community Hospitals, 2009," HCUP Statistical Brief #126, Feb. 2012, Agency for Healthcare Research and Quality, Rockville, MD. <http://www.hcup-us.ahrq.gov/reports/statbriefs/sb126.pdf> (accessed June 25, 2015). 2. At the 2010 International AIDS Conference in Vienna, Charbel E. El Bcheraoui, a CDC researcher, presented a slide showing the incidence of neonatal circumcision in the US at only 32.5%. http://www.nytimes.com/2010/08/17/health/research/17circ.html?_r=0 (accessed June 25, 2015).

HOW WE SPELL COMMITMENT



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foreskin is smaller than the glans. Separation of the foreskin and the glans happens slowly over several years. The inner layer of the foreskin and the glans shed cells (a process that occurs throughout life); these cells accumulate under the foreskin, appearing as bumps. These bumps, or “pearls,” help separate the foreskin from the glans, and gradually work their way out the tip of the foreskin, where they appear as whitish, waxy material called *infant smegma* (Latin for “soap”). Smegma is produced by both males and females, and is found in all mammals. Smegma is beneficial, and doesn’t need to be removed from under the foreskin. The inside of the foreskin of boys is self-cleansing.

There is no specific age for the foreskin to become retractable—it can happen from shortly after birth to 18 years or older. By age 10, about half of uncircumcised boys can retract their foreskin. The foreskin should not be retracted by anyone but the boy himself. Forcible retraction by parents or healthcare professionals is painful, and can cause several medical problems that may require surgical repair. These complications are all preventable simply by not forcibly retracting the foreskin! But don’t assume that healthcare professionals know they shouldn’t forcibly retract your son’s foreskin—many don’t know how to care for an intact penis. Always stay by your son’s side during well-baby checkups and let your doctor know you don’t want his foreskin retracted.

Is the Foreskin Necessary?

Contrary to popular myth, the foreskin is not a piece of unnecessary skin with no purpose. The foreskin has three basic functions: protective, sensory, and sexual. At birth, the glans is delicate and easily irritated by feces and ammonia created by the breakdown of urine. An infant’s foreskin shields the glans from irritants, and protects it from abrasion by clothing. Later, after the foreskin separates from the glans, the mucous membrane of the inner foreskin also keeps the glans soft and moist.

In an intact adult, the foreskin also plays important roles in sexual intercourse. The inner foreskin is one of the most sensitive parts of the penis, containing many nerves. As the penis enlarges and becomes erect during sexual arousal, the foreskin typically retracts and covers the upper shaft of the penis. As the outer foreskin slides down the shaft during erection, the inner foreskin “unfolds” and moves down the shaft of the penis, exposing the sensitive inner foreskin and the glans. As the shaft of the penis lengthens during erection, the foreskin provides a “reservoir” of skin to cover the penis, allowing it to enlarge, while at the same time allowing the skin of the shaft to remain mobile and loose. This reduces friction during intercourse and reduces vaginal microbleeds. Circumcision, then, removes the most erogenous part of the penis.

Why Do We Circumcise?

If the foreskin plays such key roles in health and sex, why do we circumcise? Sometimes we don't choose: in some parts of the US, circumcision is so common that many parents believe it's a routine part of birth, much like cutting the umbilical cord.

When making the circumcision decision, almost one-quarter of parents reported receiving little or no information from their doctors. And although the Internet is filled with information about circumcision, it's often conflicting. Over 90% of parents reported being unable to determine the truth of the information on any website. Plus, physicians often hold onto outdated information and are biased in favor of circumcision.^{3,4}

Most parents tend to choose circumcision for one of three reasons: hygiene, the belief that it prevents infection or cancer, and to make a child look like his father. Top reasons chosen by parents who do not circumcise their child: it's not necessary, it's painful, or the father was not circumcised.

Parents of boys with hemophilia face other risks and expenses, such as the possibility of hemorrhaging after surgery, and the costs of follow-up factor infusions and hospital visits.

Hygiene: A Parental Concern

Fears about hygiene are based on several misconceptions about the production of smegma and the care of the intact penis. Smegma is sometimes considered dirty, a sign of poor hygiene, bad smelling, and needing removal from under the foreskin. The pearls are sometimes mistaken as a sign of infection. But recall that infant smegma plays a key role in separating the foreskin from the glans. Infant smegma is odorless. No special care of the intact penis is required—external washing and rinsing are sufficient.

At puberty, specialized sebaceous glands on the glans,

which have been largely inactive during childhood, begin producing an oily substance. This oily substance, when mixed with shed skin cells, is called *adult smegma*. Adult smegma protects and lubricates the glans. If allowed to accumulate, bacteria will begin decomposing the smegma, producing an unpleasant smell. Rinsing the glans and inner foreskin daily will prevent the buildup of smegma and the odor. At puberty, a boy should be taught the importance of retracting the foreskin and cleaning beneath it when he bathes. Usually, gentle rinsing with water is enough, or occasionally using a mild soap. The bottom line: an intact penis is not a hygiene problem and requires no special care.

Appearance

“We want him to look like Dad.” “We're being pressured by the family.” “We don't want him to be teased in the locker room.” “It's just the custom.” All these reasons that parents choose to have their son circumcised are based on two assumptions: that the normal male penis is somehow “unnatural,” and that most of your son's peers will be circumcised.

In the US, our choice to circumcise our sons is heavily influenced by cultural and social factors. Our medical textbooks often portray the penis as circumcised. The normal intact penis is usually described as “uncircumcised.” Circumcision critics bristle at this term, which implies that the natural state of the penis is circumcised. In our culture, female circumcision is often called “female genital mutilation.” But male circumcision is almost never called “male genital mutilation.”

Today, parents increasingly question the practice of circumcision, and more babies in the US are being left intact, with the knowledge that the son's penis doesn't have to look like the father's. Parents can help their children feel good about their bodies and respect individual differences. Boys who are taught early that they are normal, whole, and healthy won't feel threatened by a penis that happens to look different from theirs.



3. “Periodic Survey of Fellows, American Academy of Pediatrics Division of Health Services Research, Executive Summary.” <https://www.aap.org/en-us/professional-resources/Research/pediatrician-surveys/Pages/Periodic-Survey-74-Circumcision-Counseling.aspx> (accessed June 25, 2015). 4. In a Jan. 2013 eight-page letter in the journal *Pediatrics*, 38 physicians, mostly European, accused the AAP of cultural bias in support of circumcision and then debunked all of the medical justifications the AAP used to support its position on neonatal circumcision. <http://pediatrics.aappublications.org/content/early/2013/03/12/peds.2012-2896> (accessed June 25, 2015).

Medical Concerns: Urinary Tract Infections, Cancer, HIV

Many parents, and more often doctors, mention medical justifications for neonatal circumcision. Three concerns usually top the list: urinary tract infections (UTIs), cancer, and HIV.

UTIs are bacterial infections affecting the kidneys, bladder, ureters, and urethra. A 1985 study claimed that UTIs were 10 times more likely to occur in uncircumcised boys during their first year of life; this was heralded as a justifiable medical reason to perform circumcision, and is still cited today. But the study was flawed, and since then, results of other similar studies have been inconclusive or shown opposite results. Neonatal UTIs are rare, and are usually easily treated with antibiotics: about 195 circumcisions would be needed to prevent one UTI hospitalization.

Reduction in penile cancer is often mentioned as a justification for circumcision. Penile cancer is very rare in developed countries (1 in 100,000) and is easily treated when found early. The rate of penile cancer is expected to drop dramatically with the new human papilloma virus (HPV) vaccines that block eight of the most common forms of HPV that cause cervical and penile cancer. The risk of mortality as a result of a circumcision complication is greater than the risk of penile cancer; and condoms, when used properly, are more than 99% effective in preventing sexually transmitted diseases such as HPV.

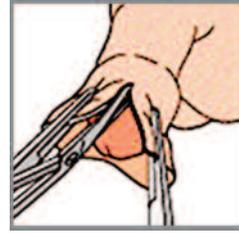
HIV is the virus that causes AIDS. Three African studies of circumcision and HIV transmission in 2005 to 2007 suggested that circumcision may slightly reduce the transmission of HIV. Within the last few years, this has been used as a justification for neonatal circumcision in the US. Circumcision does not prevent HIV transmission, but lowers the risk. Circumcised men are still instructed to use condoms to prevent HIV transmission. Circumcision has no protective effect on women who have sex with HIV-infected partners. Nor does it have any protective effect on men who have sex with men. The African studies have been widely criticized as being flawed, and no country, other than the US, has recommended that babies be circumcised to reduce the risk of HIV transmission through sex, a risk that is much better controlled through the use of condoms and prudent sexual behavior.

The bottom line: there are no medical benefits to circumcision that outweigh the risks.

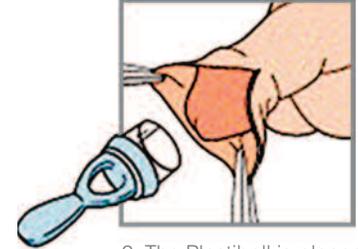
What Happens during Circumcision?

Circumcisions are sometimes done “freehand,” but most often an instrument is used. Several different circumcision instruments are used in the US; the two most common are the Gomco Clamp and the Plastibell.

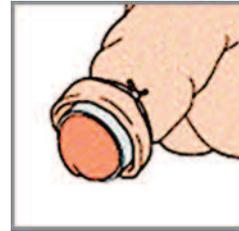
Circumcision Using the Plastibell



1. An incision is made in the top of the foreskin.



2. The Plastibell is placed over the head of the penis and the foreskin is pulled over the Plastibell.



3. A suture is tied around the foreskin over the tying groove in the Plastibell. Excess skin beyond the suture is trimmed away. The Plastibell falls off 3-7 days later.

In the Gomco Clamp method, a slit is made in the foreskin after it has been separated from the glans, and a bell-shaped plunger is placed over the glans. The foreskin is then pulled over the bell, and the clamp is placed around the foreskin and bell. The clamp is tightened, crushing the foreskin against the bell and cutting off the blood flow. The foreskin is then amputated. The clamp is usually left on for at least five minutes after the circumcision to allow for clotting.

In the Plastibell technique, a plastic bell is placed over the glans after the foreskin has been separated from the glans and the slit has been made. The foreskin is then pulled over the bell, and a suture is tied tightly around the base of the foreskin against the bell, cutting off blood supply to the foreskin. The foreskin is then amputated, and the handle of the bell is broken off, leaving the lower ring-shaped section of the Plastibell around the glans. The plastic ring and the remaining foreskin with the suture around it fall off in 5 to 10 days. The Plastibell has the lowest risk of bleeding, but it also has the highest rates of infection.

Using Anesthesia

Neonatal circumcision is painful: this is one of the few points on which most proponents and critics of circumcision agree. Tearing the foreskin from the glans (think of separating your fingernail from the underlying skin), crushing the foreskin with a hemostat, placing the bell on the raw glans, crushing the foreskin against the bell, and cutting off the foreskin all cause intense pain responses from newborns. Whether, and how, to provide pain control is debated in the medical community.

Neonatal circumcision is usually performed when a baby is one day old. Most circumcisions are performed by obstetri-

cians, some by family practitioners and, rarely, by pediatricians or rabbis. Today, anesthesia is used in only about 45% of circumcisions—a significant increase from the 1980s, when anesthesia was rarely used. But this varies greatly. Some hospitals use anesthesia for most circumcisions, and others use none. Some doctors always use anesthesia, and others never do. Among physicians surveyed, reasons most often cited for not using an anesthetic include concern about adverse effects (accidentally infusing anesthetic into a vein of the penis can result in loss of the penis); it takes significantly longer; and some physicians still feel that circumcision doesn't warrant anesthesia. Interestingly, female pediatricians and family physicians are more likely than male doctors to use anesthetics for circumcision.

Typically, newborns scream in agony during circumcision without anesthesia, often turning blue from lack of oxygen. But some parents report that circumcision without anesthesia wasn't painful for their child, who even slept through the procedure. Appearances can be deceiving. Some babies faint from the intense pain of the procedure, seeming to sleep. Several studies have measured the physiological responses of newborns during circumcision and found that the heart rate increases, cortisol (a stress hormone) levels spike, respiratory rate increases, palmar sweating increases, blood pressure increases—all indicating that the baby is experiencing pain even if not showing outward signs.⁵

If You Decide to Circumcise

The American Academy of Pediatrics (AAP) recommends that babies with hemophilia not be circumcised. But if you decide to circumcise, begin by checking whether circumcision is covered by your insurance: in 18 states, circumcision is not covered by Medicaid. With factor, the cost of the surgery for a boy with hemophilia can easily exceed \$10,000.

Circumcision has potential complications, including loss of the penis and death. Bleeding is the most common complication and, in most cases, is not serious. But for the bleeding disorder community, bleeding is a crucial concern. Newborn babies have very little blood—about 8 ounces—and can't tolerate much blood loss. A loss of only 2.3 ounces, an amount that can easily be hidden with urine in an absorbent gel diaper, can be fatal. Circumcision deaths from hemorrhaging are rare, but they almost always involve boys with undiagnosed bleeding disorders. Excessive bleeding from circumcision is a common way parents learn their child has a bleeding disorder.

If you're planning the birth of your son who may

have hemophilia, and you've decided to have him circumcised,

1. Contact a hemophilia treatment center (HTC) and talk to a hematologist *in advance*.
2. Ask to have a hematologist on hand during the surgery.
3. Make sure factor is available for the operation and for several days afterward, just in case.
4. Ask that the circumcision be done with a Plastibell if possible, to reduce the risk of bleeding. (This may not be an option; physicians are often adept at using one tool and may not want to use another, especially in a high-risk circumcision.)
5. Ask what type of anesthetic will be used for the surgery.

Also, keep in mind that infants challenged with repeated high doses of factor around the time of a surgery have a higher risk of developing inhibitors. Surprisingly, only about half of children with severe hemophilia experience excessive bleeding after circumcision, possibly related to the circumcision method used. If your child has only minimal bleeding, ask if it can be controlled with fibrin glue instead of factor infusions. This will not only reduce the cost significantly, but also eliminate an unnecessary risk for developing inhibitors.



Now available!

novoeight[®]
Antihemophilic Factor
(Recombinant)

Novo Nordisk Inc., 800 Scudders Mill Road,
 Plainsboro, New Jersey 08536 U.S.A.

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 of Novo Nordisk Health Care AG.
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 0215-00025301-2 April 2015



5. J. Lander, et al., "Comparison of Ring Block, Dorsal Penile Nerve Block, and Topical Anesthesia for Neonatal Circumcision," *JAMA* 278 (1997): 2157–62.

Be Able to Explain Why

Many Americans have a strong cultural bias favoring circumcision. Ask yourself why you want to circumcise your child, knowing that there are no medical reasons for routine neonatal circumcision that outweigh the risks. Some parents believe it's their right to circumcise; this is the crux of a heated medical ethics debate in our country and, regarding circumcisions for religious rituals, around the world. Medical ethicists believe that children can't give informed consent to circumcision, and that children have fundamental rights to bodily integrity and self-determination that can't be outweighed by the rights of parents: in other words, parents don't have a right to circumcise their children just because they want to. Ethicists add that physicians who perform routine neonatal circumcision, with no clear medical benefit, are breaking the Hippocratic Oath to "first, do no harm."

If you're pregnant or considering having a baby, the decision whether to circumcise your baby boy should be an educated and fully informed choice. Don't feel pressured by family, friends, or physicians. Watch some circumcision videos on YouTube, and read the comments following them. Google the topic, and read what intact and circumcised men have to say. Finally, ask questions on Facebook, especially in the group Hemophilia Moms. You'll get plenty of responses and opinions. Remember, if your final decision is to circumcise, it's permanent. Waiting can buy you time, allowing you to consider the options and get used to your newborn, just as he is. @

Paul Clement, a retired high school science teacher, has written extensively for the hemophilia community. A contributing editor of PEN for 18 years, Paul has a knack for making complex topics easily understandable. He received a bachelor's degree in biology and master's in science education from California State Polytechnic University. Paul lives in Southern California with his wife Linda, and has two children: Erika (30) and Brett (28), who has severe hemophilia A.

Inhibitor Insights... from page 4

PATIENT PROGRAMS

Inhibitor Education Summits

The only national educational forums for inhibitor patients to meet and learn about their rare complication. Offers lectures from experts in the field and interactive forums with parents and patients. National Hemophilia Foundation (NHF) provides these summits only for people living with inhibitors, covering most travel expenses for participants. Funded through a grant from Novo Nordisk Inc. and Baxalta Incorporated. For info: www.hemophilia.org

Inhibitor Family Camp

Camp addresses the unique needs of children with active inhibitors, and their families. The full weekend of education, support, and fun is held twice yearly, with camper costs covered. Funding provided by Novo Nordisk Inc. Camp is designed and operated by Comprehensive Health Education Services. For info: www.comphealthed.com



FINANCIAL & PRODUCT ASSISTANCE

NovoSecure™

Novo Nordisk's NovoSecure is a comprehensive patient support program for patients with hemophilia A, hemophilia A or B with inhibitors, factor VII deficiency, acquired hemophilia, Glanzmann's thrombasthenia, or factor XIII deficiency, regardless of product choice. Replacing SevenSECURE®, NovoSecure allows enrollees to apply for a variety of programs, including

- Competitive scholarship program
- Career counseling
- Life coaching with HeroPath™
- Insurance support

Novo Nordisk also offers product and copay assistance programs to eligible patients who have been prescribed Novo Nordisk products.

For info: www.mynovosecure.com

1-844-NOVOSEC (1-844-668-6732)



NAVA

Baxalta's NAVA offers highly personalized information and tools to provide education and support specific to each patient's needs:

- NAVA mentor to help you set and achieve goals to pursue your life interests
- Personal stories from people sharing their experiences with bleeding conditions
- Direct help by trained experts in navigating insurance issues and healthcare laws



NAVA also includes CARE (Coverage, Assistance, Resources, and Education) to help patients take control of their healthcare needs through insurance and product assistance. Copay or coinsurance support may be available to reduce out-of-pocket costs associated with a Baxalta product.

For info: nava.baxalta.com

Baxalta Resource Helpline 888-229-8379

To enroll in CARE: 855-322-NAVA (855-322-6282)



As I See It... from page 3

sunrise were the darkest and made us yearn for the sun like never before!

We greeted the sunrise at six miles, or halfway up the mountain, before going on to the infamous section of 99 switchbacks. The switchbacks were helpful and refreshing, and we named them after family members as we hiked. Freezing temperatures faded, and the views were astonishing! Reaching Trail Crest, we gasped at the amazing view of the Sequoia Kings Canyon Wilderness all the way to the Pacific Ocean. We were happy to see patches of fresh snow in mid-August, and even threw a few snowballs.

We reached the summit at 10:30 am—tired, but relieved, grateful, and at peace. The absolute quietness of this incredible place was interrupted only by unobtrusive shouts of joy from arriving hikers. We took a photo of us holding a hand-drawn birthday card for my mom, whose birthday is August 8; and of a toy squirrel monkey that we'd promised Alex, John's younger brother, to take to the top with us. Before heading back down, we celebrated with two little bottles of Coke, and spent the next hour in a relaxed, contemplative mood, taking our time, looking at the endless mountain ranges all around, while shivering in the cold, unrelenting wind.

The hike down to Whitney Portal seemed harder than our hike up. We were extremely tired and had one desire: to lie down in our tent and sleep. Yet the wondrous scenery of mountains and cliffs, which we hadn't seen during our ascent in the dark, made us stop in awe, taking photos and marveling at the beauty and ruggedness of this corner of the world.

The last two miles were the hardest. We needed to finish

before dark. We sang every Russian and American song we knew, and recited every Russian poem we could remember. We got some curious looks, yet our method worked so well that we barely noticed the miles pass.

During the hike, John had no traumas or joint problems. He's been on prophylaxis since age one, and since he began training on the Nordic ski team two years ago, he's had fewer joint bleeds.

After a 22-mile round trip, a total of 19 hours and 15 minutes on the trail, and a 6,145-foot elevation gain and drop, we returned to our tent happy and exhausted. We texted our family that we were victorious, overjoyed, nauseous, and tired. Then we went to sleep.

We arrived home five days later, hungry and happy, full of news and impressions, eager to hug our family and grateful for everybody's support. It's possible that John, at age 14, might be the youngest person with severe hemophilia ever to climb Mt. Whitney! This climb proved to us that whatever challenges might stand in the way—hemophilia, fear of heights, or pain—our children with hemophilia need to pursue their dreams and live life to the fullest. ☺

Elizaveta Temidis, 40, was born in St. Petersburg, Russia, and came to the US to study business in college at age 19. She is a high school mathematics and Russian language teacher with New Paltz High School and online Virtual High School. She helps run the Nyack Russian School and a Russian summer camp in the Catskill Mountains. She lives in Walkill, New York, with her husband George and sons John, 15, who has severe hemophilia A, and Alex, 12.

Richard's Review... from page 5

foreskin of Ahmose I, such as his being foreign or ill, possibly having a serious inherited condition. Hemophilia is presented as an example, not a diagnosis. Yet the statement that the Egyptians would have realized the fatal consequences of performing a circumcision because of hemophilia is not substantiated.

Subsequent writers, who have cited *X-Raying the Pharaohs* and claimed that hemophilia is diagnosed because circumcision was not performed, ignore the original speculations and alternative explanations. This simplification distorts the facts.

To me, the available information is insufficient to diagnose hemophilia. Not all royalty were circumcised, so Ahmose I is not unique. Swollen knee joints are symptoms of osteoarthritis and other medical conditions, not just hemophilic arthropathy. And there is no confirmatory evidence, such as a personal or family history of bleeding, or any medical records of a bleeding condition. Of the many ancient Egyptian medical specialists,⁴ none treated any condition similar to hemophilia. Also, the

extensive ancient Egyptian pharmacopeia⁵ includes no treatment for hemophilia or a related condition. In all the medical documentation,⁶ nothing resembles a genetic bleeding condition. And no hieroglyphic exists for hemophilia or any other bleeding disorder. Some people in ancient Egypt probably had hemophilia, yet their physicians never recognized it as a genetic condition.

We might rule out a hemophilia diagnosis in Ahmose I with additional medical investigation. An orthopedic surgeon with expertise in hemophilic arthropathy could provide an opinion on the x-rays of the swollen knees and other joints. And the DNA of Ahmose I could be reexamined for any of the known genotypes found with hemophilia. Until then, be suspicious of any claim that the Egyptian pharaoh Ahmose I had hemophilia based on the fact that he was *not* circumcised. Always check the sources of such claims, and keep an open mind. ☺

4. The ancient Egyptian medical practitioners seemed quite specialized, with special titles (some priestly), and focused on singular organs in their practices. Many doctors and dentists had royal connections, giving them a privileged position and possibly even their own tombs. 5. Or pharmacology. In modern use, *pharmacopeia* is the book containing a list of all drugs and their preparations. Today, we may say "formulary" for a list of drugs. The ancient Egyptians wrote down all their extensive medications in the medical papyri. They also had pharmacists who specialized in drug preparation. 6. The ancient Egyptians wrote on paper (papyrus), stone (stela), murals on walls (bas-relief), and pottery, and had numerous hieroglyphs for medical conditions. Medical documentation from the period exists in all these forms; some has survived, with stone the most enduring.

Alicia Morado. “It oozed for three days but finally stopped bleeding. A few months later, we found out about his hemophilia. And I would still have had him circumcised if I’d know about his condition beforehand.”

PHC Moment: If you’re pregnant, talk to your physician about circumcision *before* delivery. Read Paul’s article and bring it with you. What are the benefits? Risks? Why would you opt to do this? Are you open to circumcising, not circumcising? Do you know whether your child will have hemophilia? How does that change your decision?

Damn the Torpedoes! The Absolutists

Absolutists have already made up their minds, long before they knew whether they were having a boy or a girl, or even a boy with hemophilia. They strongly support circumcision, or are defiantly against it. Either way, these two subgroups have more in common with each other than they think: they are steadfast in their beliefs.

Ashley Gregory is dead-set against circumcision. “Since circumcision is cosmetic surgery on a penis and the foreskin is a source of pleasure, this was a nonissue for me. I would

never consider cosmetic surgery on my daughter’s genitals. I never discussed this with my doctor.”

Jameelah Malcolm feels just as passionately in favor of circumcision. “The moment my husband and I learned we were having a boy, we agreed he would be circumcised whether he had hemophilia or not. We always made it clear to his doctors what we wanted.”

Amber Brandt believes circumcision should not be done unless medically necessary. “It’s a cosmetic procedure. I am strongly against surgery and body modifications on minors unless it is medically necessary. It should only be the decision of the owner of the penis.” She adds wryly, “The rest of the world doesn’t seem to have issues with the foreskin that America has.”

Calvin Hanson agrees. “It seems the desire to perform this cosmetic surgery on infants is pervasive, and filled with myths. The vast majority of kids with or without hemophilia do not need this. It’s an outdated religious tradition which is crude and silly. If the kid wants to have cosmetic surgery when he’s older, great. I’m shocked so many parents take the attitude of ‘It’s my personal choice.’ Is it? Is it *your* body or his? When you add the complexity of a blood disorder, I’m horrified.”

Yet not all circumcisions are complicated, or cause bleeding. Jessica Hamilton Morris was aware of hemophilia in her family, but was told she was not a carrier. “We circumcised before we knew our son had hemophilia, but he did not require factor. Our next son, whether he had hemophilia or not, we were going to circumcise. So, all four of our boys are circumcised.”

PHC Moment: If you’ve already made up your mind to circumcise, talk to your medical team well in advance about risks, the procedure, at what age to operate, which method, how much factor. Read Paul’s article and discuss it with your HTC team. Will you need to return to the HTC for follow-up infusions, or can home nursing be provided?

To Strive, To Seek, To Decide

Initially, some parents may want to circumcise their son, or not circumcise, but then take time to explore options, particularly if there is a medical concern even beyond hemophilia. They approach the decision with curiosity and flexibility, speaking with the HTC medical team, discussing procedures, learning more about the operation, and sharing with other families. These are the Seekers. In the end, they may circumcise their son...or may not.

Sometimes, the decision to circumcise a second child depends on whether he has hemophilia. Victoria Hartman



a project share story

Laurie Kelley



shares, “When my oldest son was born, he was circumcised before we left the hospital. This is how we found out that he had hemophilia (I have no family history). When my second was born, they tested the cord blood to see if he had hemophilia before doing a circumcision. He tested positive, and we didn’t do the procedure.”

But fast-forward eight years. Victoria’s son had an adhesion, and his physician felt he needed to be circumcised. “Since we could do the procedure safely, we went ahead and had the procedure done just recently. It went well, and I’m glad we finally did it.” She adds, “Circumcision can be cosmetic, but it can become medically necessary. He’s happy because he feels like he looks ‘normal’ like his dad and brother now. He was part of the decision making.”

Christy Bergeon Burns’ PHC approach involved her HTC team. “I was a known carrier and found out I was having a boy. Our HTC was supportive of either decision. My husband and I decided that we did want to circumcise our son. I was leaning toward ‘not medically necessary’ but my husband leaned heavily toward doing the circumcision because of social reasons: Why make him ‘different’ in another way? We thought there was a chance he might need a surgery for a port someday, and our HTC said that some parents had circumcision done at the same time. We liked that idea.”

Steph Reitberger also kept an open mind and worked with her HTC team. “We noticed an issue with our son’s blood sugar heel stick a day after he was born. The bleeding just wouldn’t stop. We had decided before he was born to circumcise, as this was my husband’s preference. But we felt nervous about the small heel stick that would not clot, and didn’t fully understand what was wrong because hemophilia didn’t run in the family. After we got his diagnosis, we decided against circumcision. We discussed this on our first visit with the HTC. They agreed and encouraged us to hold off until he was closer to six months old; then we could make the decision.”

PHC Moment: If you’re unsure about circumcision, and your inner voice says to wait, respect it. Hold off until your child is older. You do no harm by waiting. Circumcision is irreversible. If you have any doubts, talk with you HTC team, and wait a few more months. Take time to research and reflect. You—or your son when he is older—can always choose to do it later.

Circumcising isn’t for everyone. And it doesn’t need to be an automatic decision. PHC means you can take the time to consult your HCT team, and ask what other parents have done. Victoria sums it up: “It’s up to the family to decide. I don’t criticize people who choose not to circumcise, but if it’s done safely and is in the best interest of the child, I should not be criticized for choosing to do it either.” ☺



It's time to give back

Project SHARE attempts to help patients who would never normally receive factor. Through Imran Zia, one of our partners in Lahore, Pakistan, SHARE is working to help Mah Noor, age seven, who has von Willebrand disease and lives in a village far from Lahore. Her father has been jobless for several months. Imran’s organization provides bus fare for the girl to come to Lahore to receive help when she suffers mouth bleeds and bruises. Her family can’t afford even basics like food and milk. An aunt was providing school fees for several months, but has refused to continue. SHARE not only will help provide factor, but will also seek ways to provide financial assistance. ☺

If you’d like to help, please contact us:
share@kelleycom.com

headlines

nonprofit



HFA Gambles on Las Vegas in 2016



Annual Symposium
Las Vegas
Mar. 31–Apr. 2



Hemophilia Federation of America's annual symposium is a community-centered educational event that draws hundreds of members from the bleeding disorder community to share information, learn about advancements, and build a network of support. **Why this matters:** This symposium offers a grassroots approach to community and advocacy.

For info: www.hemophiliafed.org

Victory!

Inhibitor Family Camps are designed to provide education along with fun activities in a relaxed atmosphere that helps inhibitor families establish meaningful bonds. **Why this matters:** Until this program was created, inhibitor families often felt unable to participate in regular hemophilia camps due to their unique needs.



Victory Junction
Randleman, NC
October 16–19

For info: www.comphealthed.com

soundbites

The global hemophilia therapeutics market is estimated to reach **\$13.43 billion** in 2019.

The Baxter Healthcare division that produces factor is now a separate company called **Baxalta Incorporated**.

British cyclist **Alex Dowsett**, 26, who has severe hemophilia A, smashed the world record for riding the farthest distance in 60 minutes in May. The record has since been beaten.

Save One Life, Inc., and the Mary M. Gooley Hemophilia Center together raised more than **\$65,000 for earthquake relief** efforts to the hemophilia community in Nepal.



Inalex: Share Your Experiences

Inalex Communications is a national nonprofit dedicated to meeting the emotional and informational needs of people living with bleeding disorders. Inalex offers workshops to help families learn to cope. **Why this matters:** Inalex brings programs to many areas of the US for those who are unable to attend national meetings.

2015 Inalex Workshops

Sept. 26, 2015

Michigan State University Center for Bleeding and Clotting Disorders
Big Bay, MI

Hemophilia of South Carolina
Myrtle Beach, SC

Tri-State Bleeding Disorder Foundation
Owenton, KY

Oct. 3, 2015

Virginia Hemophilia Foundation
Midlothian, VA

University of California Hemophilia Treatment Center
San Francisco, CA

Oct. 17, 2015

Mary M. Gooley Hemophilia Center
Rochester, NY

Oct. 24, 2015

Hemophilia Alliance of Maine
Rockport, ME

Oct. 31, 2015

Maryland Hemophilia Treatment Center
Baltimore, MD

Nov. 8, 2015

Beth Israel Treatment Center
Newark, NJ

Nov. 21, 2015

Hemophilia Foundation of Greater Florida
Orlando, FL

For info: www.inalex.com

manufacturer

It's a 10!

The FDA has accepted Bio Products Laboratory's (BPL) amended biologics license application for Coagadex® (coagulation factor X, human). The product is currently in two phase III trials. Factor X deficiency is extremely rare, affecting only 400–600 US patients. **Why this matters:** This is the first factor X product ever to advance this far in trials. For info: www.factorxinfo.com

To Ixinity and Beyond

The FDA has approved Emergent BioSolutions' recombinant factor IX product Ixinity, for the control and prevention of bleeding episodes and for perioperative management in adults and children ages 12 and older with hemophilia B. This third-generation product has no added human or animal proteins, during manufacturing or formulation.

Why this matters: As insurers continue attempts to limit access to therapies, another product could offer a choice if combined with flexible per-unit costs.

For info: www.ixinity.com



Share Your Story

Grifols has launched a new, unbranded website that allows people with bleeding disorders to upload video submissions of their personal stories. **Why this matters:** Social media is becoming more important as a means to educate and share with others. For info: www.mybleedingdisorderstory.com

news from LA Kelley Communications



Zoraida Rosado, Michelle Rice, Laurie Kelley, Kelly Gonzales, Elizabeth Stolz (left to right)

Pulse *on the Road*

This unique three-hour symposium for local bleeding disorder communities brings experts in insurance and urgent healthcare reform to your state. POTR answers questions about personal health insurance, state healthcare reform, and national trends and changes. Run in partnership with NHF and sponsored by Baxalta Incorporated.

Oct. 2, 2015

NHF Social Worker Meeting
Baltimore, MD

Nov. 21, 2015

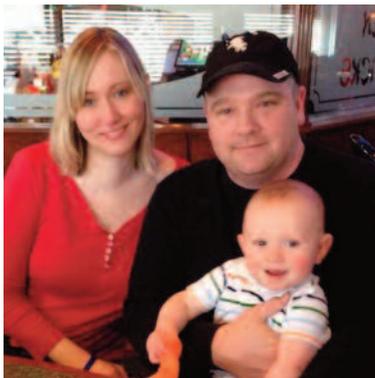
Hemophilia Foundation of Nevada
Las Vegas, NV

Dec. 5, 2015

Louisiana Hemophilia Foundation
New Orleans, LA

For info: www.kelleycom.com

Pulse *on the Road*



THANKS TO POTR for presenting at the Bleeding Disorder Alliance Illinois Family Weekend! Not only did I learn valuable information about navigating insurance issues, but Kelly Gonzalez's passionate story of how she

advocated for her family inspires me further to advocate for the bleeding disorder community. I'm pigheaded for a reason! I doubt there was a dry eye in the room once she finished her presentation.

Genny Moore
Illinois

"When Prophy Isn't Enough," May 2015

THIS WAS A VERY WELL WRITTEN, WELL THOUGHT OUT, resourceful article. I got several encouraging comments from leaders in the community about my contribution. Thank you for bringing the issue to light and exploring it.

Ashley Webb Gregory
California

MY FOUR-YEAR-OLD HAS MILD-MODERATE HEMOPHILIA AND he's on [a recombinant factor VIII], 75 IU per kilo every other day. His factor half-life is only four hours, so he's still averaging about three bleeds a month. I don't think prophy is failing us because he's getting far fewer bleeds while on it, but I do feel it needs to be better.

Marion Fawcett
Alaska

inbox

PROPHY HAS BEEN THE DIFFERENCE BETWEEN WORRYING about our son (severe hemophilia A), waiting for a bleed to happen while doing normal everyday things, versus the reassurance of having factor and not worrying! Our prophylactic schedule has enabled him to do all the things he wants without having to think about the repercussions. We are not naive to think that it is a magic bullet that prevents everything, as we have lived through microbleeds and treating more during baseball season and hard hits, but in the scheme of everyday life, prophy allows him to live a relatively normal life without the main focus being hemophilia. We are grateful for having it but still look for better treatment and a cure down the road. Doesn't everybody?

Chris Perretti Barnes
North Carolina

I FIGURED THE MEDICINE TOOK CARE OF [ANY BLEEDS], but surely this is not case, and without the proper medication at the proper time, then your body will feel the effect. My son is 21, on prophy, and it's a pain for him to remember [to do his infusions]. When he stays on track, he feels so much better. Prophy is not a cure-all, but it does help significantly to make his life a success.

Christy Scott
Arizona

FOR THOSE OF US WHO LIVED THROUGH THE FDA approvals of prophylactic infusions, we remember the transition [from on-demand to prophy] for our children and all the discussions. We knew it would not be a magic bullet, but I think just the sense that we had control over something we really didn't have any power over helped the process and journey. Is it better than infusion on demand? For my son it alleviated the very frequent question, Am I having a bleed? He started prophylaxis at six when it was approved. Life became simpler; it has served a positive purpose.

Rita Epstein
New York



Project SHARE

WARM GREETINGS FROM HFU AND the patients. We are forever in your debt for helping us through this tough time, and we don't know how many times we can thank you. We really appreciate your support.

Agnes Kisakye

Haemophilia Foundation of Uganda (HFU)

THANK FOR YOUR FACTOR DONATION.

I will use all this factor to benefit other hemophilia patients in Cambodia.

Run Chanthearithy

Cambodia

THANKS A LOT FOR THE MEDICINE,

for helping me at this time, where I am in great pain.

Abenesh Prasad

Fiji

I APPRECIATE THE FACTOR YOU SENT

to me very much. Thanks again for your thoughtfulness.

Jeffrey Stewart

Barbados

THANKS TO EVERYBODY FOR YOUR USUAL assistance to my son. Blessings!

Sylvestre Mulinda

Rwanda

WE ARE SO GRATEFUL FOR PROJECT SHARE'S

continued assistance for our ailing patients with hemophilia in western Jamaica.

Dr. Andre Williams

Jamaica



ON JUNE 17 I HAD AN OPERATION TO

amputate my left leg. The operation would not have been successful without the factor VIII that you donated. On behalf of my family, I extend my utmost gratitude. This will be a new life for me. May your organization continue its advocacy to support hemophilic patients like me. May the good Lord repay you in your entire endeavor.

Juan P. Suarez Jr.

The Philippines

Parenting Moment

We worry about what a child will become tomorrow, yet we forget that he is someone today.

— *Stacia Tauscher*

I may not be able to give my kids everything they want but I give them what they need. Love, time, and attention. You can't buy those things.

— *Nishan Panwart*

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Involved in
the communities
we serve.

From hemophilia to kidney disease to immune deficiency communities and more, ASD Healthcare supports the advocacy foundations that dedicate their efforts to improving healthcare and public policy for their communities. It's our privilege to provide financial support, as well as volunteer support through our associates who counsel at camps, cycle in fundraising tours and join in events that raise awareness.

Our involvement gives us one way to give back. But, it also keeps us connected to the people we serve and the ever-changing challenges they face. And, on occasion, it puts us in the right place at the right time to create new and innovative solutions that help us serve these communities even more.

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