PEN

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Test Your Knowledge about HEALTH INSURANCE!

Sara Evangelos

Last year's quiz, "Test Your Knowledge about Hemophilia!" (PEN, Aug. 2010) was so popular that we decided to offer another great checkup. This time, we test your knowledge of all things insurance.

In March 2010 the US government passed comprehensive healthcare reform legislation for all Americans. Now more than ever, parents and patients with bleeding disorders need to stay current on health insurance. Understanding your own insurance policy and knowing how healthcare reform affects our community will make you a smarter consumer, and might even save you some money!

Circle your answers, and then check the answer key on page 17 for more information. Download extra copies of the quiz from our website, and test your family members. Distribute the quiz to audiences at your local chapter events. Good luck!

Insurance Basics

1 Approximately how many Americans are uninsured?

A. 10 million
B. 25 million
C. 50 million
D. None, because of healthcare reform

2 Approximately what percentage of a state's budget goes to Medicaid?

A. 5%
B. 15%
C. 25%
D. 40%

3 What's a *deductible*?

A. Dollar amount you must pay before your insurance provider's coverage begins
B. Dollar amount you must pay for a specific medical service such as an office visit
C. Percentage of costs you must pay before all costs are covered
D. Highest amount your plan allows for covering healthcare services during a certain time period

4 Which of the following is an example of public health insurance?

A. Blue Cross Blue Shield
B. Medicare
C. Anthem
D. Tricare

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welcome

Laurie Kelley

Insurance and healthcare reform are truly the hottest subjects in our bleeding disorder community today. What happens in Washington, DC, and in your state capitol regarding healthcare reform will affect you in some way–from the ability to choose your product, right down to the number of dollars in your wallet. Do you know the issues in healthcare reform? To help you learn more, we want you to find out what you *don't* know. Last August's hemophilia quiz was so popular that we decided to create a quiz on insurance and bleeding disorders. Take it, and see how you do!

And to learn even more, don't forget to read your issue of *PEN's Insurance Pulse*, our insurance newsletter for bleeding disorders. We recently took our interactive program *Pulse on the Road* to Wisconsin, Texas, and Oklahoma, bringing experts in bleeding disorder reimbursement directly to families.

This issue of PEN offers lots of news and information. Learn about a new inhibitor camp for kids, a new song about factor, and how to live with bleeding disorders in your 50s. August 17 marks the 93rd anniversary of the death of Alexis of Russia, the prince with hemophilia. Richard Atwood gives us Hollywood's impressions of Rasputin, the hypnotic monk who sought to help Alexis and influenced the course of history.

inbox

LAST WEEK I HEARD "My First Factor Song." I just loved it. It's so wonderful! With the help of this song, kids will learn about the treatment process in a better way. The factor song is my phone's ringtone now. Carri did a wonderful job with the lyrics, and the music is perfect.

Priyanka Rawat
India

Head Bumps and CT Scans

GREAT ARTICLE ON THE POTENTIAL DANGERS OF THE overutilization of CT scans to diagnose head bleeds. It is interesting to note that during my data collection on older patients with hemophilia in Southern California, one HTC reported over 30% of the patients had some sort of seizure disorder. These were most likely due to undiagnosed head bleeds that had occurred before factor concentrates were available. I wonder what the percentage is now. I don't think this is being measured in the current CDC database.

Randall G. Curtis, MBA, PMP
Factor VIII Computing
California

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PARENT EMPOWERMENT NEWSLETTER • AUGUST 2011

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Memories

Victor Osuna

I remember falling off a donkey
at my grandpa's farm in Mexico.

I remember sneaking into the pool
on a rainy day, then getting kicked out.

I remember playing in the snow on
Christmas Day.

I remember joining my mom on her
trips to the grocery store.

I remember my toy robot scaring me in
the middle of the night
when I forgot to turn it off.

I remember the day my mom wasn't
waiting at the bus stop for me.

I remember playing during recess
at school.

I remember going trick-or-treating alone
for the first time. I was a ninja.

I remember the day I got my
driver's license.

I remember being home alone for three
days and missing my family.

I remember waking up after a bad dream.

I remember sacrificing my pet fish
for a science project.

I remember feeling smart when I
got the highest grade in class.

I remember being surrounded by family
on Christmas Eve.

Victor Osuna, age 20, is a courageous young man who has struggled with severe hemophilia A and a lifelong inhibitor. His two younger twin brothers, now 13, also have severe hemophilia and inhibitors. Victor has been an advocate for his brothers, and has helped to care for them at home, including giving them infusions and calling the treatment center to get help when they had bleeds–even when he himself was in pain. Victor has always been there for them. When he is not looking out for his brothers, Victor enjoys sketching. He is an amazing artist and has many sketch books filled with his artwork.

Victor's health has suffered during the past year, with many bleeds that have been very difficult to control. Everyone at our treatment center knows Victor well, and admires him for his love of life, his dedication to his younger brothers, and his cheerful smile even though he has spent most of his life in and out of the hospital. Victor bravely faces each day, reaching out and loving those around him. Thank you, Victor, for sharing your hope and cheerfulness every day.

Danielle Nance, MD
Hemophilia Care Program
Puget Sound Blood Center
Seattle, Washington

Janet Brewer

sponsored by Novo Nordisk Inc.

Inhibitor Family Camp: Because Everyone Deserves a Camp of Their Own

The bleeding disorder community is fortunate that inhibitors are rare, but the scarcity of patients makes it difficult to provide peer support locally. It's just plain hard to find other inhibitor families.

So, just like hemophilia families, we have sought one special place to connect: hemophilia camp. Our community recognizes the importance of camp and its special brand of education and peer bonding. But "regular" hemophilia camp–the place where we're all supposed to fit in–often isn't the right fit for kids with inhibitors. Why?

Because most children with inhibitors are not treating prophylactically, and many children with inhibitors have target joints and joint damage, some camp activities are off limits. Without prophylaxis, the chance of a bleed is greater because of the increased physical activity at camp. And because kids with inhibitors can't give themselves the exact puzzle piece that's missing–usually, regular factor VIII or factor IX–treating those bleeds takes longer. Sitting on the sidelines is common for kids with inhibitors.

Attendees at first Inhibitor Family Camp

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photos: Jane Cavanaugh Smith

Kevin Correa

There when you need us
Baxter's Commitment to the Hemophilia Community
sponsored by Baxter BioScience

An Ounce of Prevention: Maintaining Health in Your 50s and Beyond

Advances in medical care have resulted in longer lives for people with hemophilia. But after they reach 50, many face the same age-related medical conditions that afflict the general population, including heart disease, cancer, and joint disease.

Treating age-related illnesses in hemophilic patients is challenging for staff at the hemophilia treatment center (HTC). Why? Because there are no "textbook" cases or well-established guidelines to follow. If, as with so many hemophilic men over 50, HIV or hepatitis C is added to the equation, treatment becomes more complicated.

And when these health conditions go undetected–or when known, go untreated–they can quickly spiral out of control.

From Racing Boat to Recliner

Jeff Harper, 52, has severe hemophilia and hepatitis C. For most of his life, Jeff didn't let health concerns slow the pace of his energetic lifestyle.

His passions are diverse: from racing boats to fishing, from restoring cars to hunting. "I was a pretty active guy," Jeff says. "The pursuits I enjoy, while not always strenuous, involve a lot of movement and activity. Other than the chronic pain I experienced in my knee and hip, I generally felt healthy."

The pain in Jeff's hip was a concern for years. "The HTC had been good about sending me [for orthopedic exams]" Jeff recalls, "and the ortho guys would tell me what I already knew: I needed a new hip."

Pressing responsibilities in his career pushed Jeff to delay hip replacement surgery. But in 2009, the pain in his hip became unbearable, and he couldn't put off the surgery any longer.

First, he had to find an orthopedist with experience replacing hips in hemophilic patients. Once Jeff found the right doctor, he learned that the soonest he could schedule the replacement was nine months later.

As a result, Jeff endured several months of pain, immobilized in his house. Not surprisingly, he gained over 30 pounds.

Joint disease like Jeff's is common in aging hemophilic patients because prophylaxis wasn't widely available for most of their lives. And although it's not immediately life threatening, untreated joint disease often leads to a more sedentary lifestyle. In turn, this can trigger other medical conditions. Muscle atrophy, osteoporosis, and as Jeff experienced, weight gain are among the problems that may arise.

Weight gain deals a double blow. It puts more pressure on already stressed joints, and it also increases the risk of developing

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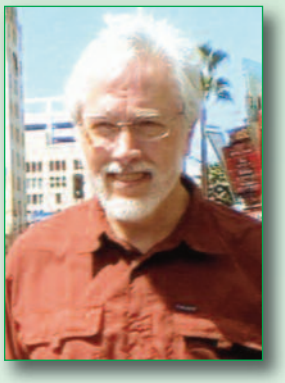
Being active was a priority for Jeff Harper until joint disease sidelined him in his 50s

Jeff roughs it during a hunting trip

Jeff and son John take a breather while saltwater fishing

richard's review

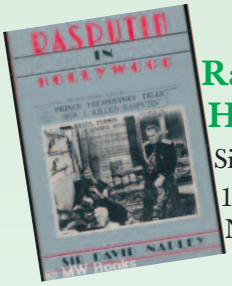


Ann Woodruff

Richard J. Atwood

Did you ever wonder what's behind those disclaimers shown at the beginning or end of movies, stating that the characters do not represent real people, either alive or dead? The answer is a famous film that prominently portrayed a boy with hemophilia–Alexei Romanov–and the ensuing trial after the film's release.

One of the old movie cable channels recently showed *Rasputin and the Empress*. I was amazed at how soon after the real events Hollywood decided to make the movie: only 15 years after the execution of Tsar Nicholas, Tsarina Alexandra, and the royal children, which ended 300 years of Romanov rule and allowed the Communists to govern Russia. The film led to a lawsuit that forced filmmakers to use disclaimers to acknowledge libel laws.



Rasputin in Hollywood

Sir David Napley
1989, Weidenfeld & Nicolson

Sir David Napley's *Rasputin in Hollywood* covers in detail the British lawsuit against Metro-Goldwyn-Mayer over the film. In 1933, less than six months after the American movie *Rasputin and the Empress* debuted in theaters, the movie was retitled *Rasputin the Mad Monk* and released in England. The wealthy Prince Felix Youssoupoff, who had written a book about his role in killing Rasputin in 1916 and eventually fled to Paris, considered suing MGM because the film's character Prince Chegodieff had defamed his image. Instead, Felix's wife, Princess Irina, brought suit because the film depicted Rasputin raping the character Princess Natasha, thus defaming Irina's image. Although the movie was filled with historical inaccuracies, and many characters and settings were altered, it stated that some characters were still alive.

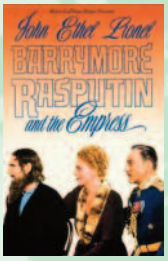
Irina's case went to jury trial in London in 1934, with the underlying legal questions of whether talking pictures represented libel or slander (an important distinction in English law), and whether a depicted rape of a character defamed the person supposedly represented. After four days of testimony by questionable expert witnesses, and two viewings of the film (with the sensitive scenes cut), the "special jury" of nine men and three women ruled in favor of the plaintiff, Irina. Appeal was denied. The legal ruling: a fictional rape that is shown or even alluded to, and that may depict a real person, is considered "defamation of character" if that rape did not actually occur.

After the trial, most filmmakers began using the disclaimer that the characters do not depict real people. Yet these disclaimers have no real legal strength because they don't prevent lawsuits, though lawyers still want to include them.

Napley, a British legal commentator and solicitor, was well qualified to summarize the 1934 trial, which he personally attended. In his book he points out most of the movie's historical errors, as well as legal errors made during the trial, although the nuances of English law may not be understood by all readers.

Despite the fact that Napley also made some factual errors of his own, his story of this trial demonstrates that legal proof does not equal the truth. Many subplots and much pertinent information never reached the jury, and MGM was never sued for the film's many other misrepresentations. MGM finally settled the 1934 lawsuit for $185,000 (translating to £1.8 million in 1989, when Napley published his book). Still, the film wasn't hurt: the extra publicity increased the film's attendance, and MGM was already making a profit.

Incidentally, there was a real Prince Chegodieff, who sued MGM for using his name even though it did not depict him in the movie, and won. The Russian exiles kept the lawyers busy.



Rasputin and the Empress

1933 [1999], MGM
Director: Richard Boleslavsky
Writer: Charles MacArthur
Cast: John, Ethel, and Lionel Barrymore
Academy Award nomination: Best Original Story

As the movie begins, Alexei (Tad Alexander) walks in a procession, yet later falls down while running in the Kremlin Palace garden, resulting in a right knee bleed. Alexei's doctor, with advice from a Viennese physician, explains the heredity of hemophilia and its effect on blood coagulation, and notes that a blood test exists. Alexander, who did not alter his Iowa accent, depicts hemophilia in a melodramatic style, similar to the performances of the Barrymores.

As Alexei screams in pain, Rasputin (Lionel Barrymore) uses his spinning pocket watch and his intense eyes to hypnotize the boy, who then falls asleep. After being healed, Alexei is able to walk. He never limps again during the film, but is carried down steps by his father the tsar on the way to the family's execution.

Film buffs, take note: this is the only movie to include all three Barrymore siblings in leading roles. What a shame that it was so poorly written.

Kathryn Ondek

Your Map to Insurance and Healthcare Reform

Pulse on the Road, sponsored by Baxter Healthcare Corporation, is a three-hour symposium that addresses insurance and healthcare reform topics of urgent importance to families with bleeding disorders. The program brings to life the pages of *PEN's Insurance Pulse*, the only newsletter dedicated to bleeding disorder insurance issues. The symposium is a combination of lecture and interactive workshop, giving families a chance to ask questions in a live forum.

Now in its second year, Pulse on the Road started its latest tour at Great Lakes Hemophilia Foundation's annual meeting at Wisconsin Dells on June 11. An audience of 85 people listened to experts from LA Kelley Communications, Baxter Healthcare, Patient Services, Inc., and National Hemophilia Foundation; and a representative from the state's chronic disease program.

The first part of the program looked at how changes in the hemophilia community over the past 15 years have created fertile ground for healthcare reform. "Insurance 101" reviewed key insurance terms and concepts. Results from a 2010 patient survey on healthcare were examined, followed by an overview of the Affordable Care Act. The second half featured three breakout sessions: Advocacy, Out-of-Pocket Expenses, and Medicaid.

Pulse on the Road was also presented in San Antonio for the Texas Bleeding Disorder Conference on June 26 to an audience of over 200 patients and families, with simultaneous Spanish translation. And the program made a third stop at Oklahoma Hemophilia Foundation's annual chapter meeting in Tulsa, July 30.

When attendees in Texas were asked if they had learned something new from the three-hour program, every hand in the room was raised!

Read more about Pulse on the Road events in 2011: http://www.kelleycom.com/events.html

Anderson Fine Arts

Pulse on the Road in Wisconsin

Anderson Fine Arts

Pulse on the Road visits at Great Lakes Hemophilia Foundation annual meeting

Laurie Kelley addresses Pulse on the Road attendees at Lone Star Chapter of NHF Texas Bleeding Disorder Conference

Zoraida Rosado of LA Kelley Communications gives $20 to an attendee for answering a question correctly

Pulse *on the Road*

Hemophilia of North Carolina Family Retreat
Pine Knoll Shores, NC
August 27, 2011

Bleeding Disorder Foundation of Washington
Location TBA
September 10, 2011

Hemophilia of South Carolina Annual Meeting
Myrtle Beach, SC
December 10, 2011

5 **Name the two types of private insurance.**

A. Fee-for-Service and Indemnity
B. Nontraditional and Preferred Provider
C. Traditional and Nontraditional
D. Point-of-Service and Exclusive Provider

Do You Know?

What type of insurance do you have?
Public or private?
Traditional or nontraditional?

6 **Many patients have an arrangement with their insurance company and physician that allows the physician's office to bill and receive payment for services directly from the insurer. What is this called?**

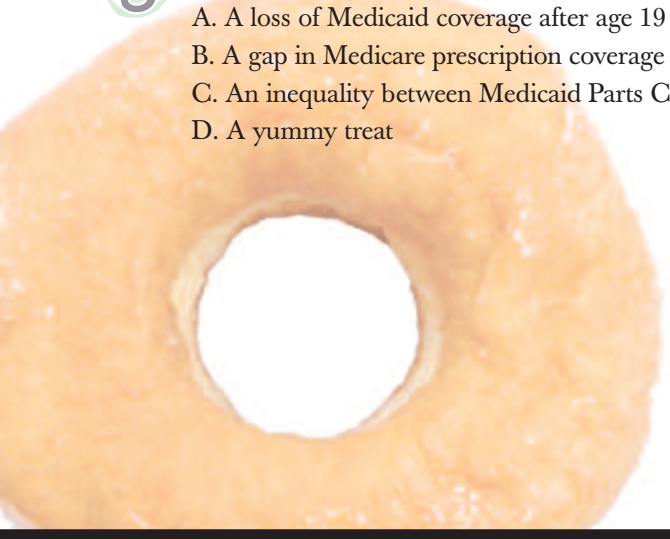
A. Insurance rider
B. Coinsurance
C. Fee for service
D. Assignment of benefits

7 **An *annual cap* is the maximum amount…**

A. your plan is allowed to charge for yearly deductibles.
B. your plan pays for healthcare services in a single year.
C. your plan allows per year for the pharmacy benefit.
D. your plan pays for healthcare services while you hold the policy.

8 **What's the *donut hole*?**

A. A loss of Medicaid coverage after age 19
B. A gap in Medicare prescription coverage
C. An inequality between Medicaid Parts C and D
D. A yummy treat



Know Your Insurance Plan

9 **What's the most important number to know when trying to estimate and manage healthcare costs, even when you have good insurance?**

A. Your plan's total premium cost
B. Your per-unit price of factor
C. Your plan's annual deductible
D. Your out-of-pocket maximum

10 **All of the following items should be in your health plan's Summary of Benefits except which one?**

A. Your coverage and eligibility information
B. Events that can cause you to lose coverage
C. Your rights to appeal a coverage decision or claim denial
D. Description of your bleeding disorder coverage

11 **Most insurance policies have two "sides": the medical benefit and the pharmacy benefit. Under which benefit is factor covered?**

A. Factor is always covered under the medical benefit.
B. Factor is always covered under the pharmacy benefit.
C. Private insurance covers factor under medical; public insurance covers factor under pharmacy.
D. Every plan differs.

12 **What's included in calculating out-of-pocket insurance costs?**

A. Deductibles and premiums
B. Copayments and coinsurance
C. Medical procedures not covered
D. All of the above

13 **Which of the following is not an example of an insurance policy *rider*?**

A. Adding coverage for pregnancy
B. Excluding coverage for hemophilia
C. Increasing hospitalization days for catastrophic care
D. Reducing your premium cost

What If...

14 Your employer offers more than one health insurance plan. How do you choose the best plan?

A. Ask your healthcare provider.
B. Talk with your HTC social worker.
C. Check the health plan's website.
D. Flip a coin.

15 You reach your health insurance plan's annual maximum. What must you do?

A. Pay all of your healthcare costs out-of-pocket.
B. Purchase a supplemental insurance plan.
C. Switch to another insurance plan.
D. Do nothing, because there are no annual maximums.

16 Your insurance company cancels your coverage. What should you do?

A. Call Patient Services, Inc.
B. Purchase donut hole insurance.
C. Appeal the decision in court.
D. Wait for your employer's next open-enrollment period.

17 Your insurance company tells you that from now on, you can't use your current Brand X factor, but must now use Brand Y. This is an example of…

A. Drug formulary
B. Malpractice
C. Preferred drug list
D. Capitation

Bonus Question!

Which tier is factor on?

18 You have applied for your state's pre-existing condition insurance plan (PCIP) coverage, and you must wait six months to qualify. Which of the following is *not* an effective way to obtain factor while you wait?

A. Your product's manufacturer
B. Patient Services, Inc.
C. Your home care company
D. COBRA

19 You are going to college, full- or part-time. How will you obtain health coverage?

A. High-risk insurance pool
B. Campus health center
C. Parental insurance
D. All of the above

20 Your 22-year-old son aged out of parental health insurance coverage. Now that healthcare reform has extended dependent coverage, can you get him back on your policy?

A. No.
B. Yes.
C. It depends on the policy.
D. You need to buy a second policy to cover him.

Matching

Match the acronym with its correct definition.

PCIP	Healthcare reform legislation enacted in 2010
ACA	Helps when you lose insurance, but it's expensive
RICE	Provides coverage for pre-existing conditions
COBRA	The amount the you must pay for deductible, coinsurance, copayments
PSI	Immediate treatment for acute injury
OOP	Provides coverage for uninsured children under 19
CHIP	Allows your doctor to bill your insurance company directly
AOB	Provides financial help with premiums and copayments

True or False?

21 **Take notes every time you contact your health insurance company.**

True
False

22 **Under healthcare reform, you are now required to share information about pre-existing conditions with prospective employers.**

True
False

23 **Once your child turns 19, he or she will automatically qualify for Medicaid.**

True
False

24 **All hemophilia treatment centers (HTCs) are in-network.**

True
False

25 **Medicaid has a lifetime cap.**

True
False

26 **Medicare has a lifetime cap.**

True
False

27 **Healthcare reform has completely eliminated lifetime caps.**

True
False

28 **Healthcare reform has completely eliminated exclusions for pre-existing conditions.**

True
False

Getting Help

29 **Who is the best contact when you need help dealing with health insurance and bleeding disorders?**

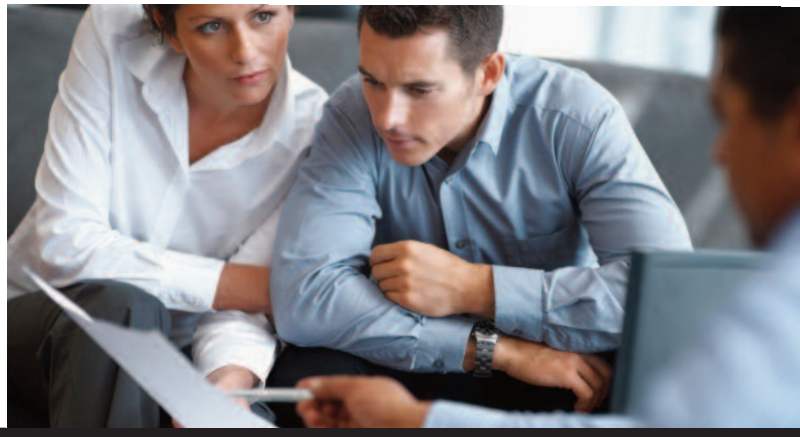
A. Your insurance plan's specialist in bleeding disorders
B. Your HTC social worker
C. Your employer's human resource representative
D. All of the above

30 **A special program provides health insurance to uninsured, low-income children under age 19, including the homeless. What is it called?**

A. CHIP
B. PCIP
C. HIPAA
D. PIPPA

31 **Which program offers insurance if you have hemophilia, have been uninsured for at least six months, and have been denied private insurance coverage?**

A. PCIP
B. PPACA
C. AHBE
D. HIPAA



Think You Know Healthcare Reform?

32 **What does ACA stand for?**

A. Annual Cost Assessment
B. Anti-Cap Annuity
C. Affordable Care Act
D. Alternative Care Agency

33 **ACA is the same as which of the following?**

A. ACAP
B. ACAPP
C. PACA
D. PPACA

34 **Who is now required to have health insurance under healthcare reform?**

A. People with pre-existing conditions
B. College students
C. Anyone with a bleeding disorder
D. All of the above

35 **According to healthcare reform legislation, up to what age can your child be covered under parental health insurance?**

A. 18
B. 21
C. 25
D. 26

36 **Health insurance *exchanges* are designed to create a competitive insurance marketplace where consumers can buy affordable, high-quality health plans. When will these new exchanges take effect?**

A. They are already in effect.
B. 2012
C. 2014
D. Exchanges have been cut from healthcare reform.

Bonus Question!

Why should the bleeding disorder community care about exchanges?

37 **When will most of the healthcare reform provisions take effect?**

A. They already took effect in 2010.
B. 2012
C. 2014
D. Never, because healthcare reform has been overturned.

38 **Which parts of healthcare reform don't apply *fully* right now?**

A. People up to age 26 can stay on their parents' insurance plans.
B. New health insurance exchanges are established.
C. Lifetime caps on healthcare benefits are eliminated.
D. All of the above.

39 **Healthcare reform legislation includes some insurance mandates (no lifetime caps, increased dependent coverage, eventually no pre-existing condition exclusions) that will raise costs for insurance companies. How might these costs be covered?**

A. Increasing the cost of premiums
B. Increasing direct patient copayments and deductibles
C. Adding a 10% tax on tanning services
D. All of the above

How did you do? Turn to page 17 to check your answers and get more information on each question. We guarantee you'll learn something new today!

Special thanks to Michael Bradley, Vice President of Healthcare Economics and Reimbursement, Baxter BioScience, for his expert advice and assistance with this quiz, and to Michelle Rice, Regional Director for Chapter Services, National Hemophilia Foundation.

a project share story

Kathryn Ondek

HEMOPHILIA FEDERATION INDIA
Healing Hemophiliacs in India Since 1983

PROJECT SHARE
It's time to give back

Gift of Factor IX from Kedrion

March 2011

With donations of factor IX difficult to come by, imagine our surprise when Project SHARE recently received over $1.1 million worth of factor IX. The gift was from Kedrion S.p.A., a global biopharmaceutical company headquartered in Italy, which specializes in the development, production, and distribution of plasma-derived products.

"We chose to donate our product to Project SHARE because the organization has an established relationship with an extensive network of hospitals worldwide, and a very strong reputation in the hemophilia community," notes Federico Rolando, Corporate Business Development at Kedrion and Operations Director at Kedrion Biopharma Inc. "We very much admire the efforts that Project SHARE has made over the years in order to provide factor to people in developing countries, and for this reason we are proud to work with them and support them in their mission."

The lucky recipient of this lifesaving gift was India, where the donated factor was distributed to many of the country's hemophilia chapters. Because of the high population of hemophilia patients in India, Project SHARE decided this was a country that needed our help.

"This donation was wonderful!" exclaims Dr. Kanjaksha Ghosh, president, Hemophilia Federation (India). "Think of all the hemophilia patients we were able to help. India has approximately 13,270 registered hemophilia patients, so the need for factor is great."

In 2010, Laurie Kelley visited hemophilia patients at King Edward Memorial (KEM) Hospital, Mumbai. "Laurie and I discussed various challenges faced by the patients," recalls Dr. Ghosh, "such as the difficulty of getting factor for their important surgical procedures." The extremely high price of factor IX in India makes it unaffordable for most of the 1,946 registered hemophilia B patients.

Then, less than one year later, the Kedrion donation of over 1 million IU of factor IX concentrates arrived in the form of AIMA IX and Uman Complex.

Hemophilia Federation (India) chapters shared 85% of the donated factor. The remaining 15% was kept at KEM Hospital to be used for surgeries. The donated factor, adds Dr. Ghosh, "has already saved four patients' lives in Pondicherry, Kunnamkulam, and Chennai."

For the many hemophilia B patients in India, says Dr. Ghosh, the precious factor donation "would have never been possible without the sympathetic ear, magnanimous heart, and Midas touch of both organizations."

Kedrion Biopharma Inc. is now the exclusive distributor of Koate®-DVI in the United States.

KEDRION
UNITED STATES

SAVE ONE LIFE

Become a Sponsor!

Help us celebrate our tenth anniversary by reaching 1,000 sponsorships. We have just over 250 deserving children and adults with bleeding disorders waiting for your support. It costs only 65 cents a day!

Go to Become a Sponsor at www.saveonelife.net or call 978-352-7652.

We look forward to welcoming you to our Save One Life family.

Imagine caring for your child with hemophilia—with no factor, refrigerator, running water, electricity, or transportation to a clinic.

This is the reality for thousands of families in developing countries.

For just $20 a month, you can help an impoverished child with hemophilia. Become a sponsor today!

www.saveonelife.net / contact@saveonelife.net
Caring for people with hemophilia around the world—one at a time.

Inhibitor Insights... from p. 4

An Idea Is Born

Sitting out is something our kids have accepted. But wouldn't it be nice if when you talked about being in pain, missing a lot of school, or regularly using crutches and wheelchairs, someone else nodded in agreement? Wouldn't it be nice if during self-infusion classes, someone else knew what it's like to get infusions three or four times a *day*–instead of a week? It's not unusual for a child with an inhibitor to be the only hemophilia camper with these added challenges, and that can be isolating.

The first seeds for family camp were sown when Laurie Kelley interviewed Jane Cavanaugh Smith, mother of a teen with inhibitors, for the book *Managing Your Child's Inhibitor*. Jane shared her appreciation of hemophilia camp, but also voiced her frustration. With Laurie's encouragement and knowledge of program planning and community needs, Jane left the interview with a mission: to give the inhibitor community a camp of its own.

Jane then brought me into the planning process. As CEO of Comprehensive Health Education Services, a company dedicated to providing health-care education related to chronic health conditions, I understood the infrastructure and commitment needed to pull off a large-scale program. And as the parent of a teen with an inhibitor, I shared Jane's experiences and motivations.

Blake Katzman, age 7, learns self-infusion at camp

Taylor Smith (left) and Mikayla Brewer (right) join the dancing

Zakary Jarrett, age 12, develops his archery skills

Inhibitor Family Camp 2010

The first Inhibitor Family Camp was held in October 2010 at Victory Junction Gang Camp in Randleman, North Carolina, with a generous educational grant from Novo Nordisk Inc. Kyle Petty (son of NASCAR racing icon Richard Petty) and his wife Patty founded Victory Junction in 2006 to honor their son Adam, who dreamed of starting a camp for children with serious health conditions. Sadly, Adam was killed during a NASCAR race before his dream became a reality. The Petty family partnered with the Association of Hole in the Wall Camps (founded by the late Paul Newman) to ensure that their camp would meet the needs of children with a variety of medical issues and physical abilities.

The goal of Inhibitor Family Camp 2010 was to strengthen families and the community through education and support. Camp featured guest speaker Lauren Mednick, PhD, from the Medical Coping Team at Children's Hospital Boston. With expert instruction, six young boys successfully self-infused for the first time. Peer support was strong all weekend, especially during the Parents' Rap Session, Super Sibs activity, and Teen Social. Children challenged themselves physically with archery, horseback riding, bowling, fishing, and mini-golf. And it didn't take long for even shy campers to join the dance party after every meal.

One camper's mom noted, "It was the first time in a long time that I have done anything in the hemophilia community that I have not left feeling frustrated. I felt like I could be myself. I didn't have to explain my child or worry that another family just didn't 'get' us." And one teen commented, "I stopped going to hemophilia camp because of the pressure they put on me to self-infuse. They don't understand that with the frequent and large-volume infusing I have to do, a central line works best. Here, I felt accepted for who I am."

Inhibitor Family Camp 2011

Inhibitor Family Camp will return to Victory Junction on October 14–16, 2011. Camp is open to families with children ages 6–19 who live with a measurable inhibitor; these children would not usually meet a true peer at regular hemophilia camp. Sessions will include Management of Pain in Children with Dr. Maureen Strafford, associate professor of anesthesiology, Tufts Medical Center, Boston, as well as informal rap sessions for parents. Optional self-infusion classes will help children perform that first needlestick, and special events will be geared to siblings and teens. Camp offers fun activities where families can play together with others who truly understand how their lives are affected daily by inhibitors.

A Stronger Community

One of the best aspects of inhibitor camp is the depth of connections made in one short weekend. Unlike a hotel conference setting, the informal camp atmosphere encourages us all to relax and open up, sharing our triumphs and fears. People who once greeted each other with a polite "hello" leave camp with heartfelt hugs, tears, and promises to stay in touch. Families develop a true sense of belonging through peer support.

For information on acceptance criteria and registration:
www.comphealthed.com/Inhibitor-Family-Camp.php

Janet Brewer has a master's degree in education from Simmons College, Boston. For 20 years she worked in public schools, teaching and advocating for children with unique learning needs. Janet has served her local chapter and NHF. In 2009, she founded Comprehensive Health Education Services (CHES) with business partners Eric Lowe and Daniel Reilly. CHES provides programming and training for people living with a chronic condition. Janet is the mother of Christopher, 22, and Stephen, 19, who both have severe hemophilia A; and daughter Mikayla, who is a carrier. Both boys have had an inhibitor, but Stephen's has not successfully tolerized.

Transitions... from p. 5

other issues such as heart disease, high blood pressure, and diabetes. And when you're in your 50s or older, weight gain increases your risk of other diseases and complications.

If I Knew Then What I Know Now

In 2010, Jeff received a new hip. "I felt like a million bucks after the surgery," he says. But looking back, he would have done things differently. The hip replacement was "something I should have done *much* sooner," Jeff admits.

Maintaining your health requires more than simply addressing concerns as they arise. For instance, a prostate exam isn't typically given to a 25-year-old because the incidence of prostate problems in that age group is so low. But as you age, the number of medical screenings you need increases, because your age itself becomes a risk factor for certain ailments.

For some diseases, such as colon cancer, early detection is crucial. Because colon cancer frequently starts as a small polyp, if detected early, it can be removed often before cancer has a chance to develop. If you're skipping your physicals, you may miss that window of early detection.

No less important is the need to tackle health concerns that aren't necessarily revealed in a screening. If you're worried about impotence, incontinence, or some other topic unfit for dinner table conversation, it can be challenging to bring these things up with your physician.

Medical issues that are difficult to discuss are also likely to impact your quality of life. But the sooner you address them, the sooner you'll see the positive differences that treatment can make.

Taking Control

Maintaining your health is a partnership with your HTC, especially in your 50s and beyond. But your responsibilities extend beyond the HTC walls. You–and you alone–are in control of two essential aspects of your health: diet and exercise.

Your metabolism slows as you get older, which means that even if you are eating the exact same foods, you might start putting on extra weight. There are several benefits to exercise that you probably already know about: exercise helps combat weight gain, relieving pressure on already stressed joints, and it reduces the risk for developing conditions like high blood pressure and heart disease. But exercise will also help you maintain your mobility as you age. And your mobility is directly linked to your quality of life.

Though it wasn't permanent, Jeff had a tough time dealing with his immobility. "I couldn't get around outdoors, or work on cars, or boat or fish. I lost so much of my lifestyle. My quality of life suffered."

Today, Jeff is getting his health back on track. No, he's not biking dozens of miles a day or logging his daily caloric intake. He's starting at a pace he knows he can sustain. And as he correctly notes, "Any exercise that doesn't exacerbate a health issue is worthwhile. It doesn't have to be strenuous to be beneficial."

Jeff is more mindful of what he eats, reducing his intake of sweets and soda. And thanks to his new hip, he can enjoy the outdoors again. "Right now, my wife and I take walks with our neighbors in the evenings," says Jeff, adding that he plans to supplement his walks with swimming at the gym.

Nobody is asking you to run a marathon or eat a diet of lettuce and tofu. But eating a healthy diet and exercising will certainly help you maintain, and perhaps improve, your health. If you're not in the habit of doing either, how do you begin? As usual, start with your HTC. They'll be able to recommend both nutritional and exercise programs that are appropriate for you.

To his peers in the hemophilia community, Jeff advises, "Don't do like I did and put off treatment. Talk to your doctors, listen, and plan ahead."

That's valuable advice, even for younger hemophilic men. Thanks to prophylaxis, better care, and safer factor concentrates, many of them will not experience the health issues that the generation before them endured. But Jeff's recommendation still applies to any age: visit your HTC annually and seek medical attention at the first sign of a problem.

headlines

nonprofit

Come to NHF's Annual Meeting

November 10–12

"Inspiration in the Windy City" is this year's theme for the three-day, 63rd National Hemophilia Foundation Annual Meeting offering educational sessions, networking opportunities, and social events for all ages. Individuals and families arrive with questions and concerns, but leave with answers, encouragement, and hope. Why this matters: It's the largest national hemophilia consumer meeting in the world.

Contact: sroger@hemophilia.org
www.hemophilia.org

Insurance Riders? Pledge Your Support!

September 15–17

Hemophilia Federation of America (HFA) will hold its first bike ride/fundraiser to benefit its Helping Hands program. Helping Hands provides emergency financial assistance to people with bleeding disorders. In 2010, HFA assisted 216 families with more than $90,000 distributed. Riders will embark on a 156-mile journey over the C&O Canal Trail beginning in Cumberland, Maryland, and finishing in Washington, DC. Why this matters: Many bleeding disorder families suffer during hard economic times, especially when insurance copayments are rising.

Make a tax-deductible donation:
info@hemophiliafed.org or www.hemophiliafed.org

Or mail check to: HFA
210 7th St. S.E., Ste 200 B
Washington, DC 20003

Click, Walk, Donate!

Become a "virtual walker" in the Virtual Walk for Hemophilia, and help NHF receive up to $60,000 in sponsorship funds while also raising money for your local NHF chapter! A new online campaign lets you create a walker using your photo and join the computer-based walk. The top three participating local NHF chapters with the most virtual walkers will receive sponsorship funds: first place $15,000; second place $10,000; third place $5,000. Bayer will also award up to $30,000 to NHF. Why this matters: Fundraisers like this make it easy for the entire community to give to support national and local nonprofits. Sponsored by Bayer Corporation.

For info: www.hemophilia.org

featured by LA Kelley Communications

My First Factor series is designed to help young children ages 18 months to 4 years understand their bleeding disorder

My First Factor: *Week*

My First Factor: Week helps toddlers adapt to regular infusions of factor. By Shannon Brush, mother of a son with hemophilia. Illustrated by Brooke Henson. Published October 2010 by LA Kelley Communications, Inc. Sponsored by Bayer HealthCare.

To order: www.kelleycom.com

My First Factor Song

"My First Factor Song" helps toddlers and young children understand the need to infuse. Lyrics by Carri Nease, mother of twins with hemophilia. Vocals by Frankie Weeks. Performed by Whole Music. Released June 2011 by LA Kelley Communications, Inc. Sponsored by Baxter Healthcare Corporation.

Download song and lyrics: www.thereforyou.com/song

manufacturer

Less is More: Extended Half-Life Products

Biogen Idec has signed an exclusive, worldwide research collaboration agreement with Amunix to develop recombinant blood coagulation factors VIIa, VIII, and IX with improved therapeutic properties. The two companies will jointly conduct preclinical research on novel protein therapeutics that incorporate Amunix's proprietary technology platform XTEN, which extends circulating half-life and reduces dosing frequency. Why this matters: Extended half-life products mean fewer infusions–good news for patients with tough-to-stick veins and those seeking a more normal lifestyle.

Source: *IBPN*, May 2011

Factor XIII: It Just Keeps Getting Better

The prevalence of factor XIII deficiency is about 1 per 2 million people, with an estimated 600 diagnosed patients worldwide. In February, the FDA granted marketing approval for Corifact®, CSL Behring's human plasma-derived factor XIII concentrate. Now Novo Nordisk Inc. has submitted a Biologics License Application seeking US regulatory approval for a recombinant factor XIII product. Why this matters: Until this year, factor XIII patients had to rely on plasma, which carries the risk of blood-borne viruses.

Source: *IBPN*, May 2011

Benvenuto Kedrion!

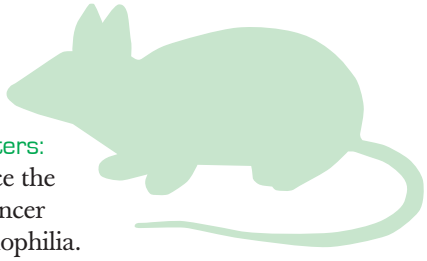
Kedrion S.p.A., an Italian plasma manufacturer, has entered the US market as distributor for Koate®-DVI, a plasma-derived factor VIII product. Koate-DVI was first produced by Bayer Corporation, then sold to Talecris Biotherapeutics several years ago. Talecris was just purchased by Grifols. Why this matters: Consolidations and acquisitions continue in the hemophilia community, and consumers need to know if and when their products change hands.

For info: www.koatedviusa.com
www.kedrionusa.com

KEDRION
UNITED STATES

science

The Mouse That Roared "Cure"



In a study led by Dr. Katherine A. High, a hematologist at the Children's Hospital of Philadelphia, mice with hemophilia B were cured of the disorder through a novel form of gene therapy. First, the study team developed enzymes that were able to cut the defective gene for factor IX from the chromosome. Then the team packaged these enzymes in a genetically engineered virus (adeno-associated virus, or AAV) targeting the liver where factor IX is produced. The team also produced a second set of AAV, which carried a "good" gene for factor IX. When both of these viruses were injected, one set of AAV cut the defective gene for factor IX from the chromosome; this allowed a good gene (from the second set of AAV) to be inserted into the space left by the defective gene. Why this matters: This could significantly reduce the unintentional formation of cancer cells while trying to cure hemophilia. Currently, when genes are delivered to a cell by a virus, the genes are randomly inserted into the chromosome, sometimes resulting in cancer. By cutting out the defective gene, the chance of the correct gene being inserted into the correct location on the chromosome is improved, reducing the chance of inducing cancer.

Source: Children's Hospital of Philadelphia, www.chop.edu

Pump It Up: New Device to Inject Factor

Medgenics is developing Biopump, a technology for the sustained delivery of therapeutic proteins to treat hemophilia A. Skin cells obtained by a biopsy are genetically engineered to produce factor VIII by infecting them with a virus carrying a good copy of the factor gene. The cells, now able to produce clotting factor, are reimplanted on the patient's own skin, where they continue to produce factor. Medgenics has entered into an agreement with Baxter Healthcare Corporation for the joint development of the factor VIII Biopump. Why this matters: Medgenics believes this approach has multiple benefits compared with current treatments, which include regular, costly injections.

Inhibitor Development: Does Product Choice Matter?

Italian investigators who reviewed and analyzed published clinical results have found that product choice does not seem to affect the risk of inhibitor development in previously untreated children with severe hemophilia A. Data from 800 patients enrolled in 25 studies published between 1990 and 2007 found that the inhibitor incidence rate did not differ significantly between recipients of plasma-derived and recombinant factor VIII concentrates. Why this matters: Some have rushed to blame the purer recombinant products for triggering inhibitors, but in truth, no one yet knows why inhibitors develop.

Source: *IBPN*, May 2011

Inbox... from p. 2

THANK YOU SO MUCH FOR THE ARTICLE on CT scans. My son has severe hemophilia A and is 3 years old. At 12 months, he was learning to walk and fell on cement, bumping his head. We took him to the local ER for on-demand treatment, and they automatically wanted a CT. My son showed no signs of concussion or severe injury. We were just following hemophilia 101 and getting him his factor infusion. I questioned three different doctors about why he would need a CT when he would be getting dosed 100% with factor. Not one of those doctors could give me a compelling reason to have a CT except that it was protocol. Even a call to my HTC did not convince me, and in the end he had the CT. I was still new to hemophilia and hadn't perfected my advocating abilities. I hope other parents will read your article, now that CTs are more scrutinized, and ask questions and push back. I would not hesitate to sign a waiver if I was put in the same situation today. I believe CT scans are very important, but I also know my child.

Heidi Forrester
Washington

I WAS PLEASANTLY SURPRISED TO SEE ONE of my Comfy Caps Kids on the last page of the article about head trauma and CT scans. The goal of Comfy Caps is to take the stigma out of protective headgear and give children with special needs the dignity they deserve. Comfy Caps was founded because my son has a rare platelet disorder that specialists nationwide have yet to figure out. He's eight years old and just an amazing little boy!

Leah J. Brundage
Founder/Owner, Comfy Caps
www.comfycaps.biz

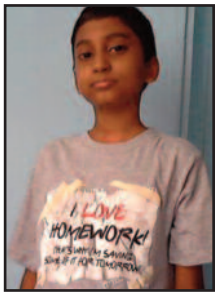
Project SHARE

AFTER MY TWO CONSECUTIVE SURGERIES for a pseudotumor, I am already out of the hospital and recovering! This would never have happened without your constant support. I will always be grateful to everyone involved in prolonging my life through a successful operation. After three recurrences of the pseudotumor, I'm happy to say that there are no signs of bleeding now, and no signs of recurrence–that is the power of factor VIII. I

am in physical therapy to restore my leg power because after a month of no weight-bearing or walking, I can't walk without crutches. I've noticed an improvement, and maybe soon I can go back to work. Thank you all, and God bless. Kindly extend my gratitude to all who made this donation possible. Maraming Salamat Po!

Randolf Apanay
Philippines

THANK YOU AND PROJECT SHARE VERY much for the factor I received for Adrian. After he received the factor, the blood in his urine has stopped completely. May God bless you so that you can continue the good work you and your team are doing.



Lillawattie Dass
Guyana

Test Your Knowledge... from cover

Check Your Answers!

1. Correct: C. Most uninsured people have moderate or low incomes, pay for more than a third of their care out-of-pocket, and don't have enough cash, savings, or investments to pay medical bills if a family member is hospitalized.

2. Correct: B. Currently, about 16% of most state budgets cover Medicaid costs. In the coming decades, the cost of Medicaid is expected to rise faster than the overall cost of healthcare for several reasons, including increased enrollment.

3. Correct: A. B defines a *copayment*. C defines *coinsurance*. D defines a *maximum*, or cap.

4. Correct: B. Medicare is a public health insurance program–paid for by the government–that covers people over age 65 and people with certain chronic medical conditions, including bleeding disorders. Blue Cross Blue Shield and Anthem are examples of private health insurance, available through employers and also sold to individuals. Tricare is a military health insurance plan.

5. Correct: C. The two types of private insurance: (1) *traditional* indemnity plans (also called Fee-for-Service or FFS) and (2) *nontraditional* managed care plans, which include Health Maintenance Organizations (HMO); Preferred Provider Organizations (PPO) or Exclusive Provider Organizations (EPO); and Point-of-Service (PPO) plans. About 90% of families with hemophilia use nontraditional managed care plans.

6. Correct: D. Assignment of benefits (AOB) allows patients to request that health benefit payments be made directly to a physician or hospital. Medical providers may refuse to accept AOB if they would rather bill their patients directly. Advantages? Patients don't have to deal with claim forms. Disadvantages? It's harder to track your insurance costs. Remember: regardless of any AOB, you are fully responsible for payment of your medical expenses. If an insurance company rejects your insurance provider's claim, the physician will bill you directly.

7. Correct: B. An annual cap, or maximum, is the amount that your insurance plan will pay for healthcare services *during a specific year*. After you reach the cap, you are responsible for paying all your bills for the rest of that year. Not all policies have annual caps, so check your policy carefully. This is different from a lifetime cap (answer D). Under healthcare reform legislation, lifetime caps on health insurance policies have been eliminated and are being phased out (see question 27). Good news: healthcare reform prohibits new plans and existing group plans from imposing annual caps on insurance coverage as of Jan. 1, 2014.

8. Correct: B. Most plans with Medicare prescription drug coverage (Part D) have a coverage gap called the donut hole. After you and your prescription plan have spent a certain amount for covered drugs (typically $2,840), you must pay all prescription costs out-of-pocket, up to a yearly limit (typically $4,450). Once you've reached that limit, the donut hole coverage gap closes, your prescription plan again helps to pay for your covered drugs (called catastrophic coverage), and you are responsible for a small copayment. Healthcare reform included benefits to make Part D more affordable by gradually closing the cover-

age gap. Starting Jan. 1, 2011, when you reach the donut hole, you'll automatically get a 50% discount on covered brand-name drugs and a 7% discount on generic drugs.

9. Correct: B. Factor is the most expensive aspect of bleeding disorder treatment. If you don't know your product's per-unit cost, call your factor provider and insurance company today.

10. Correct: D. A Summary of Benefits should come with every health insurance plan, and should contain items A, B, and C, plus an explanation of your rights to continued coverage if you or your dependent should lose eligibility. It's your job to read and understand your Summary of Benefits. But you'll need to know how this summary relates to your bleeding disorder coverage. Discuss it with your health insurance company, doctor's office or HTC, and employer's human resource department.

11. Correct: D. For most people with bleeding disorders, factor is covered under the medical benefit (major medical), which covers all clinical services such as doctor visits, diagnostic tests, surgery, and inpatient drugs. If factor is covered under your pharmacy benefit, you may have to pay a percentage of factor costs as a copayment.

12. Correct: D, usually. Your out-of-pocket (OOP) costs are the medical care expenses that aren't reimbursed by your insurance plan, plus the cost of any services not covered. Check your plan's Summary of Benefits, speak with your employer's human resource specialist, or talk to your HTC social worker to help understand and predict your annual OOP costs so you can budget for them.

13. Correct: D. Riders are legal documents that modify coverage under a specific insurance policy. Riders can add coverage, or take it away.

14. Correct: B. Insurance expert Mike Bradley answers: "The most proactive thing for patients and their caregivers to do is to get all the information they can from their employer, and then work with their HTC social worker to thoroughly assess their options." Make an appointment to speak with your employer's human resource specialist and your HTC.

15. Correct: A. The annual maximum (cap) is the dollar amount of benefits your health insurance will pay per year. Annual caps may be placed on services such as prescriptions or hospitalizations, and may be based on the dollar amount or the number of visits. After you reach your annual cap, you are responsible for paying the remaining costs for the year. Remember: between now and 2014, healthcare reform legislation is phasing out annual caps, but your current policy may still have one.

16. Correct: A. Patient Services, Inc. (PSI; www.patientservicesinc.org) is a nonprofit that helps people with chronic, costly medical conditions pay their premiums or copayments. PSI offers many kinds of financial assistance, and helps people secure factor during coverage gaps. There's no such thing as donut hole insurance (see question 8). Even if you choose to appeal a coverage cancellation, you'd still be without coverage for a time and you'd need to fill the gap; the same is true of waiting for the next open-enrollment period.

17. Correct: A *and* C. For private insurance, the list of medications that the plan will cover is called a drug formulary. For public insurance, this is called the preferred drug list (PDL). Formularies and PDLs are a way for insurance companies to control the costs of prescription medications. A formulary or PDL can include both brand-name and generic drugs; it may also use *tiers*, or classifications of drugs, to create a pricing scale.

Bonus answer: Factor is usually covered under the medical benefit, so no tiers. But when factor is covered under the pharmacy benefit, it may be on a formulary tier—normally tier 4 *specialty drugs*, the most expensive. Most health plans use two or three tiers (generic, brand, and preferred brand) and charge a set copayment for each. For tier 4 drugs, plans may either charge a copayment or coinsurance (see question 3), which could be between 20% and 40% of the drug's cost—or even higher.

18. Correct: D. COBRA (www.dol.gov/ebsa/cobra.html) is a federal program that allows you to pay your previous health insurance premium (plus a 2% administrative fee) to maintain health coverage for up to 18 months if your employment ends or you lose coverage for another qualifying reason. But even with increased government participation, COBRA is still unaffordable for most people who have lost their jobs. If you have COBRA, you have health insurance, so you can't qualify for PCIP coverage. Begin looking for help by contacting your HTC social worker.

19. Correct: D. These are all possibilities—some better than others—depending on age and eligibility guidelines. Effective for plans beginning on or after Sept. 23, 2010, healthcare reform allows people up to age 26 to remain on a parental health plan, with few exceptions. Students without parental insurance can sign up for a school plan through the campus health center, but that will likely be inadequate for bleeding disorder treatment. If you're over 26, Mike Bradley advises, "You'll need to find additional forms of insurance. That's difficult for hemophilia patients because they can't get an individual plan or qualify for most Medicaid plans. Their best option is to apply to get on a high-risk pool plan, but to qualify they must be uninsured for six months."

20. Correct: C. Begin by contacting your insurance company and asking how to get your son back on your existing insurance policy. Healthcare reform required all insurers to expand dependent coverage by Sept. 2010, but also states that this change doesn't have to take effect until the plan's open-enrollment period. Health insurance plans are also required to send this information directly to all plan enrollees.

21. Correct: T. Always document every contact with your insurance company. Get names and phone extensions of people you speak to, record times and dates, and take notes on everything discussed. You may need this information later—for example, if you must appeal a claim.

22. Correct: F. You do not have to share any personal health information with prospective employers. (See PEN, Aug. 2010, "Transitions," for an interesting take on disclosing your medical condition online.)

23. Correct: F. States are required to provide Medicaid for children until they turn 19. Medicaid, along with CHIP (see question 30), helps lower the number of uninsured children. But when children turn 19, they may lose their age-based Medicaid eligibility, and adult Medicaid eligibility guidelines may apply instead. In 2010 more than 40% of young adults who were previously covered by Medicaid or CHIP became uninsured after age 19. One reason? This age group has trouble finding jobs that provide adequate health insurance.

24. Correct: F. HTCs may be in-network or out-of-network, depending on the health plan. Never assume anything—talk to your insurer to find out.

25. Correct: F. There is no lifetime cap on Medicaid.

26. Correct: F. Medicare has never had a lifetime cap on benefits. But it does have caps on what it will pay for certain procedures and hospitalization days.

27. Correct: T, but not yet. Under the new law, lifetime caps are being phased out. Beginning Sept. 23, 2010, individual and group health insurers are prohibited from placing a lifetime limit on the aggregate dollar value of coverage. So watch out: your policy may still have a lifetime cap. And if your plan is grandfathered—if it existed on or before March 23, 2010—it may be exempt from some parts of healthcare reform legislation.

28. Correct: T, but not yet. The new law includes rules to prevent insurance companies from denying coverage to children under age 19 because of a pre-existing condition, effective for plans beginning on or after Sept. 23, 2010; for new plans; and for existing group plans. Effective Jan. 1, 2014, the law prevents insurance companies from refusing to sell coverage or renew policies for anyone because of a pre-existing condition.

29. Correct: D. You should have a consistent contact person, starting with your HTC social worker, and also at your health insurance company and place of employment. Your contacts should understand your situation and needs, and should know how your plan covers bleeding disorders. Cross-check everything! Remember: you may need to educate your insurance company about bleeding disorders.

30. Correct: A. The Children's Health Insurance Program (CHIP) was originally called the State Children's Health Insurance Program (SCHIP). Based on federal guidelines, each state determines its own program's eligibility rules, benefits, payment levels, and operations. Check your state government's website for information on its CHIP program.

31. Correct: A. Pre-Existing Condition Insurance Plan (PCIP) was developed as a bridge to provide coverage until 2014, when health insurance exchanges are established (see question 36) and

you can no longer be discriminated against because of a pre-existing condition. But if you're enrolled in a state high-risk pool, you are not eligible for PCIP. PCIP plans differ state to state. To learn more: https://www.pcip.gov. PPACA: see question 33. AHBE: see question 36. HIPAA is the Health Insurance Portability and Accountability Act of 1996.

32. Correct: C. US healthcare reform, or the Patient Protection and Affordable Care and Act (PPACA), was passed by Congress in March 2010. It's now known as the Affordable Care Act or ACA. The act contains many benefits for the bleeding disorder community.

33. Correct: D. PPACA and ACA refer to the same healthcare reform legislation. PPACA stands for Patient Protection and Affordable Care and Act.

34. Correct: D. Under ACA, most people are required to have health insurance. Who is exempt from obtaining insurance or paying the penalty? People who would have to pay more than 8% of their income for health insurance; people with incomes below the threshold required for filing taxes; people who qualify for religious exemptions; undocumented immigrants; people who are incarcerated; and members of Indian tribes.

35. Correct: D. As of Sept. 23, 2010, your child with a bleeding disorder can stay on a parent's insurance until age 26, even if he or she marries or is a full-time student. (See question 19.)

36. Correct: C. As of Jan. 1, 2014, if your employer doesn't offer insurance, you can buy it directly in an exchange. An American Health Benefit Exchange is a state-directed website that will match uninsured people with providers of either public or private health insurance. According to the Department of Health and Human Services, exchanges will increase competition among private insurance plans through comparison shopping and better-informed consumers, and will pool small businesses together, giving them the purchasing power of large businesses.

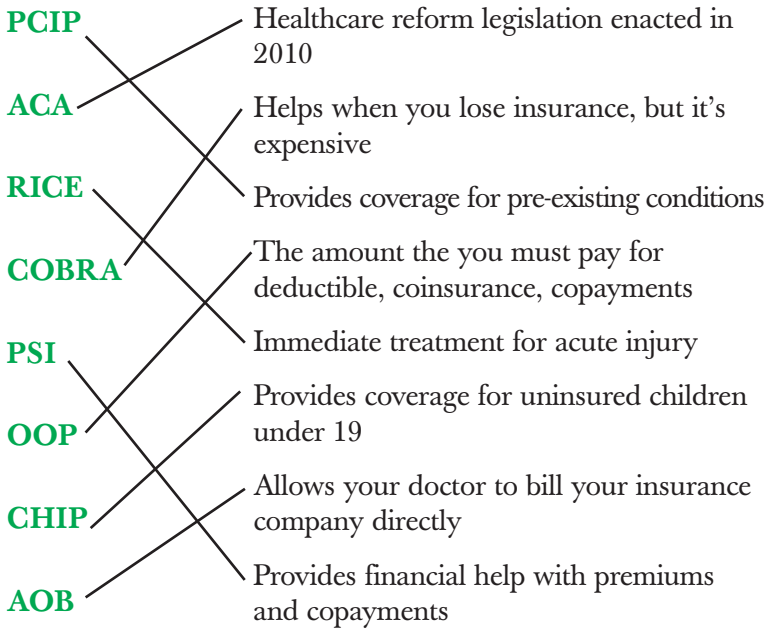
Bonus answer: In theory, exchanges should be positive: they offer a choice of health plans that meet certain benefits and cost standards, and allow you to compare plans in your state based on price and quality. People who buy insurance through an exchange may qualify for tax credits to help reduce premiums and out-of-pocket costs; ask your HTC social worker to help you find out if you qualify.

37. Correct: C. Most of ACA's provisions will take full effect in 2014. Although Congress continues to debate healthcare reform, the legislation has not been overturned. For a list of ACA provisions by year: http://www.healthcare.gov/law/about/order/byyear.html

38. Correct: B. Already, ACA allows people up to age 26 to stay on parental insurance plans. Healthcare exchanges won't take effect until 2014, although some states have already established exchanges. And although the legislation prevents insurers from placing lifetime limits on policies that started on or before Sept. 23, 2010, lifetime caps for other policies will not be fully phased out until 2014.

39. Correct: D. One of the concerns about ACA is who pays for the higher costs of healthcare reform. Many employers fear that premiums will rise, increasing the overall cost of business. Patients worry that out-of-pocket costs will rise. In its current form, ACA has various provisions, including a 10% tax on tanning services, to help offset the increased costs. Sound crazy? Look it up!

Matching – Answer Key



Pre-Existing Condition Insurance Plan (PCIP); Affordable Care Act (ACA); Rest, Ice, Compression, Elevation (RICE); Consolidate Omnibus Budget Reconciliation Act (COBRA); Patient Services, Inc. (PSI); out-of-pocket (OOP); Children's Health Insurance Program (CHIP, originally called SCHIP); assignment of benefits (AOB)

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Parenting Moment

It's always been my feeling that God lends you your children until they're about eighteen years old. If you haven't made your points with them by then, it's too late.
–Betty Ford

To us, family means putting your arms around each other and being there.
–Barbara Bush

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