

# PEN

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## Running on Empty? It's Time to Care for the Caregiver

*Laurie Kelley with Dan French*

A social media firestorm erupted last year when Maria Kang, a striking 32-year-old fitness enthusiast, posted a glamorous photo of herself on Facebook, exhibiting the sleek body and rock-hard abs of a toned athlete, with her three children, all under age three, at her feet.<sup>1</sup> Her caption “What’s Your Excuse?” caused the post to go viral, with over 16 million views. Stressed, harried moms united to blast her with hundreds of angry comments.

*Excuse?* How about genetic predisposition to weight gain?

How about illness, family crisis, unemployment, accidents, single parenthood, caring for elderly parents...and obviously, Kang doesn’t have a child with a chronic blood disorder. Hospital visits, surgeries, port infections, infusions, inhibitors, bleeds, menorrhagia, lost days from school and work. Hey Maria, try a few days in our running shoes.

And yet, take away the virtual hype, and Kang’s post should make us think. Are we, the caregivers—especially moms—taking care of ourselves? Does stress make us ignore our health? It’s a fact that chronic stress is a risk factor for poor health, particularly weight gain. And weight gain is a major health problem in America. National statistics are startling: over 68% of Americans are overweight, with 34% obese, and that number rises annually.<sup>2</sup> Somehow, stress is hurting our health, and we’re not doing a good job countering it.

Let’s examine what happens to the body under stress, see how chronic stress affects our health, and learn what we can do, slowly and incrementally, to take better care of ourselves. Let’s improve our health as caregivers—now.

*“My anxiety and stress hit the roof with two toddlers with severe hemophilia, 21 months apart. Crawling, climbing, learning to walk, navigating infusions, when to start prophylaxis, whether to get the boys ports...it was all so much, for me and the boys, their big sister, and my marriage too. I felt alone, often sad, depressed, and stressed.”*

*—Rebecca Robbins*

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1. www.mariakang.com; www.facebook.com/MariaMKang.  
2. frac.org/initiatives/hunger-and-obesity/obesity-in-the-us/. Accessed 10.14.14.

# welcome

I've always been small-framed with a high metabolism, thanks to genetics. Staying slim was aided by growing up with six rambunctious brothers. I was the girl everyone hated in college: I could eat anything and didn't put on weight.

Boy, did that change as I hit middle age, after having three children. And my genetic advantage? Diabetes runs rampant in our family, so abdominal fat (a risk factor for type II diabetes) must be avoided. Genetics also gave me a child with hemophilia. Childcare and a grueling travel and work schedule slowly killed off most exercise. I was too busy—or too tired. By age 39, I was putting on extra abdominal weight. Fearful of the sword of diabetes hanging over my head, I kicked myself into gear at age 40 and started working out. My first attempt at running was painful: half a mile, and I was cooked.

But working out improved over time. My kids got more independent. I put fitness first. I soon shed the third-baby fat, and my weight plummeted. But I—the road warrior—pulled a tendon and suffered a back spasm that lasted eight years off and on. Why? Too much stress on my body, not enough stretching, and eating very little protein. I hung up the running shoes for a *long* time. And I complained about my aching back *all* the time.

At age 54 I set a personal challenge: climbing Mt. Kilimanjaro in Africa, a six-day hike over unforgiving terrain. I was nervous about my back, and to prepare for the climb, I just kept repeating the kind of exercising I had always done. But my weight wasn't budging (I had gained 17 pounds by now) and my fitness level plateaued.

That's when I discovered Dan French, a local personal trainer, and began more effective workouts. Dan got me in shape for Kilimanjaro. In two months, I had dropped ten pounds of fat, gotten toned, and overhauled my entire diet. Protein was paramount. I learned when to eat, how to eat, and what to eat. My weight steadied, but its composition changed dramatically, from 27% fat to 22%. Believe me, that's a big difference: I was putting on muscle.

Kilimanjaro wasn't easy, but I summited, with no back pain. Inspired, I kept Dan as my trainer. Three years later, I feel like I have my 25-year-old body back. Now at age 57, I can run eight miles. I cycled 105 miles in seven hours for a charity ride. I have energy to spare, and this year I wore a two-piece bathing suit for the first time in 30 years. (Now, I'm not saying I *look* like a 25-year-old. But given a C-section, stretch marks, and the

Never too old: Laurie Kelley, 57, with trainer Dan French



Karina Bernard Photography

effects of aging on my skin, I'd say not too shabby.)

Having a proper diet and keeping fit also helped me weather one of the most stressful times in my life: ending my 30-year marriage. Along with my family and faith, Dan's exercise and diet regimen became my anchor.

As mothers, it's hard to put ourselves first, but it's crucial that we value ourselves as much as we value our families. I've learned that we can all make changes, however slight, that will improve our health at any age.

Most of all, I've learned that the human body is an amazing machine that yearns to shine and excel. It responds to anything you do to it. Ignore it—stay sedentary and eat unbalanced meals—and you end up with injuries and backaches, like me, and maybe even trigger hereditary problems such as diabetes or heart conditions. Give your body consistent attention, and it will reward you, protect you, and carry you far.

As for me, I'm looking *forward* to my 60s, coming up way too soon! ☺

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EDITOR-IN-CHIEF Laureen A. Kelley | SCIENCE EDITOR Paul Clement  
CONTRIBUTING WRITER Richard J. Atwood | 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

Kimberly Philo



Kim Philo

## Active with Hemophilia



Spin cycle: Kim with son Alex

As parents, it seems we always believe that our children come first, that nothing is more important. Guess what? If we don't begin by taking care of ourselves, it becomes increasingly difficult to take care of our children.

This morning, as I was out pounding the pavement, training for my first marathon, I was thinking about the conversation I had with Laurie Kelley about how to write this article. She helped me to realize I must take a step back and look at myself as if I were looking from the outside in. How can I start carving out time for myself?

I am one of the rare females with moderate hemophilia: 2% factor VIII deficient, to be exact. I wasn't diagnosed until age 11, after I hit my knee on the playground at school. Because I was a girl, hemophilia was not the first thing the doctors considered. I went several weeks without the proper diagnosis. As many readers may know, the longer you go without factor for a bleed, the greater the potential for damage. I have lived with hemophilia complications all my life, due to my target knee joint.

After I had worked for years to become more capable of managing my bleeding disorder, my husband Jeff and I had a son. We assumed we could handle whatever hemophilia threw our way, because we now had experience, but we were thrown a bigger curve ball than we could ever have imagined. Not only does our son Alex have severe hemophilia A, but he was also born with developmental delay, global hypotonia (making it very difficult to maintain balance and muscle control), and cortical visual impairment. Alex developed inhibitors before he was two years old, after his first surgery. Now, at age 12, he is still nonverbal and nonmobile...a total-care child.

Talk about stress! Time for myself? That seemed like a pipe dream. Every day seemed filled with taking care of Alex's needs.

So, the question again: How do we carve out time for ourselves? I admit that when Alex was born, it was a difficult period in our lives. We definitely didn't take the personal time we needed, and that was clear to all who knew us. For me,

food was a comfort. I gained weight, and for a person with hemophilia, the heavier you are, the more stress it adds to the body—especially the knees, hips, and ankles. This needed to change. I had to find something that would motivate me toward a goal of better well-being.

About six years ago, Jeff and I decided to celebrate our anniversary by joining a gym together, and started the crazy idea of taking care of ourselves. Because of Alex's needs, we worked out "together" by taking turns at the gym. For me, with a target knee joint, I started my road to better health in the swimming pool, doing as many laps as possible. Once I had built up more muscle strength in my legs, I added biking. After several months of that, I added running.

In July 2011, I participated in the largest organized bike ride in the world, RAGBRAI (Register's Annual Great Bicycle Ride Across Iowa, sponsored by the *Des Moines Register*) for seven days and 464 miles. Never in my wildest dreams did I think I would be able to do that with a target knee joint! After a few months of biking, I had gained significant muscle strength around my knees, so I decided to start running. Eventually, I ran my first 5K!

Since that time, I have completed many 5Ks, several 8Ks, a 10-mile run, seven half-marathons, two more RAGBRAI bike rides, and three Gears For Good bike rides (raising money and awareness for people with bleeding disorders). Currently, I am training to run the Disney Marathon in January 2015. Talk about never in my wildest dreams!

As parents, Jeff and I want to show Alex that anything is possible, despite whatever you may think is in your way. Don't let hemophilia stop you. Instead, make it a reason to be strong and stay strong.

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## How to Use Pain Meds Safely

### Part 1

**P**ain is no stranger to people with hemophilia: joint bleeds are painful, and repeated bleeds into a joint cause damage to cartilage, resulting in a painful form of arthritis called *hemophilic arthropathy*. A trip to your medicine cabinet usually yields some form of painkiller (analgesic) to get you through the worst of the pain. But when you have inhibitors, you may need something stronger for prolonged bleeds or chronic arthropathy.

Most people don't think twice about taking analgesics. But these meds can potentially kill: every year, many people overdose accidentally. People with inhibitors frequently need painkillers and may be at higher risk of serious side effects. When was the last time you thoroughly read the package insert on your pain med? What do you need to know to be safe when taking pain meds?

### Two Types of Pain

Pain is either *acute* or *chronic*. Acute pain lasts hours or days. Chronic pain lasts six months or longer. Acute pain is considered necessary, even beneficial—alerting our bodies to danger or injury, and prompting us to protect ourselves or get treatment. But chronic pain is a disease state in itself, and is often

destructive and debilitating, harming our general well-being.

If you have hemophilia, your acute pain is usually caused by bleeding that leads to swelling in joints and muscles. Chronic pain, by contrast, is usually caused by arthritis in joints, a result of repeated bleeds that have damaged the joint's cartilage—a common problem for many people with inhibitors. The two types of pain require different treatment approaches and different pain meds.

Proper treatment of pain depends on the type you have. Pain meds are divided into two broad groups: *opioid* and *non-opioid*. Mild acute pain, like a headache, is often treated by non-opioid over-the-counter (OTC) pain meds, available without a doctor's prescription. There are two basic types of OTC pain relievers: (1) acetaminophen and (2) a broad class of drugs called non-steroidal anti-inflammatory drugs (NSAIDs), such as naproxen and ibuprofen.<sup>1</sup>

Opioids, such as morphine and oxycodone, are available only with a prescription. These meds are used to treat moderate-to-severe acute pain and chronic pain.

When used as directed, pain meds are usually safe and effective. But when misused, all pain meds can be dangerous and even deadly. Most drug overdoses are not intentional, but are

caused by ignorance. People don't read product inserts carefully, or they combine multiple drugs, not realizing that this could result in an overdose or make their normally safe medication toxic. Also, many people believe that because OTC drugs are available without a prescription, they must be safe and can be taken without harm. Not true! In fact, OTC pain meds are powerful drugs that can be deadly, and they should be used with caution.

What do you need to know about pain meds to keep yourself or your child safe? In the first of this two-part series, we'll look at the risks of acetaminophen, the most commonly recommended pain med for people with hemophilia.

### Acetaminophen

For hemophilia, acetaminophen (Tylenol®, Excedrin®, Anacin®) is the most often recommended drug for mild-to-mild/moderate pain because it's generally effective, and it doesn't affect the blood's clotting ability, like almost all NSAIDs do. Acetaminophen reduces pain and fever and won't cause gastrointestinal bleeding, as NSAIDs can. But acetaminophen has no anti-inflammatory properties, as NSAIDs do, to help reduce swelling in joints and muscles.

When taken as directed, acetaminophen is generally safe. Over 50 million Americans use acetaminophen weekly, but it can cause liver damage. Don't take a higher dose than is recommended. Don't take acetaminophen for more than ten days or while drinking alcohol.

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1. High-dose NSAIDs for moderate acute pain are available by doctor's prescription.

Richard J. Atwood



Linda Weaver's Studio

# Honoring Hemophilia Social Workers

The single red rose on the cover catches your eye first. Then, the title and its lengthy subtitle grab your attention. Looking inside at the contents, you know you're holding a treasure.

The book is *A Journey of the Heart: Hemophilia Social Workers' Stories of Patients and Mentors Who Forever Changed Their Lives* (Park Place Publications 2013). Editors Linda Gammage and Dana Francis, themselves hemophilia social workers, began the Stories Project by asking other hemophilia social workers across the United States and Canada to "write from the heart" about their personal mentors, and about people with hemophilia who had touched their lives. This effort resulted in 24 stories and one poem that reveal just as much about the social workers as they do about the patients with hemophilia, all worthy of the limelight.

The writers of the stories tended to be the survivors—those who have lasted the longest. Not everyone continues as a hemophilia social worker. Over the years, many have tried it and then quickly left. The job is frustrating and difficult, with new problems arising even before existing ones are solved. But the social workers who do make it may be different—as if answering a calling. These special people have added enduring compassion to their list of professional qualifications.

Full disclosure: I know many of the contributors to *A Journey of the Heart* and have worked with some. To me, they are amazing professionals. In fact, it takes ten pages of biographies in the book just to describe them. And these short summaries omit so much. Reading their biographies, I was surprised at how talented these social workers are as wordsmiths.

Hemophilia social workers are valued members of the comprehensive team at your HTC. Section 1131 of the Public Health Service Act, the original legislation that federally funded HTCs beginning in 1975, states that psychosocial and counseling services are to be provided by the interdisciplinary team of health professionals. When comprehensive care of hemophilia was summarized in federal publications published in 1979 and 1981, social workers were included on the core team. And the *Standards and Criteria for the Care of Persons with Congenital Bleeding Disorders*, a document published by National Hemophilia Foundation (NHF), also lists a psychosocial professional (identified as a licensed social worker) as a core team member at the HTC.

The place of these professionals on the HTC healthcare team is ensured, but unfortunately, social workers seem to take the brunt of federal budget cuts. Not all HTCs can afford a full-time social worker. Many social workers work only part time at HTCs, yet they still provide the necessary range of services.

What do hemophilia social workers do? The easy answer: almost everything nonmedical. For example, this might mean verifying that a patient has insurance prior to treatment. In many cases, the psychosocial needs of a patient have to be resolved before the medical needs can be addressed. The psychosocial services listed in the *Standards and Criteria* include mental health, basic human needs, family, social support system, insurance/financial, legal issues, education, and vocational guidance. Even those broad categories don't cover all the services provided by hemophilia social workers.

Hemophilia social workers also conduct research. The earliest example I have found is in a 1949 medical journal article: two social workers at Beth Israel Hospital, Boston, studied the social adjustment of six patients with hemophilia during three years of prophylactic treatment with fresh or freshly frozen normal human plasma. These social workers found that the prophylactic regimen had emotional and socioeconomic benefits for the patients with hemophilia, but it was also a very costly treatment. Some problems just do not go away.

Hemophilia social workers continually update their skills. At a regional training conference I attended about 15 years ago, one of the hemophilia social workers demonstrated the usefulness of hypnosis in her clinical practice. The group enthusiastically volunteered me to be hypnotized—but I was brought out of hypnosis and told that the social worker had found me "too susceptible."

*A Journey of the Heart* reveals the empathy shown by hemophilia social workers in their professional efforts. When you see the social workers at your HTC, offer your thanks, or maybe even a hug, to show you appreciate their services and compassion.

*A Journey of the Heart* is available from HANDI at NHF: 800-42-HANDI ☺



## It's Official: We're Stressed

Anyone who raises a child with a bleeding disorder experiences stress beyond that of everyday life: You must watch your child suffer the excruciating pain of a bleed, stay up all night with him, and worry about head bleeds. You must learn to stick your child with a needle. Plus, you must understand and monitor insurance policies, and cover medical costs. You truly have some great reasons to seek refuge in food or drink, visual distractions like movies, or just collapsing into bed at night.

Concerned about how caregivers cope with hemophilia, Novo Nordisk funded the first large-scale survey of caregivers of children with hemophilia, with and without inhibitors, to measure the impact of stress, and to learn which parts of daily living are most stressful.<sup>3</sup> An online questionnaire with six areas targeting caregivers—emotional stress, financial burden, personal sacrifice, medical management, child's pain, and transportation—was used to assess stress and its impact. A total of 310 caregivers completed the survey; 88% of these were mothers of a child with hemophilia, and of those, 50% were ages 35–44.

Not surprisingly, child's pain was identified as the greatest source of caregiver stress, followed by emotional stress, financial, transportation (to a hospital), personal sacrifice, and medical management. Bleeding episodes and having an inhibitor also added to stress. Most of the caregivers were "sometimes" to "nearly always" worried about what will happen to their child with hemophilia in the future when they are not around. About 65% felt that taking care of a child with hemophilia is "mentally trying." One-half worried about not taking care of the child properly, while 60% agreed with the statement "Sometimes I feel like we live on a roller coaster: we are in a crisis when my child with hemophilia is acutely ill, but feel OK when things are stable."

The Novo Nordisk survey quantifies what we already know: caregivers of children with hemophilia are chronically stressed. Most recommendations on handling family stress focus on getting trained to diagnose bleeds, learning to infuse,

*“Seeing your child in pain is the worst stress. I feel I hurt as much as him.”*

*—Amber Cranfill*



*“Having multiple bleeders in a single-parent home is non-stop hardships: bleeds, prescriptions, pain management, doctor/clinic visits, school, work or lack of, insurance, financial—and just planning out what's for dinner.”*

*—LouAnn Kyle*

and joining support groups. These can help—competency and social support are crucial. But we need to go deeper, to the physiology of stress.

## The Physiology of Stress

Stress has many causes: being stuck in traffic, having to speak publicly, infusing a child with hemophilia, being attacked by a rampaging bear. Stress initiates a chemical chain reaction known as the “fight-or-flight” response. Your body responds the same way—regardless of the source—when it receives the message from the brain that it's tense, upset, or threatened. Even *anticipated stress*—anxiety from a situation that has not yet happened—can trigger the fight-or-flight response, which has a powerful effect on the body, compelling it to do something about the stressful situation.

Here's a simplified version of the physiology of stress. When you're stressed, your brain releases chemicals that trigger a physical reaction. First, the hypothalamus (a gland located in the brain that's responsible for maintaining the balance between stress and relaxation in your body) secretes corticotropin-releasing hormone. This hormone activates the adrenal glands (located on top of the kidneys), causing them to secrete several compounds, including the kickstarter chemical *adrenaline*, its close cousin *norepinephrine*, and the stress hormone *cortisol*.

Adrenaline works immediately, causing your breathing to become rapid and shallow, and your heart rate to accelerate. This elevates your blood pressure. Your body slows down any metabolic function that is not needed to fight or flee: The immune system is temporarily suppressed. Pain is dulled. Digestion pauses. Your body can then concentrate its available energy on action, and use muscles for a physical stress response—the fight or flight.

Adrenaline also raises blood sugar levels by stimulating the liver to rapidly change *glycogen* (a compound used by the muscles and liver to store energy) into *glucose* (the sugar used by the cells as primary fuel) so it's available to muscles. Adrenaline also causes fatty tissue to release fat into the blood, in case it's needed for additional energy in the fight-or-flight response.

Cortisol also stimulates a response. Among its many effects on the body, cortisol increases the burning of fat. Cortisol also makes you ravenously hungry. So if your stress remains unresolved, or if the stress hormones aren't counteracted through physical activity (fighting or fleeing), the elevated levels of cortisol not only stimulate appetite, but also encourage fat

3. M. Dekoven, S. Karkare, L. Kelley, D. Cooper, H. Pham, J. Powers, W. Lee, and T. Wisniewski, “Understanding the Experience of Caring for Children with Haemophilia: Cross-sectional Study of Caregivers in the United States,” *Haemophilia* Oct. 2014. doi: 10.1111/hae.12501.



Only recently have we come up with the technology to turn lazing around into a way of life. We've taken our sinewy, durable, hunter-gatherer bodies and plunked them into an artificial world of leisure.

—Christopher McDougall, *Born to Run*

cells deep inside your abdomen to store *more* fat. Abdominal fat cells make up *visceral fat*, the fat that surrounds your organs and is most dangerous to your health. Too much visceral fat can alter the way your internal organs work, and can place extra stress on your heart.

The fight-or-flight response is a marvelous feat of biological self-protection. And it has one final trick: cortisol also increases your craving for high-fat and sugary foods. How do you manage feelings of stress, especially when your appetite has been triggered? Comfort food. But eating more high-calorie foods results in the deposit of more fat.

The bottom line? Chronic stress is a significant risk factor for weight gain.<sup>4</sup>

Life is stressful for most caregivers of children with bleeding disorders, and you may damage your health by overeating in response to the fight-or-flight stress response. You also harm your health if you lack energy and don't exercise. It's true: chronic stress leaves you exhausted, as you attend to your child's needs, and as your body deals with the internal physiological stress reaction.

Chronic stress suppresses your immune system, making you more susceptible to fungal, viral, and bacterial infections. It can also cause insomnia, migraines, exhaustion, depression, and more. Chronic exposure to high levels of stress hormones is unhealthy.

## The Cure for Chronic Stress

We can't eliminate all the daily stressors that contribute to chronic stress, but there's one thing we *can* do to reduce the

level of stress hormones: exercise! Most of us try to alleviate stress by using distraction. We spend time with family, sleep more, turn to food or drink, watch TV, or surf the Web. But all this distraction means less time getting the physical activity we need. Stanford University recently released a study finding that our increasing girth may be due to declining physical activity. From 1988 to 2010, the percentage of women who report that they never exercise increased from 19% to 52%. And the study revealed that in 2010, 61% of women had too much belly fat, up from 46% in 1988.<sup>5</sup> These statistics show that we're not doing the one thing that could offer the greatest and longest-lasting benefit: exercise. Sustained, consistent movement raises the heart rate, activates muscles, and reduces stress hormones.

When you're stressed, your body is chemically and physiologically preparing to move—to fight or flee. Sitting in a chair all day, watching TV, or being glued to the computer when you're stressed is the worst thing you can do. You need to move to manage those stress hormones. Distraction alone won't do it!

The best kind of movement for your body is some sort of structured exercise or physical activity. There are two types of exercises you need to engage in regularly:

1. Strength training (anaerobics)
2. Cardio (aerobics)

*Strength training* targets various muscle groups to tone them and make them stronger. It can involve movement, using light free-weights, weight machines, or resistance bands. Or it can mean holding static positions (called *isometrics*), as when you do a plank or sit-up against a wall. The key is *resistance*. Your muscles work hard lifting, pushing, pulling, tightening. If you work them hard enough, you even tear them a little: that's one reason you may feel sore after a workout. And then they rebuild, stronger than before.

You don't need heavy weights, and you don't need to fear "bulking up" like a body builder. Women's muscles generally



4. Stress can have the opposite effect on some people, who may lose weight when stressed because they don't eat. But given the national statistics on obesity, it appears that most stressed people tend to eat more, exercise less, and put on weight. 5. Stanford University researchers examined government surveys conducted from 1988 to 2010 and found that our increasing girth was likely caused by a decline in physical activity rather than an increase in caloric intake. <http://med.stanford.edu/news/all-news/2014/07/lack-of-exercise--not-diet--linked-to-rise-in-obesity--stanford-.html>. Accessed 10.14.14.

*Women have been taught to believe it's selfish to put yourself first. But putting yourself first makes you a better mother. You can't take care of your children if you don't take care of their mother.*

—Tammy Davenport

don't respond to weights that way. Just use light weights and perform higher repetitions (or reps, the number of times you continue doing the same exercise or movement), and you'll tighten and strengthen your body. Over time you'll see tighter abs, sleeker arms, and a firmer butt!

When you carry a bit more muscle, you'll burn more calories. Muscles are the furnace of calorie consumption. A pound of fat burns only two calories a day to maintain itself, but a pound of muscle burns six calories, even while you sleep!

*Cardio* raises your heart rate and keeps it up, strengthening your heart and improving blood circulation. Cardio is overall body movement: walking, hiking, running, cycling, jumping rope, dancing, swimming. The key is *endurance*. The heart is a muscle, and to stay strong, it needs to pump steadily at a higher rate than it pumps at rest, over a period of time (say, 30–60 minutes) several times a week.

So one key stress solution is an exercise routine that trains your body to respond to stress in a healthy way. Try to find both a strength training routine and a cardio routine. Walking briskly for 30 minutes a day, while carrying 1- to 2-pound weights in each hand, is a great way to start.

Regular physical activity counteracts the stress hormones produced by the fight-or-flight reaction. Listen to your body, and give it the movement it naturally craves and needs!

## Tips to Get You Started

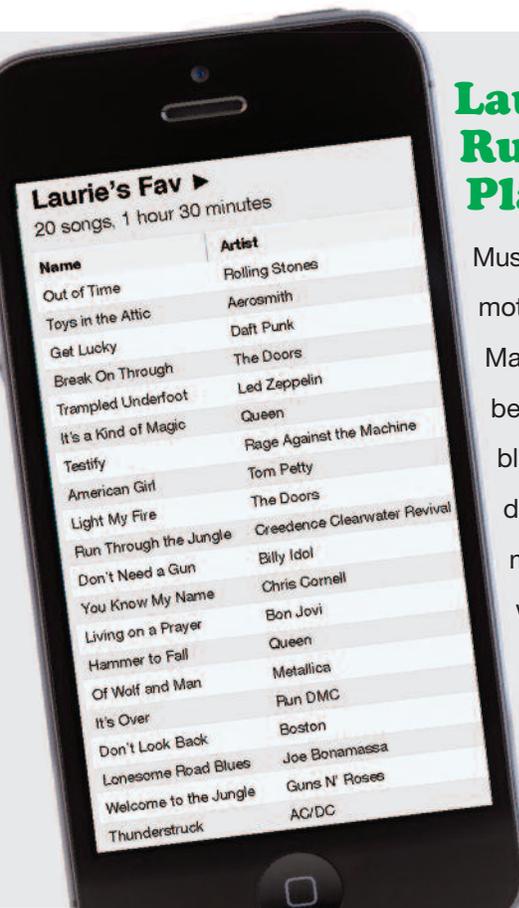
Don't be intimidated by starting a new exercise routine. But don't go all gangbusters, either. Do it wisely:

1. **See your doctor.** Before you make any significant changes in your physical activity, your doctor will need to check your joints and take vital statistics: heart rate, cholesterol, weight. This information can be used as a baseline later, to see how much you've improved over time. Talk to your doctor about your diet (see page 12). Visiting your doctor is especially important if you're overweight, over age 40, have any health concerns, or have been inactive for a long time.
2. **Set a goal and announce it to the world.** It's easier to get motivated when you have something to work toward and everyone knows about it! Do you want to lose a set number of pounds? Inches? Fit into a particular outfit? Be ready for a special upcoming event? Enter a road race? Do a charity walk (like for hemophilia)? Lift a certain amount of weight? Post your goals on Facebook.
3. **Find an activity you enjoy doing.** This will help you stay motivated and reach your goals. Don't like swimming? Try paddle boarding. Golf? Maybe not enough movement. How about cycling, jogging, tennis, hiking, rock climbing?
4. **Make it social!** Consider a personal trainer if it's in your budget. Join a hiking club, the YWCA, or a local gym. Take Zumba or dance lessons that work up a sweat. Take regular power-walks with your neighbors.
5. **Get some basic equipment.** For example, you'll need good running shoes, resistance bands, or light weights (see box p. 9).



## Laurie's Running Playlist

Music is a proven motivator for moving. Maybe you like the beat of Memphis blues, country rock, disco hits, or heavy metal. Whatever works for you! I have several playlists, with lots of songs, but this is one of my favs.



*I'm a nurse and have a child with hemophilia. I wasn't sleeping well, had gained weight, and was irritable. I found stress relief in CrossFit. It's so encouraging: people cheer you on with each goal you reach. When you do something that makes you feel stronger, it affects your life in all ways. I felt more confident—it's as much mental as physical.*

—Amber Wells

*“Twelve years ago I was overweight, unhealthy, and tired. I decided if I was going to take care of my children, I had to take care of myself first. It’s been a long and rewarding journey. I’ve been practicing yoga for six years, and am now completing my certification to teach yoga. I do not have a perfect body. Kids and hemophilia have taken their toll. Yoga has been my one constant. I am stronger, happier, and healthier than ever.”*

—Tammy Davenport

- Record your progress.** Use a calendar or chart to note mileage, weight, number of reps. Many people in the bleeding disorder community use apps like MapMyRide or MyFitnessPal, and you can add your friends who also have the app. Seeing how your friends are doing can help get you in a friendly, competitive spirit!
- Read about exercise, nutrition, and sports.** Subscribe to a health-and-fitness magazine like *Shape*, *Fitness Rx for Women*, or *Oxygen*. These make great gifts for moms!
- Be safe.** Use a helmet for cycling, sunscreen for protection, ice for sore muscles, protective gear when needed. Stretch after exercise. And don’t forget an ID if you’re out running or cycling on roads solo.
- Always change the exercises.** It’s important to train as many different muscle groups as possible, and in different ways. Don’t overdevelop one muscle while ignoring others. Create a workout routine that focuses on your core (abs, pelvis, and lower back muscles) at all times. Body-weight exercises such as push-ups, lunges, and sit-ups work multiple muscle groups (see pull-out poster on pp. 10–11). They also help strengthen your core. Invest in a large stability ball (65 cm. diameter), and sit or lie on it whenever you do any strength exercise.

## Ahem, So What’s Your Excuse?

Can’t make it to the gym? Don’t have time to work out?

Moms of children with bleeding disorders are often in the car, driving to the HTC, waiting at the HTC, or sitting at a school event. For an excellent workout when you’re pressed for time, try these ideas:

- Sitting at a red light, squeeze your abs as tightly as you can. Hold. Release. Repeat.

## What’s in Laurie’s Basement?

You certainly don’t need all these things, but try a few and see what works best for you. I started in 1980 with just free-weights—and still own the same set! The first three items are the most expensive and largest. Check Craigslist for used equipment. You can also improvise if you don’t want a lot of equipment: for example, lift full milk jugs as weights, or use a chair to do tricep dips.

- Stand—don’t sit—in the waiting room. Stand whenever you can!
- While standing, rise up and down on your toes repeatedly.
- While talking on the phone, do lunges across the room. You can even do them standing in one place.
- While cooking, place both hands against the counter and lean toward the counter, like a standing push-up. Repeat.
- While standing, kick your leg out straight behind you and tighten your butt. Repeat.

You can exercise anyplace, anytime! No excuses!

*“My ultimate stress relief is gardening. It’s peaceful and low impact on me physically. And I love to hike and hit the beach for a walk. Nature has an amazing way of working out things that are deeply rooted, and balancing my frustration. I enjoy aqua Zumba too. It’s safe on my body, fun, and interesting.”*

—LouAnn Kyle

## The Benefits of Yoga and Relaxation

Fitness and stress relief are not all about pushing yourself to the physical limit. Consistent movement may be the best stress reliever because you’re counteracting stress hormones and toning your muscles, but you also need to teach your body to relax.

Tense, tight muscles can be caused by stress—muscles clench and tighten like a knot, ready for fight or flight. Or they can be the result of exercise—muscles tear and rebuild. No matter the cause, you need to stretch and relax your muscles to keep them flexible and avoid injury. Stretching is a vital part of any workout and exercise regimen.

»» page 13

*“A healthier diet can truly affect our moods, which helps relieve stress. I start my day blending a smoothie using fresh fruit, Greek yogurt, and skim milk, with protein powder, peanut butter, or chia seeds. I never skip meals, especially breakfast. I drink a lot of water! Significantly reducing sugars plays a major role in helping with mood crashes. When I’m able to manage my moods, I can help my kids effectively cope with theirs.”*

—Kimberly Rosenfelt

- Treadmill (for winter)
- Stationary bike (for winter)
- Press bench
- Bosu® ball\*
- Stability ball\*
- Medicine ball (8 lbs)
- Set of free-weights (4–25 lbs)\*
- Resistance bands\*
- Yoga mat
- Chin-up bar (in doorway)
- Foam roller\*
- ThighMaster (really!)
- Music\*
- Mirror
- Timer\*

\* Highly recommended

# Dan's Top Ten

Ten top favorites to hit major muscles in 45 minutes. For each exercise, do a 1-minute set; rest 30 seconds; do next set. Do three sets each before going to the next exercise.



## 1. Squats



1. Stand with your feet slightly wider than shoulder width.
2. Make sure your feet point straight ahead.
3. Bend your knees and try to keep all the pressure back on your heels.
4. Pretend you're reaching back to sit on a chair. Keep your head up, stomach tight, chest up, and back straight.
5. Repeat throughout a 1-minute set.

## 2. Russian twists



1. Sit on a mat with your legs together, knees bent, and heels on the ground.
2. Interlock your hands and hold them in front of your chest.
3. Lean back about 45 degrees, and start twisting side to side.
4. With each twist, touch your hands to the sides of your hips. Your head should turn with each twist.
5. Keep your stomach tight.
6. Repeat throughout a 1-minute set.

## 3. Lunges



1. Take a large step backward with your right leg.
2. Bend your right knee while keeping your back straight and head up; bend until the knee comes close to touching the ground or as low as feels comfortable.
3. Make sure your left knee never extends over your front toes.
4. Slowly come back up and do the left leg.
5. Alternate legs throughout a 1-minute set.

## 4. Holding wall sits



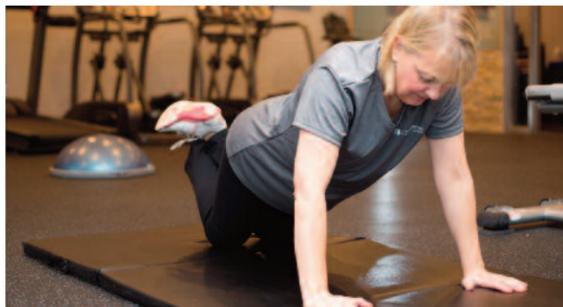
1. Stand with your back against a secure wall or door.
2. Lower your body, bringing your feet forward and bending your knees to about 90 degrees.
3. Your feet should be shoulder width apart, and your knees should never extend past your toes.
4. Hold that position throughout a 1-minute set.

## 5. Plank

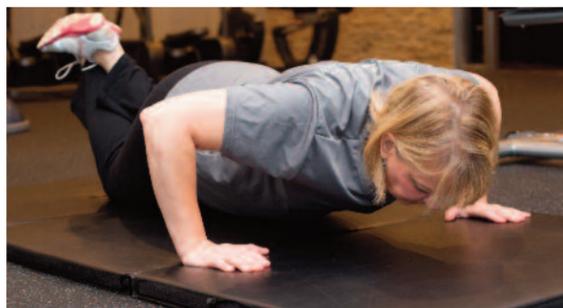


1. Lower your forearms to the ground so your elbows and hands are flat on the ground, elbows directly under your shoulders.
2. Lift up on your tiptoes and keep your back flat. Make sure to breathe, focus on your core, keep your abdominals tight, and squeeze your glutes.
3. Hold throughout a 1-minute set.

## 6. Push-ups



1. Place your hands on the ground, slightly wider than shoulder width and directly aligned under your shoulders.
2. Keep your knees on the ground, and cross your ankles.



3. Lower your body by bending your elbows 90 degrees.
4. Keep your stomach tight and back flat.
5. When pushing back up, exhale and push with your chest muscles.
6. Repeat throughout a 1-minute set.

## 7. Crunches

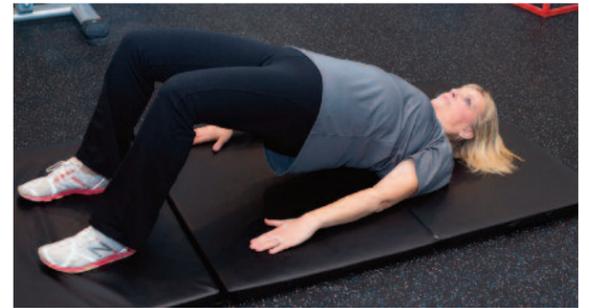


1. Lie on your back and place both hands behind your head to support your neck.
2. Bring your torso and head upward while keeping your lower back flat on the ground.
3. Aim your chin toward the ceiling; avoid bringing your chin into your body.
4. Exhale on the way up, during the crunch, and focus on tightening your stomach and pushing your lower back flat to the mat.
5. Repeat throughout a 1-minute set.

## 8. Bridges



1. Lie on your back and place your arms at your side with your feet close to your body, knees bent, slightly wider than shoulder width.



2. Lift your hips on the ground as high as you can.
3. When you are at your highest point, squeeze your glutes and hold a few seconds.
4. Slowly lower your hips toward the ground, and just before you make contact with the ground, lift your hips back up again.
5. Repeat throughout a 1-minute set.

## 9. Mountain climbers



1. Get into an elevated plank position, on your hands and toes.
2. Extend one leg straight behind, and the other bent, tucked under your chest.
3. Keep your neck relaxed and your hips slightly higher up than the tops of your shoulders.
4. Switch the position of each leg quickly, alternating by extending and tucking.
5. Try to have a soft landing because this generates less force on your knees.
6. Repeat throughout a 1-minute set.

## 10. Pull-ups



1. Using a pull-up bar, place your hands a little wider than shoulder width, with palms facing you.
2. Pull yourself up toward the bar without jumping, and try to get your chin over the bar.
3. Slowly lower yourself down; but before your feet touch the ground, try lifting up once more. (If this is too difficult, use a stepstool or chair to assist the pull-up, and then slowly lower yourself.)
4. Repeat throughout a 1-minute set.

# Don't Cheat EAT (SMARTER)



**W**hat you eat—and how much—affects stress and the way you manage it. Caregivers may “stress eat,” and then rationalize: “I deserve it.”

Sometimes, eating anesthetizes emotional upset. Remember that the stress hormone cortisol is an appetite trigger, encouraging you to eat high-fat, high-sugar foods in response to stress. The easiest (and most pleasurable) way to do this is to eat carbohydrates, the energy food. Because they usually taste great, most of our snack foods—chips, cake, cookies, crackers—are carbs. Carbs are comfort food.

Problem is, if you're not regularly moving and getting exercise, all those carbs you eat in response to stress get stored as fat, especially in the abdomen. This is a risk factor for diabetes, and can increase your risk of cardiovascular disease, cancer, and a host of other ailments.

Look at food labels for a breakdown of nutrients in everything you eat. Check out the balance of carbs, protein, and fat. Aim for foods that are higher in protein compared to carbs and fat.

Here are some foods to avoid, and to aim for:

## Avoid...

### white carbs

- white bread
- white rice and pasta
- bakery goods
- plain bagels
- refined sugar

### “bad” fats

- ice cream
- butter
- whole milk
- chocolate
- cream

White carbs will spike your sugar levels—and appetite. They are digested quickly for instant energy, but they make you hungrier in just two hours!



## Aim for...

### “good” fats

- all-natural peanut butter
- extra virgin olive oil
- egg yolks
- nuts
- fish

### protein-rich foods

- low-fat milk
- protein bars or shakes
- egg whites
- Greek yogurt
- raw nuts
- meats
- all-natural peanut butter

### natural carbs

- fruits & vegetables
- whole-grain bread

Protein takes longer to digest than carbohydrates, and it won't spike your blood sugar levels. Protein helps regulate your appetite, helps repair tissues, and builds muscle. Try to eat protein at every meal.

A good combination? Try to get about 25% of your daily calories from protein (especially if you are working out regularly), 50% from whole-grain carbohydrates and fruits, and 25% from good fats. Replace your white rice and bread with whole-grain rice and bread. Cut back on caffeine. Eliminate white sugar. And cut out sugary soft drinks, perhaps the main offender. Drink lots of water.

Instead of eating three big meals a day, graze: eat smaller meals more frequently. This helps steady your blood sugar levels so you don't experience a sugar crash, which might make you want to reach for carbs for a boost.

Write down what you eat each day. Like most people, you probably underestimate the amount of unhealthy food in your diet. You'll be amazed at the positive results if you consistently follow these nutrition guidelines. For more info on a healthful diet, read the book *Read It Before You Eat It* by Bonnie Taub-Dix to learn how to correctly read a food label and understand ingredients.

*Coming down with shingles due to stress, and fighting with the school over my son's IEP made me sick, bedridden for a month. I wasn't taking care of myself. I started practicing yoga, reached out to friends to express my emotions, and rekindled my love for nature. Getting involved with the local chapter to connect with other families has been a lifesaver. Knowing I am not alone on this journey has built my confidence and my family's cohesion.*

—Lucy Watt

Yoga is a proven way to carefully, consistently, and progressively stretch tight muscles. Yoga also helps calm the stressed mind through breathing techniques. Practicing yoga and slow breathing helps more oxygen reach your brain and muscles. And this helps relieve muscle tension.

Controlled breathing alone can also reduce the stress response, and less stress can mean less visceral (belly) fat. Yoga can also gently tone and strengthen muscles; that's especially helpful for people who can't participate in moderate or difficult physical activity.

You don't need to join a yoga practice, although this is a great idea. You can find many illustrated books on yoga in your library or on Amazon.com, and there are lots of yoga DVDs. Practice yoga every day, for as little as 15–30 minutes, to see remarkable changes in your physique, your breathing, and your handling of stress.

Massage is an excellent stress reliever that also works out the muscular aftereffects of exercising. Massages are great gifts for stressed moms, or a great gift to give yourself.

Other stress relievers that aren't physical? Social time with friends. Laughter. A hobby like painting, gardening, crossword puzzles, crocheting, reading, playing the piano. Anything that means you've invested time in yourself makes you feel better and look better, and will help you handle stress now and in future. Even though physical exercise is essential, don't let it consume you to the point where you forget that you have other abilities and interests—things that define you, that make you feel whole and special.

## Make 2105 Your Year!

Many people look to January 1 to make changes in their lives. But why not start today? Make a plan: How will you boost your physical activities to better manage the stress of daily life and bleeding disorders? What can you do that you enjoy and

*Don't be so hard on yourself. We want it all to be perfect—dinner on the table, clothes ironed. Tell yourself you're doing the best you can. Take time for yourself, and you can improve. Do it a bit at a time.*

—Amber Cranfill



*My husband and I walk three miles every morning. I also like yoga and good long stretches to help clear my head. The most important thing is that I have time just for "me" every day.*

—Kimberly Rosenfelt

that gets you moving to burn off stress?

Set some goals, and post them publicly—on your fridge, on Facebook, on MapMyRide. Chart your progress, and share it. Reward yourself when you reach milestones: buy a new outfit, a new book, a special dinner. Don't reach for the old rewards of comfort food and inactivity!

Make the commitment *today*. Commit to a year of fitness, however you define it, and to lowering stress. Start slowly, and then take it further. Add more weights, more miles, more activity. With consistent training, even 30 minutes a day, you'll be amazed at the change in your body and stress levels.

You can't avoid stress, but you can manage it. *Your body craves movement and wants to serve you.* The body is a marvelous machine that sometimes gets rusty. It's time to focus on that machine, treat it right, and treat yourself like the special parent you are.

And what about Maria Kang? Good for her—she stayed slim, trim, and healthy after three children. But the goal isn't to look like a certain type of person, or to have a certain shape or even a certain fitness level. The goal is to become the best *you* can be, physically, mentally, and emotionally. So take steps, however slowly, to reach your potential at every age. Don't lean on excuses! Make *you* the priority in 2015. You need it. You deserve it. ☺

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**Dan French** has been a personal fitness trainer for seven years. He has a BA in exercise science from the University of Maryland, and the highest certification in personal training, ACSM fitness specialist. He is co-owner of Renew Fitness, Salem, New Hampshire, a women-only studio. Dan struggled with his weight for more than a decade, and then lost 60 pounds in less than a year at age 22. He decreased his blood pressure and cholesterol, increased his energy, felt more confident, and established an active, healthy lifestyle. He changed his major in college to pursue personal training and help others in the same way exercise and nutrition helped him. Dan lives in Newton, New Hampshire, with his wife Katrina and pug Koji. For info: [www.RenewFitnessNH.com](http://www.RenewFitnessNH.com).

**Laurie Kelley** is president of LA Kelley Communications and has worked in the bleeding disorder community for 25 years. She regularly works out (with Dan), cycles, and runs. She also enjoys many outdoor activities, including rafting and hiking. Her goal in 2015 (when she turns 58) is to try mountain biking and get back to rock climbing.

Acetaminophen overdose is the leading cause of calls to US poison control centers—more than 100,000 instances annually. Every year, acetaminophen overdose is responsible for more than 56,000 emergency room visits; 26,000 hospitalizations; and an estimated 458 deaths due to acute liver failure.<sup>2</sup> In fact, acetaminophen is the number one cause of acute liver failure, placing it above viral hepatitis as a cause.

About half of acetaminophen overdoses are intentional, as in suicide. The other half are unintentional. Unintentional overdose often occurs because people are either unaware that acetaminophen can be dangerous, or they mix drugs. Even if you're aware of the dangers of acetaminophen, you may not know what's in the other drugs you're taking at the same time. Acetaminophen is found in over 600 drugs, including many cold medications, and this may not be prominent on the label. Consumers may also be led astray by a label's wording: sometimes acetaminophen is abbreviated "acet" or "acetamin," or is listed in the ingredients not by its common name but by the abbreviation of its chemical name: APAP.<sup>3</sup> If you're traveling abroad, know that in countries outside the US, Canada, and Japan, acetaminophen is called paracetamol.

## Overdosing

Unfortunately, overdosing on acetaminophen is easy—there isn't much difference between the maximum recommended dose and a potentially dangerous dose that is toxic to the liver. FDA guidelines limit the daily maximum dose of acetaminophen to 4.0 grams (g), or 4,000 milligrams (mg). (1 g equals 1,000 mg.) But for some people, even taking acetaminophen at below the FDA recommended maximum dose may be dangerous—a small percentage of people who take acetaminophen can't efficiently metabolize (break down) the drug, and they suffer liver damage even though they are taking less than the recommended maximum daily amount.

In 2011, McNeil Consumer Healthcare (a Johnson & Johnson company, the manufacturer of Tylenol and largest seller of acetaminophen) voluntarily lowered its recommended maximum daily dose from 4.0 g to 3.0 g, that is, from eight extra-strength (500 mg) tablets to six extra-strength tablets daily.

People may unintentionally overdose on acetaminophen by taking more than one drug containing acetaminophen. Suppose you're taking extra-strength Tylenol (500 mg) for a joint bleed, and then on top of that, you take NyQuil® Nighttime Relief (containing 650 mg of acetaminophen) to get some sleep because you also have a cold. If taken at the recommended dose of six Tylenol tablets a day, this combination is



over both the 4.0 g (4,000 mg) maximum daily dose and the newly recommended 3.0 g dose.

It's also easy to overdose on acetaminophen by taking repeated doses that are only slightly over the recommended maximum dose. Some people fall into the trap of thinking that more is better, and knowingly take a little more than the recommended dose—because it's "close enough" not to cause problems, right? This is dangerous thinking! Taking multiple small overdoses, called staggered overdosing, is often more life-threatening than taking a single, large dose. Why? It's harder for physicians to detect staggered overdosing because blood acetaminophen levels are low (as opposed to a single large dose, which is easily detected); and people often don't go to a hospital for help until after the damage is done.

Why would anyone not go to a hospital for acetaminophen overdose? Because they may not know they have overdosed! An acetaminophen overdose doesn't typically produce immediate symptoms, and when symptoms do appear, they can mimic those of the flu—often, the reason people are taking acetaminophen in the first place.

Symptoms of drug-induced liver damage, which may not show for several days or more, include loss of appetite, nausea, vomiting, fever, and abdominal pain. In more serious cases, urine may be dark (indicating blood in the urine), and the skin and eyes may be tinged yellow (called *jaundice*, an indication that the liver is not effectively removing the breakdown products of red blood cells). Usually, if the damage is not severe and caught early, the liver recovers once the drug is stopped or with medical treatment. But if the damage is severe, the liver will stop functioning effectively. This is acute liver failure, and without a transplant, it will cause death.

2. In a 2013 telephone poll of approximately 1,000 adults conducted by Princeton Survey Research Associates International, 51% of respondents were unaware of any safety warnings associated with Tylenol. The poll also found that many Americans also believed it was safe to take several different meds containing acetaminophen at once. For example, 35% of respondents said it was safe to combine the maximum recommended dose of extra-strength Tylenol with NyQuil®, a cold remedy that also contains acetaminophen. According to the FDA, this is not safe. 3. Fortunately, this is now uncommon. With greater awareness of the potential of liver damage from acetaminophen, most drug manufacturers now prominently list acetaminophen in the active ingredients of the drug facts panel of their products, often in bold yellow highlighting.

## How to Take Acetaminophen Safely

1. *Always read the package insert!* If the product you're taking contains acetaminophen, check the package insert for correct dosing.
2. *More is not better!* Take the lowest possible dose of acetaminophen you need to control your pain.
3. *Don't take more than one product at a time that contains acetaminophen!* And never drink alcohol when taking medicines that contain acetaminophen.<sup>4</sup>

Here are more ways to stay safe:

- Keep your daily acetaminophen dose below 3,000 mg (3 g). That's six extra-strength 500 mg pills, or ten regular-strength 325 mg pills. (This is less than the FDA recommendations.)
- Do not take acetaminophen for more than ten days unless you are under a doctor's supervision; this increases your risk of liver damage.
- If you have viral hepatitis, ask your doctor before using acetaminophen; you may be at higher risk of drug-induced liver damage due to previous liver damage.



- Consult your doctor if you take carbamazepine (anti-seizure medication) before taking acetaminophen. This drug can put you at higher risk of severe skin reactions to acetaminophen.
- Be aware of these rare but serious and potentially fatal skin reactions caused by acetaminophen: Stevens-Johnson Syndrome (SJS), toxic epidermal necrolysis (TEN), and acute generalized exanthematous pustulosis (AGEP). If you develop a skin rash or reaction while using acetaminophen, stop taking the drug and seek medical attention immediately.
- If you use warfarin (blood thinner, brand name Coumadin®), ask your doctor before taking acetaminophen, which interacts with warfarin, increasing bleeding time.

If your child uses acetaminophen:

- Never give your child adult doses.
- Dose children based on weight, not age. McNeil Consumer Healthcare recommends consulting a physician before giving Tylenol to children under age two.
- To measure liquid acetaminophen for a child, use the measuring device that comes with the child's medication. Don't use household teaspoons, which can vary widely in volume.
- Keep all pain medications out of reach of children, and securely replace childproof caps. ☺

## Become a Sponsor!

Go to [Become a Sponsor](http://www.saveonelifenet.net) at [www.saveonelifenet.net](http://www.saveonelifenet.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.saveonelifenet.net](http://www.saveonelifenet.net) / [contact@saveonelifenet.net](mailto:contact@saveonelifenet.net)

*Caring for people with hemophilia around the world—one at a time.*

**In case of overdose, contact the Poison Control Center: 800-222-1222**



See the next issue of PEN for Part 2:  
The benefits and dangers of NSAIDs and opioids

4. More than three alcoholic drinks a day significantly increases your risk of liver damage by decreasing the ability of your liver to properly metabolize acetaminophen.

# headlines

## NONPROFIT

### Save the Date!

HFA Symposium  
March 26–28, 2015

St. Louis



Hemophilia Federation of America Symposium is a family-friendly educational meeting dedicated to improving the lives of people living with and affected by a bleeding disorder. **Why this matters:** HFA Symposium offers community members the opportunity to learn and grow personally and collectively, and become strong self-advocates.

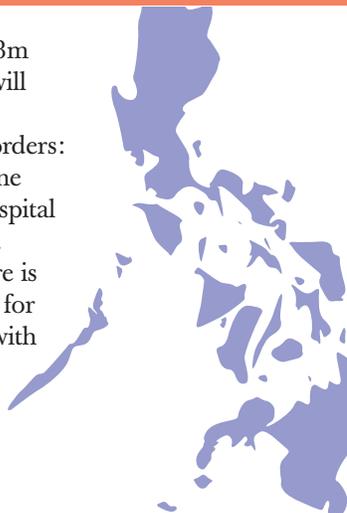
For more info: [www.hemophiliafed.org](http://www.hemophiliafed.org)

## WORLD

In the Philippines, Senate Bill 2343m sponsored by Senator Grace Poe will provide four treatment centers for hemophilia and other bleeding disorders: one center in Metro Manila and one each in a public or state-owned hospital in Luzon, Visayas, and Mindanao.

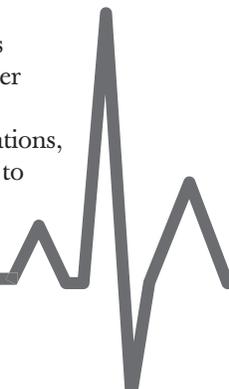
**Why this matters:** Currently there is no official HTC in the Philippines for the approximately 10,000 people with hemophilia.

For info: GMA News Online,  
Aug. 13, 2014



## NEWS FROM LA KELLEY COMMUNICATIONS

**Pulse on the Road**, our unique symposium devoted to educating patients about insurance and healthcare reform, visited 400 families on August 10, at the Texas Bleeding Disorder Conference in Austin. The joint event was hosted by Lone Star Chapter and Texas Central Chapter. Families learned about the history of the hemophilia care and cost, why the Affordable Care Act was created, and how ACA impacts bleeding disorder insurance coverage. Highlight: Michelle Rice, vice president, Public Policy & Stakeholder Relations, explained how to make appeals and grievances to your payer. Funded by Baxter Healthcare.



## MANUFACTURER

### More Good News about Copay Assistance

Several co-pay assistance programs are offered by manufacturers. **Why this matters:** Insurance reform has left many people confused and needing guidance about factor coverage and out-of-pocket costs.

**Bayer HealthCare** has eliminated income requirements associated with Kogenate® FS Co-Pay Assistance Program, and has increased the maximum assistance provision from \$6,000 to \$12,000 per patient. For patients with hemophilia A who use Kogenate FS, and who have private insurance.

For info: [www.kogenatefs.com](http://www.kogenatefs.com) or 1-800-288-8374

**Baxter Healthcare** CoPay Assistance Program has been modified. It now covers a patient's out-of-pocket costs related to deductible, copayment, and coinsurance for eligible Baxter factor or bypass products; and provides 100% of eligible out-of-pocket costs up to \$12,000 every 12 months. Applicant must have a current prescription for an eligible Baxter factor or bypass product; a diagnosis of hemophilia A or B (inhibitor patients included); commercial insurance.

For info, enrollment: 1-888-BAXTER9 (1-888-229-8379)

## SOUNDBITES

- ⊙ The US FDA has approved Novo Nordisk's **NovoSeven RT** for treating bleeding episodes and perioperative management of patients with Glanzmann's thrombasthenia.
- ⊙ Baxter announced positive results from its phase 3 clinical trial of **BAX 855**, its investigational extended half-life recombinant factor VIII (rFVIII) treatment for severe hemophilia A.
- ⊙ **Malaysia** has won the bid to host the World Federation of Hemophilia Congress in 2020.
- ⊙ Baxter Healthcare will divide into two companies in 2015; the biopharmaceutical division that produces factor will be **Baxalta Incorporated**.
- ⊙ LFB, through its Massachusetts-based US **rEVO Biologics** subsidiary, enrolled its first patient in a phase III clinical trial of LR769, a new recombinant form of human factor VIIa.
- ⊙ Baxter's **Rixubus**, a recombinant factor IX product, is now approved for children and adults with hemophilia B for control and prevention of bleeding episodes, perioperative management, and routine prophylaxis.
- ⊙ **HealthCare.gov** was redesigned recently, offering a shorter, simpler online application in time for open enrollment, starting November 15.

## Grifols Launches New 2,000 IU Alphanate®

Alphanate is indicated for the control and prevention of bleeding in patients with hemophilia A, and for surgical or invasive procedures in adult and pediatric patients with von Willebrand disease when desmopressin (DDAVP) is ineffective or contraindicated. It is not indicated for patients with type 3 VWD undergoing major surgery. This is the largest assay plasma-derived factor VIII and von Willebrand factor available on the market.

**Why this matters:** The higher potency allows patients who previously used a 1,500 IU assay to reduce their potential total administration time by 30% every day.

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

webinar

## At the CoRe

Listen in on the next CoRe Conversations! This hour-long webinar explores topics of interest to the hemophilia community.

*The Art of Transition*

The importance of facilitating transitions in our lives, and some tools to do it proactively.

Dec. 9, 7 pm ET / 6 pm CT / 4 pm PT

**Why this matters:** Live discussions can be inconvenient to attend, but webinars make live presentations accessible to all.

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

## New Technology for Lower Costs?



Expression Therapeutics LLC and ABL, Inc. are developing new cell lines to improve manufacturability and reduce the costs associated with large-scale production of recombinant factor VIII.

**Why this matters:** Expression's recombinant factor VIII platform generates 100 times greater expression than current products, potentially lowering per-unit costs.

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

## Plants that Make Factor?

Researchers from University of Pennsylvania School of Dental Medicine and University of Florida College of Medicine are using plant cells to teach the immune system to tolerate rather than attack infused clotting factor. Using a combination of factor VIII DNA and another substance that can safely cross intestinal walls and enter the bloodstream, researchers fused the genes into tobacco plants, and fed the resulting plant solution to mice with hemophilia. The mice formed on average seven times fewer inhibitors. Supported by National Institutes of Health and Bayer.

**Why this matters:** Plant-based therapies could potentially be a way to prevent antibodies from forming or to lower the incidence of antibody formation; and could be a cost-effective, safe alternative to current treatments.

For info: Katherine Unger Baillie, [kbailie@upenn.edu](mailto:kbailie@upenn.edu) or 215-898-9194



## A Pathway for Copay Help and More

Pfizer has three assistance programs to help hemophilia patients:

1. Pfizer Factor Savings Card provides financial support to eligible patients to help cover out-of-pocket copay, deductible, and coinsurance associated with their Pfizer factor costs. Eligible patients can save up to \$5,000 annually.
2. Rx Pathways provides eligible patients with their Pfizer prescriptions for free or at a savings, and offers reimbursement support services in some cases.
3. Pfizer Trial Prescription Program allows eligible patients new to Pfizer factor products to receive a one-time supply up to 20,000 IU of factor at no cost.

**Why this matters:** High cost of factor, increased copays, and economic hardship have left many hemophilia families in need of financial assistance.

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

## HERO's Journey

HeroPath™ Life Coach, a new program sponsored by Novo Nordisk, kicked off in Chicago in August. Life coach Jeffrey Leiken offered teens and young adults coaching and peer support to help them excel in their daily lives and chart a clear path forward. Participants and coaches took part in dynamic group sessions, personal one-on-one discussions, and exciting social activities. The HERO (Hemophilia Experiences, Results, and Opportunities) initiative is the largest international study on the psychosocial impact of hemophilia on patients and their loved ones. **Why this matters:** Data uncovered through HERO supports the need for additional education on how to manage life transitions and interpersonal relationships.

HERO facilitator Jeff Leiken



To view photos: [www.clients.tinasmothersphotography.com/heropathweekend](http://www.clients.tinasmothersphotography.com/heropathweekend)

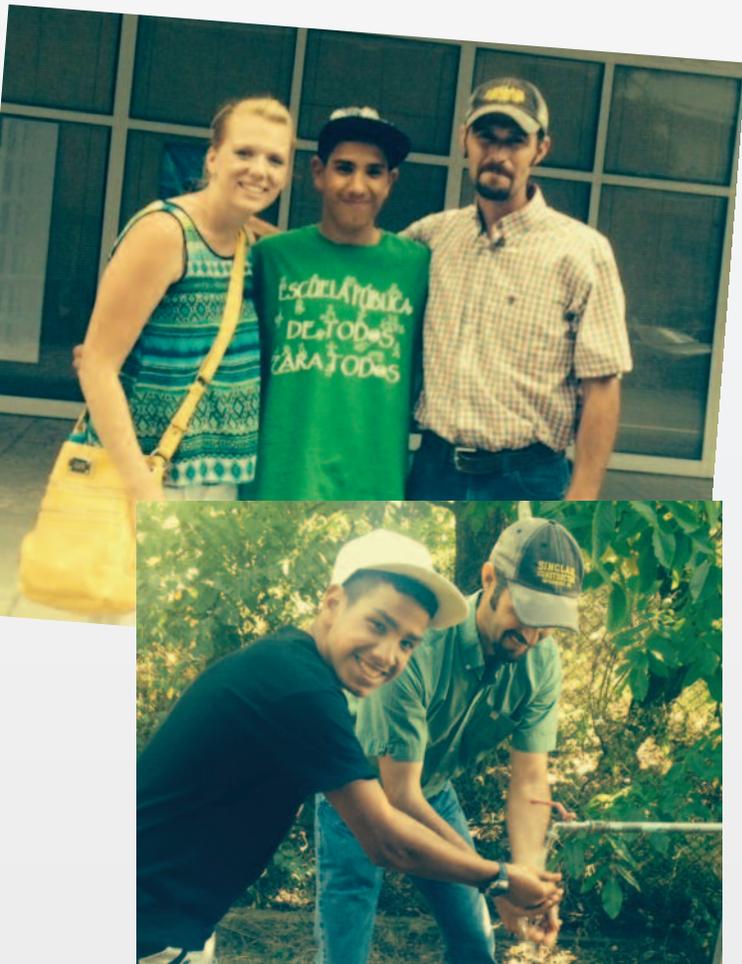
# ADOPTION UPDATE

In the August/September issue of PEN, we profiled children and families involved in the adoption process. Here's an update on two of those adoptions, as of October 1:

**Sarah Henderson** reports on traveling to Eastern Europe:

"Our first trip to meet Gabriel was everything and nothing we expected. It was amazing to see the culture and environment where he was born and raised, and to learn about his past. We were on an emotional roller coaster as we waited for our first meeting and then, as the week went on, each moment brought us closer to our goodbye. We had a wonderful connection with Gabriel, and he's so excited to become part of our family.

"Gabriel soaked in everything we could tell him about our family and where he will be living. The most memorable part of the trip was watching him read the photo book we'd brought him to the other children in the orphanage. He excitedly explained about his new siblings, cousins, and extended family. The last page of



A new family: Sarah and Josh meet Gabriel for the first time



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the book was a family portrait, without words. He told the other kids in English, 'family.' Then he became silent, looked again at the picture, put his hand on it, and said quietly in English, 'My family!'

"We've been home a month and already received our provisional immigration approval. We're close to having everything in order to proceed. Each step seems to be going much quicker than we anticipate. We are still prayerfully hopeful that we will have one more (official) family member for Christmas!"



**Pam Thomas**, Across the World Adoptions, reports on Michael's adoption:

"Michael has a lovely family waiting in California. They have already submitted their dossier to China and are preparing for the trip to adopt him and bring him home!" ☺

# inbox

THE ARTICLE ON MICROBLEEDS [MAY/JUNE 2014] was awesome! You hit it right on the head. I experience them a lot and knew they were small bleeds. Now I have a title to put with what I experience.

Chad Brown  
FLORIDA

I AM WRITING TO COMMEND YOU AND YOUR staff on an excellent article on waiting children with hemophilia overseas. Your recent PEN article [Aug/Sept 2014] moved me to tears! Thank you for the steps you have taken to make your readers aware of these precious children who suffer without adequate care! This issue is near and dear to my heart, as I am the adoptive mom of a beautiful little guy from China who has severe hemophilia A. I am also the lead mentor mom for hemophilia for an advocacy organization called No Hands but Ours, which advocates for children in China with special needs and assists families who are considering adoption of children with special needs.

Kelly Cartwright  
VIRGINIA

<http://www.nohandsbutours.com/2014/06/30/training-wheels-learning-to-live-with-severe-hemophilia/>

I WANT TO THANK YOU FROM THE BOTTOM OF my heart for the beautiful article on hemophilia adoption. I have shown it to friends and family as well as to my son's teachers, and everybody said that the article was well written. It was interesting to read the perspectives of the different families and of Pam Thomas and see how much we have in common and how committed we are to those children.

My hopes and prayers are that there may be families who will consider adopting a child with hemophilia in future.

Jasmin Davidson  
TEXAS

### As I See It... from page 3

In the process of becoming a healthier individual, I've learned that taking the time for myself to train for events—and also eating better—has helped me become a more grounded person with fewer bleeding problems. Plus, I have reduced my stress level significantly. I've found that keeping a calendar and sticking to it has helped me stay on track and set aside that time for *me*—because it's scheduled on the

I HAVE A NINE-YEAR-OLD SON WITH SEVERE hemophilia, and after reading your article, my husband and I want to see about adopting a child with hemophilia. It never occurred to us that this was a need. Thanks so much!

Suzanne Crittenden  
SOUTH CAROLINA

### Project SHARE

BY THE LORD'S MULTITUDES OF GRACE AND your donation [of factor], our children stayed alive. This new academic year, Alazar started grade 9 and Daniel joined grade 3. Thank you for your kind investment in the lives of these children. God bless you richly.

Tadesse Belay  
Ethiopia

Tadesse Belay



Thanksgiving in Ethiopia: Tadesse with sons

IN HONOR OF MY BAT MITZVAH, I AM SENDING [Project SHARE] bags of toothbrushes, deodorant, soap, tissues, and a razor. I hope it helps [the families overseas]. Thank you so much for allowing me to do this.

Grace Schapiro  
NEW JERSEY

calendar. And I know I am creating more years ahead, for Jeff and Alex and myself. ☺

Kimberly Philo holds a BS degree in health services administration from University of Central Florida. She works as a consumer advocate for BioRx.

Jeff Philo created and posted a video on YouTube documenting Kim's first RAGBRAI adventure: "2011 RAGBRAI—Kim's Bike Ride Across Iowa" at <https://www.youtube.com/watch?v=wjBipyjiPaQ&list=UUTI-hqmjkZGer-m3ZxnA32Lw>. Please follow Kim's marathon blog: [www.ActiveHemophiliac.blogspot.com](http://www.ActiveHemophiliac.blogspot.com) or find her on Facebook as she documents her journey: ActiveHemophiliac.



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