

VOLUME ONE

# HELLO FACTOR

REAL STORIES OF PEAKS AND TROUGHS

## JAMES' STORY OF SURGERY AND RECOVERY

Any factor and physical activity regimens mentioned in this magazine were developed for James only after consultation with his care team, and may not be appropriate for all patients. Your factor regimen may be individualized after consultation with your care team.

# GROWING UP



It's common for you or your caregiver to sometimes feel overwhelmed by your bleeding disorder. Few people outside of the hemophilia community really know the grit and determination that you need on a daily basis just to maintain factor levels. Finding support and understanding can sometimes be as difficult as holding to a steady prophylaxis routine.

Here at Takeda, we want to celebrate individuals like you that are on this challenging journey, and are making the most of it. We know it's tough—but we also know that anything difficult helps make you who you are, by your response to it. And we know that matters.

**We want to introduce James, who has lived with hemophilia for over 50 years.**

An immigrant from the Philippines, James has gone through a childhood with treatment plans very different from what we have today, a huge family move to an unfamiliar country, self-doubt, countless bleeding episodes, and two major joint surgeries...all to become the positive and courageous man he is today.

**How James got where he is now matters. We hope you'll be as inspired by his story as we are.**

# & GROWING CONFIDENT

*Tropical rolling hills and distant mountains. Farmers plowing their fields by driving water buffalos, or wading in flooded rice paddies to harvest their crops. Roofs of thatched leaves sheltering families from the spring storms. In the 1970s, life in the rural Philippines was tough. Having a bleeding disorder made it even tougher.*

In the small farming village where he grew up, James would watch the other young boys play, but from a distance. His parents had experience with hemophilia A, and learned the hard way. "One of my brothers passed away of hemophilia at the age of five," James explained. "He fell, hit his head, and had bleeding in his brain." Consequently, his parents were always concerned, keeping one eye on James and the other looking out for anything that might be a bleeding risk.

*"My parents would limit my activities a lot. They loved me, but wanted to make sure I couldn't hurt myself."*

So James was taught to watch his step everywhere he went. He could never roughhouse, because a small scrape or bruise could quickly become a big deal with his hemophilia. "Once in a while I would horse around with the other kids, but there were consequences. I'd get bruised and then bleed, so then my mom or dad would know." He sometimes felt that he let his parents down, even if a bleed happened because of a total accident.

However, as every person with hemophilia (or their caregiver) knows, you can't stop every bleed from happening. You can be prepared and cautious but sometimes kids have to be kids, and bleeds will happen.

Whenever James did have a serious episode, his whole family would have to travel miles and miles from their village to the closest hospital for access to proper care. He had no dedicated care team. "I'd only get treated when I had a bleeding episode," he said. This was in the '80s, and there was no factor replacement therapy available. Rather, he'd receive a blood transfusion.

"I would have an IV drip and stay in the hospital for

a couple of days. Afterwards, I would just stay home because I couldn't really walk well or do anything, so I'd have to wait for the swelling [in my knees or ankles] to go down."

But while he was laid up, James discovered a love of reading. He devoured books and really took to



learning new subjects. He focused on making study plans and setting goals with his schoolwork. His grades improved quickly with his focus, filling him with the kind of pride and confidence a different kid might have gotten from sinking the winning shot in a basketball game.

When he was 16, James' family moved to Los Angeles. "The number one reason was because of the hemophilia...so that we could get the right care," James said. He went to a children's hospital and was met by a care team that included a hematologist, a nurse, a physical therapist, and a social worker, all specializing in hemophilia, and he saw first-hand how serious his treatment as an individual would be taken.

A bright, curious teenager, James listened eagerly

as his care team explained how factor replacement worked in his body. This led to an important discussion about factor levels and how to prepare for physical activities. Eventually his care team recommended a prophylaxis regimen. It took James a long time to do that first infusion himself, but his care team "helped me through the psychological part of it. Then, as soon as I began to self-administer, things changed for me."

His hematologist became a mentor, since he was filled with questions about the best ways to manage his specific situation—the best plans he could make for himself. He made James feel like he was normal, that hemophilia was just another thing in his life. He taught James that having hemophilia is OK, telling him, "You're not a freak...you're not different. You're unique."

A few years after college, James went to the wedding of a friend, where he met a cute girl who was also from the Philippines, Carla. A whirlwind courtship began, and soon he was bringing her with him to hemophilia community events, where she learned more about his condition by talking with others like him. She even got over her fear of needles, watching how swiftly James used them to infuse. She was impressed by his responsibility and self-awareness, that he knew how to ask for help and support from others. His hemophilia pushed him to be a better man, the kind who set goals and worked to see them through. They were married in 2002.

The couple has since moved to Las Vegas, where they run a ceramics studio together. Kids come into the studio with their parents to paint and glaze cups, plates, and other pieces, while James helps them all learn a fun, new artistic skill. Helping these children in his studio makes him look back on his former doctor's reassurances about being a person living with hemophilia, giving him pause.

"If I saw [that doctor] today, I would thank him for saying what he did to me. Because hearing it helped me change my perception of hemophilia, my understanding of hemophilia. It gave me a little bit more confidence."



## STAYING COVERED DURING SURGERY: Q&A

*But it's not all confidence all the time with James. He talked to us about the two times he was most concerned about his hemophilia A: when he had surgery.*

**S**urgery carries a great risk for people with hemophilia A—but with James' early onset joint damage starting to cause pain and mobility issues, it was a consideration he took seriously. With help from his care team, he eventually chose to have operations for his elbow joint, and later, his knee. We talked to him about what it meant to take the risk of these surgeries as someone with hemophilia A, and what others could take away from his experience.

### **Tell us a little about going under the knife—twice.**

A lot of bleeding episodes happen in the joints; mostly knees, elbows, and ankles. There was no specific accident that caused me to need surgery, but I can probably attribute it to the bumps and bruises I got as a kid. I was concerned about whether the surgeries would be successful. Surgery can be especially risky and complicated for people with hemophilia. **Before both procedures there was a lot of discussion around how I'd be kept at a sufficient factor level.** And for me, we decided to use factor prophylaxis during both surgeries, so they could continue to track my levels.

### **Were there differences between the two surgeries?**

During my elbow surgery and for two days after I received a continuous IV drip, which gave me the necessary factor coverage. After surgery I needed to infuse before and after physical therapy. I got a port, which made this easier.

My factor plan was different with my knee surgery, which was 10 years later. There was no IV drip. My surgical team gave me factor before and then right

after surgery. Then it was every 12 hours until I was discharged. When I got home, I needed to infuse every day for about a week. **I trusted my care team that I'd be covered.\***

### **What about your recovery? We heard that can be difficult.**

Yeah, and my hemophilia probably prolonged the time I needed to heal. For both surgeries, I had to do a lot of PT (physical therapy). I worked with a physical therapist who gave me exercises to do at home. You have to see all the sets of exercises through, even if it gets really boring. And it does get boring, repeating the same movement over and over and over. I would set goals with my care team for my range of motion. I really wanted to recover quickly, but you can't just get back on your bike after a knee replacement. You have to be patient and go through the steps laid out for you. My wife Carla helped me out a lot by holding me to my regimen and motivating me through all the sets of PT.

### **Sounds like you had someone in your corner.**

The best thing about Carla was the moral support she provided. She was really understanding. I felt like I had something to prove, to grow by pushing through recovery. I wanted to be active again, to go out with her like we did before the surgeries. She was a big part of my recovery.

## Coverage in the Operating Room

Bleed control was a priority for James. He and his care team chose factor while planning his surgeries because:

- The proteins needed for clotting are available immediately after infusing with factor
- Only factor is measurable in the bloodstream, so surgical teams could check it throughout the procedure
- Knowing his surgical team understood his factor levels and had a plan to keep him stable was a comfort to James as a patient

\*Every treatment regimen for patients with hemophilia A is different. James' regimen was based on his needs as determined by him and his care team.

# CARLA

## SUPPORTING JAMES WITH PURPOSE

Carla is the type of person who greets people with a warm hug. You instantly can feel the depths of her tender heart and devotion, qualities that run deepest when it comes to her husband and best friend. These qualities were critical as he underwent his surgeries, the first of which was only a few months after they were married.

Like James, Carla always wants to be prepared. To help her understand what to expect, she talked with his care team. They assured her they would keep his factor level up to provide bleed control during surgery. They also explained what he would need from her during the recovery process, what she needed to keep an eye on, and how long it would be until he regained mobility. She knew from talking to James about his childhood that he didn't enjoy being treated like he was fragile, so she knew she needed to have a light touch.

Since James couldn't bend his elbow after the surgery, Carla had to learn how to mix and help administer his factor through a port. After she did it, she realized she wasn't squeamish about needles. And she felt like she was a better person for helping James through this time. Like what happened with James, hemophilia had also helped Carla realize the kind of dedicated person she could be—the kind she wanted to be.

*“He didn't normally like being babied or spoiled. But taking care of him was my favorite part.”*



## Carla's Post-surgery Tips for Caregivers

- Your loved one may feel frustrated or impatient that their body isn't cooperating; encourage them to set goals with their care team to regain mobility
- Understand the PT exercises and motivate your loved one to perform them at home
- Learn to help infuse factor (through a port or through a vein) with instruction from the care team
- Help ease the swelling with ice, as directed by your care team
- To avoid getting burned out, take stock of yourself by practicing deep breathing or taking a peaceful walk once in a while
- It will take time, but have expectations that your loved one will see recovery through

“I pushed him to keep repeating the PT exercises,” she notes, proudly. “His care team had prescribed five or six reps for each move, it got very repetitive. So yes, I was the annoying caregiver.” However, that was just what James needed.

“Otherwise,” he said, “I would get complacent. Without her, the healing process would have been much slower.”

About 10 years after James' elbow surgery, Carla found herself helping James to recover from a knee replacement. Carla again consulted with James' care team. **Since she had done this before, she thought she was fully prepared for this one. But every surgery is different.**

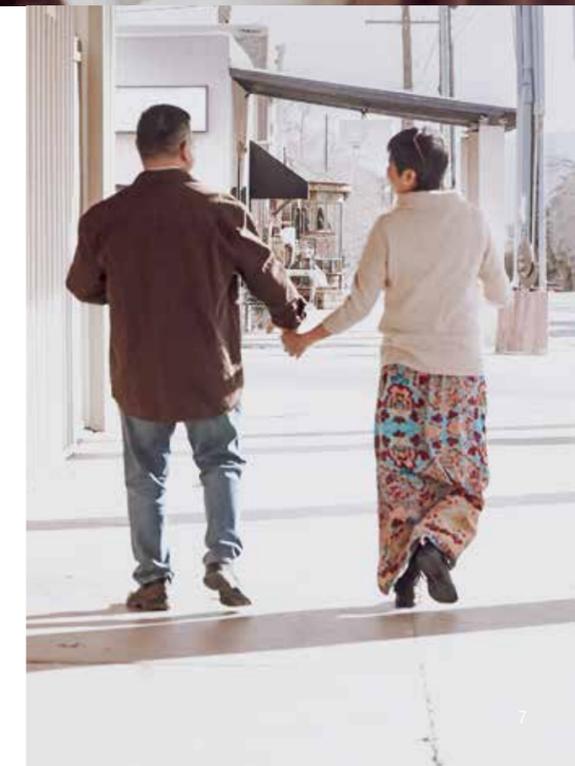
This time, James came home with 25 staples in his swollen knee. The swelling took longer to subside than the swelling in his elbow did.

Although this was concerning, Carla set to her caregiving duties. This go-round, she was better at helping him infuse with factor through a port. In time, with Carla's loving care, James was back on his feet and their lives were in step once again.

## Important Things to Know About PT<sup>1</sup>

Today, there's a great deal of knowledge about hemophilia and the routine care for postoperative patients has been largely standardized. Carla and James have put in the time with hours and hours of PT after James' two surgeries. Here's what they've learned from their experience.

- PT is essential for recovery after joint surgery; talk to your care team about how much range of motion you can expect to regain
- Be patient and see all the sets of exercises through, even if it gets really boring
- It may be performed at home and/or a rehabilitation center or hospital, and may begin soon after surgery
- PT and your medication go hand in hand, so continue your regimen as prescribed during PT
- You may receive pain medicine and/or cold compresses during the rehabilitation period
- Your affected joint may be immobilized for a while with a splint
- Having a positive outlook during PT can help



# IT'S GO TIME: KEEPING FIT



Being active is important to James. Once his hematologist told him that he could participate in many of the activities he wanted with the proper preparation, he knew he could make a plan for success.

Planning ahead is fundamental when living with hemophilia—that's why before he starts any physical activity, James consults with his care team and sets goals. For example, his favorite thing to do since moving to the US is riding his bicycle, so he wanted to make sure he could continue to enjoy it after he had surgery.

For James, the measurability of factor was an important aspect of his treatment plan, knowing that he wanted to continue riding his bike. He tries to know all the things that could go right or wrong in a given situation, then makes sure he is prepared for any of them when he's on a ride.

Like how much extra factor he can carry on him. What to do if there's a breakthrough bleed. What to do if he has a fall. Or if he's unconscious from a fall. Or how to address his first aid responsibly. And so on. Every moment has a contingency that James has thought through and considered carefully. That sort of preparation makes him feel more confident when he is faced with an obstacle. The terrain, the weather, the other riders, the condition of his joints: James knows how to be ready, in a character-defining way.

One morning, James and his friends saw a notice for a charity bike event in Los Angeles. He told his care team about it, and after a thorough evaluation, they worked with him to retool his regular infusion schedule to allow for the extra physical activity of training for the event. James was most concerned about protecting the elbow and knee that had been

through surgery. His care team was confident that with the right conditioning, preparation, and factor coverage, he could ride with his friends in the event.

That was all James needed to hear. With his goal in mind and event bib in hand, he met his friends at the starting line at 5 AM. To them it might have been just another bike ride but, for James, keeping up with them was a meaningful accomplishment, and so much more than just staying active post-surgery. The ride marked for James that the hard work to regain his mobility after surgery had paid off.

*“Crossing the finish line was such a great moment...tiring, but also rewarding. I was so proud of myself.”*

They all had such a good time, James and his buddies rode the event three years in a row. After those events, he realized that he wanted to do more, see what he could really achieve. He saw his chance a couple of years later: a daylong, point-to-point riding event between two cities in California.

For this ride, James really dug into his preparation. Again, his care team advised him on how to train

and told him that maintaining his factor regimen would be important to help minimize the risk of bleeds. After all of his hard work post-surgery, the long days with Carla at PT, and the pain he fought through to regain his mobility, James realized that he could trust his own body for the duration of this journey. By the day of the ride, he and his care team had planned for every possible contingency.

He and his friends made the full trip and delighted in taking the train back home. It was an exhilarating, almost surreal accomplishment for James, knowing that a few short years before, he'd had knee replacement surgery, and hadn't known how well he would walk again—let alone ride a bike through the day, surrounded by friends encouraging him, and rising to the challenge they shared together.

## GOING PLACES WITH FACTOR

*“The number one piece of advice that I would give to someone traveling: always think ahead.”*

Even though it's against his nature to not have a plan, being on vacation is one of those rare times James gets to be spontaneous. When it's time to hit the road with Carla, it takes a huge weight off James' mind to know he can really relax. For him, prophylaxis is a well-practiced routine, and he looks forward to trips that have nothing else “routine” about them.

Still, planning is essential for traveling, even for a simple road trip. After his bike excursion, James learned that he can be more adventurous, as long as he's made the right preparations with his care team beforehand. He always consults with his hemophilia treatment center (HTC) prior to traveling to discuss whether he needs to alter his infusion schedule. Carla also plays a big role, making sure James packs enough factor to last through the trip plus extra in case of emergency, and that there's always a cold place to store it.

Most trips go smoothly. However, James notes, “the number one challenge is getting my factor through TSA.” Passing through airport security, he often has to explain what the factor is, because they always want to take it away, since it is a liquid vial containing more than 3 ounces. But eventually he gets through, and he has begun to see every trip through airport security as a teachable moment for the TSA—a time for hemophilia awareness, if you will.

Each year, James and Carla pick a different destination for their vacation. They've been all over the United States and Europe, with their favorite spot so far being Hawaii. They find it fun to go where the locals go, asking restaurant and hotel staff for tips of what they do in the area and following their lead.

Fully recovered from knee and elbow surgery, James now has the self-assurance to go with the flow and take these new experiences as they come. It's not a sentiment that's lost on him. He's grateful to be traveling the world with Carla on his own terms, being spontaneous and able to have new adventures because he's realized he can carefully organize his routine for just that: to get more out of life.



### Getting Prepared to Travel With a Bleeding Disorder<sup>2</sup>

The Centers for Disease Control and Prevention recommend that before leaving on your trip, you:

- Get a travel letter and a copy of your prescriptions from your doctor
- Pack enough factor for regular infusions, travel delays, and emergencies—over-prepare!
- Talk to your doctor to make sure your medications are safe to be put through airport security X-rays, and if so, request from the TSA they be inspected by hand
- Plan for contingencies, like where to go in case of emergency; make a list of HTCs or other resources in the area
- Update your vaccinations if needed



One of the first things you sense from James when you meet him is his generosity. Perhaps it's because of all the care and support that he's received from his family, medical staff, and others throughout his life. Or it could be the influence their advice has had on him and the knowledge he's gained from it. Whatever the reason, James feels both a desire and responsibility to help others. It also shows when he is spending time with Carla in their studio, teaching local families in the community about ceramics.

When James first moved to his new home near Las Vegas, he made integrating with the local hemophilia events and foundation a priority. This gave him the opportunity to meet other people with bleeding disorders and, moreover, to help younger community members feel more comfortable with who they are, in part by sharing his experiences.

Showing us around the ceramics studio he owns with his wife, James recounted to us the time when a local HTC, familiar with his story, had reached out to ask if he could talk to a young boy contemplating knee surgery. The boy wanted to understand exactly what James went through when deciding to have his own knee replacement, and how he had dealt with the post-surgery challenges.

*“It feels great to be able to give back.”*

James told the boy about his past in the Philippines, and how he'd always felt sad not getting to play with the other kids. He didn't want this boy to miss out on anything in his childhood—provided he could make an appropriate plan. So he explained to the boy what he'd come away with from his surgeries: the strength of learning to pull through, the confidence to take on new challenges. Experiencing firsthand how deeply his caregiver supports him, even through pain and struggle.

Even though every person with a bleeding disorder is different, with his or her own path for treatment, James wanted to help the boy make an informed decision for himself. He felt he needed to let the boy know that recovery from surgery was possible and you may still be able to do what you want to do. “I wanted to help him feel comfortable with who he is, that was most important,” James said.

When asked if he thought his life's experience set a good example for the boy, James humbly smiled. With that, he turned to go help some customers in the studio pick out their pottery from the shelves.

If you think about it, you can see the connection between the ceramics in James' studio and his resistance to being seen as a fragile sort of person. These objects, like him, might be delicate, but they are also strong, heated by a fire that hardens their exterior and helps them prepare for life. When you spend time with James, you get a feeling that no matter what setback he is faced with because of hemophilia, he is truly unbreakable.



# PAY IT FORWARD

## Support From the Community Matters

Here are some hemophilia resources you can connect with to help shape your plans and your goals, or just to have someone in your corner. They can also direct you to the nearest meet-ups and events in your area.

**National Hemophilia Foundation**  
(212) 328-3700  
[www.hemophilia.org](http://www.hemophilia.org)

**Hemophilia Federation of America**  
(202) 675-6984  
[www.hemophiliafed.org](http://www.hemophiliafed.org)

**World Federation of Hemophilia US**  
(877) 417-7944  
[www.wfh.org/usa/home](http://www.wfh.org/usa/home)

**BleedingDisorders.com**

James has hemophilia A. He's found balance in the peaks and troughs of his life through profound relationships with both his wife and his care team.

Read how he has managed two major surgeries with poise and remained a positive, active part of the Las Vegas hemophilia community.



REFERENCES: 1. Escobar MA, Brewer A, Caviglia H, et al. Recommendations on multidisciplinary management of elective surgery in people with haemophilia. *Haemophilia*. 2018;24(5):693-702. 2. Travel Safe with a Bleeding Disorder. Centers for Disease Control and Prevention website <http://cdc.gov/ncbddd/hemophilia/travel-safe.html>. Updated June 3, 2019. Accessed February 20, 2020.

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