

Meet John Pepper

One Man's Experience with Joint Replacement

Sixty-six-year-old John Pepper had bleeding issues with both of his knees growing up in Ferndale, Michigan. John has severe Hemophilia A and as a child in the 60s and 70s his target joints would bleed often. This required aspiration of his knee, treatment with whole blood, and occasionally a cast and a 3-day hospital stay.

John did his best to learn what he needed to do to avoid bleeding episodes. In high school he swam daily in gym class which helped build muscle but, ironically, John found his left hip bothering him more than either knee.

When Enough Was Enough

John's hip pain progressed after many decades of discomfort. He was unable to get up from his chair at work without a struggle. This was very inconvenient as he needed to move regularly on his shipping job for an aerospace company. One supervisor even urged John to quit, illegally harassing him. "He was a peach" John says sarcastically. "And I'm still working here 17 years later."

John visited an orthopedist who recommended cortisone shots as a first line of treatment. The first treatment relieved the pain for a full 6 months. The second only lasted a couple of days. Although in John's words he was "terrified" of joint replacement surgery, he was running out of options.

Ultimately, as he was playing with his two-year-old granddaughter, he realized he couldn't walk on the grass. Many people wonder when to make that final decision to move ahead with surgery. That day was John's turning point to proceed with a full hip replacement.

How Did John Find an Orthopedic Surgeon?

John needed to find a surgeon he felt comfortable with. Wisely, he found himself interviewing surgeons to see if they were a good fit. The first surgeon he interviewed didn't answer questions well, nor did he seem compassionate. And not all surgeons his doctor sent him to would work with John due to his bleeding disorder. Finally, John found a surgeon he trusted; one in the same hospital as his HTC which helped everyone coordinate his bleeding disorder care.

"I would never think of having surgery without involving my HTC.," says John. John's HTC worked directly with the surgeon to plan factor treatment before and after the surgery. The HTC staff knew the surgeon as many HTCs do, and they were able to coordinate well together.



John & his granddaughter

Pre- and Post-surgery

Prior to surgery, John had to see a dentist to be sure his teeth were healthy. Any possible infection in his mouth could affect his new replacement. He was also prescribed antibiotic treatment pre-surgery for the same reason. His surgeon wanted to be sure John was fit for the surgery and the recovery, ordering water therapy to help strengthen John's hip muscles.

John was treated with increased doses of factor during the surgery and for 5 days afterward as he healed. For 6 weeks he took part in physical therapy. "I knew the physical therapy was important for my recovery and I wanted to get back to work. Fortunately, I had zero issues after the surgery and because I worked hard at it, I actually returned to work weeks earlier than we expected."

John also had his left knee replaced in 2023. He found the recovery to be a bit more difficult as he had to exercise with a 10-pound brace, but he has had such good results with both replacements he's considering having his right knee replaced soon.



John's knee surgery



John catches the big one

How is John Doing Now?

John says he's doing great. "I wish I would have done my surgeries earlier. These replacements are the best thing I ever did for myself." The HTC and the orthopedic department were a godsend to be able to move like I do. You just need to have the confidence and trust in your surgeon and HTC staff."

Emergencies Happen. We're Here to Help!

During an emergency, it's good to know that Cascade pharmacy staff are always available after hours to help you during those unexpected difficulties.

Cascade contracts with an answering service who receives all calls when the office is closed. If you have an emergency and request to speak to our on-call staff directly, we are immediately paged and will return your call as soon as possible. Please understand that the answering service cannot answer any medical questions or take medication requests as they are not medical professionals. Those conversations require a call back from our team. *We are always happy to help when you need it most!*



Colleen Joiner, LMSW, CCM

Dear Readers,

Joint arthropathy and arthritis are common conditions for many of us as we age. Joint damage in the bleeding disorders population tends to be much more prevalent and severe; particularly for those who didn't have the benefit of prophylactic treatment in their younger years. In fact, even some younger people in the community find they have intrusive pain and joint dysfunction and are contemplating surgery to improve their lives.

Deciding when or if to have surgery is an important discussion between you, your hematologist, and your orthopedic surgeon. It's beneficial to do your research to discover the pros and cons of surgical options and the recovery process. You may also want to consider your age and how long your replacement is expected to last, if that is your plan of care.

To get you started, we hope our interview with Steve Houghton, PT, OTC, COMT, FAAOMPT will answer some of your questions. Steve has many years of experience working in a Hemophilia Treatment Center and beyond. I hope you find our conversation informative and helpful if you're considering a joint replacement. Stay healthy and enjoy the spring!

Colleen

Cascade Hemophilia Consortium Mission

To enhance the system of care for people with bleeding disorders and related complications, by assuring the lowest possible price for the full range of treatments, HIV and hepatitis related therapies and other medications available to treat their disease; to provide access to these medications for those without insurance or inadequate insurance coverage; to support the comprehensive hemophilia treatment centers in treating and educating consumers and their families so they may become knowledgeable and proactive in managing their own care.

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An Interview with Physical Therapist
Steve Houghton
PT, OCS, COMT, FAAOMPT



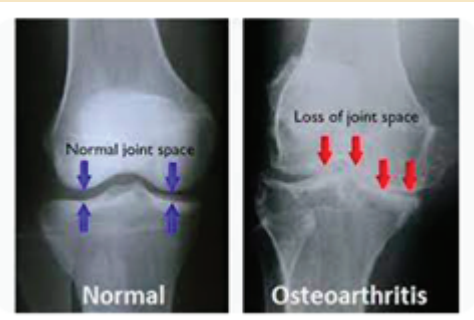
New Joints, New Life: Restoring Movement through Joint Replacement

Colleen: Hi Steve! Thanks for your willingness to share your expertise with our readers. I know you have many years of experience with the bleeding disorders community. Can you explain the process a person goes through to determine if they are a candidate for joint replacement?

Steve: First, the patient will need to see an orthopedic surgeon. Joint replacement surgery is typically determined by the amount of joint damage present. A surgeon will take an X-ray and visualize the amount of bony destruction present as well as the loss of normal joint space. Range of motion

and strength measurements will be taken, and an assessment will be made of the patient's ability to walk functional distances as well as how much pain is present when they walk.

From a surgical point of view, the X-ray images will be a major factor in determining if a joint replacement is appropriate. Other factors such as the patient's medical health and their ability to tolerate an unpleasant surgical procedure and rehabilitation will also be assessed. The real concern is that the patient has lost so much in terms of strength, mobility, and cardiovascular fitness due to their steadily decreasing activity level because of joint pain.



Colleen: How does the team determine whether a joint replacement is warranted vs. a less invasive procedure?

Steve: The decision will be related to the amount of pain the patient is experiencing and the amount of dysfunction they have in their mobility (i.e., limited ability to walk). Generally, there isn't a time when waiting longer will make it impossible to perform a joint replacement. Some surgeons will suggest you wait as long as possible to replace a joint. Others will say that the joint should be replaced when your mobility and quality of life is being substantially impacted by the pain you're experiencing.

Less invasive procedures can be utilized when there is mild to moderate damage to the joint. In mild to moderate arthritis, arthroscopic procedures can be utilized to clean out the joint. This does not reverse the damage that is present but simply provides some level of temporary improvement

Colleen: Is there a difference between some of the older patients who didn't have the benefit of prophylactic treatment as kids and the younger ones who have used prophy? How does this affect the surgery?

Steve: Arthritic damage for people with bleeding disorders, particularly those individuals who did not have prophylactic treatment available to them as a child, tends to begin earlier and can become quite severe.

Arthroscopic surgery is utilized for mild arthritic damage. Once the joint becomes heavily involved, the cushioning joint cartilage will become lost or severely thinned resulting in a "bone on bone" situation. This is very painful and dysfunctional.

Colleen: Is it best to go through your HTC to find an orthopedist? If the patient doesn't find their orthopedist through the HTC, it's important for the patient to connect the surgeon with the HTC team, right?

Steve: Yes, and yes! Most orthopedic surgeons are not familiar with the nuances and complications of replacing a joint in someone with a bleeding disorder and may refuse a patient for that reason. We strongly recommend the patient utilize a surgeon who is familiar with bleeding disorders. These surgeons have learned to work closely with the HTC staff to manage their post-op bleeding concerns. Typically, (as in always) patients are referred to surgeons the HTC staff has been previously connected with. A patient also needs to get to a physical therapist, post-surgery, who is familiar with the nuances of working with this population.

Colleen: Which joints are most appropriate for replacement? Are some generally more successful than others?

Steve: In general, knee and hip replacements are by far the most commonly replaced joints. Millions of these joints have been replaced for many decades. They've been well researched, and improvements in prosthetics have been made. Less commonly replaced joints include the ankle and elbow. Shoulder replacements sit somewhere between those two extremes and are rare for people with bleeding disorders.

Elbow replacements tend to last longer because the elbow is not a weight bearing joint and is therefore not subjected to the extreme force that a weight bearing joint is. Ankle replacements are challenging because of the complicated nature of the ankle joint and the relatively small size of the ankle bones (less bony mass to anchor the joint replacement due to the small bone size). Ankle replacements have improved in recent years; however, the long-term success of these joints is still not fully understood because they are performed in such a small number of cases. We just don't have the data yet.



Hip and knee replacements are "easy" to redo (or revise as the surgeons call them). That being said, they cannot be revised repeatedly.

Colleen Does someone with a bleeding disorder have a greater risk of complications than someone without one?

Steve Yes, for several reasons. Obviously, many of our older patients are HIV positive and the suppression of their immune system is a concern in terms of post-operative infections. A second concern is the obvious issue of their tendency to bleed postoperatively. The HTC team can generally manage this, but it is still a concern compared to those without a bleeding disorder.

Joint replacements are somewhat tough surgically. The involvement of multiple joints in the bleeding disorders population makes recovery more challenging. Imagine how difficult it is to recover from a knee replacement, or even to use a walker when your ankles and elbow joints are also heavily involved.

Colleen: What is the recovery process like post-surgery?

Steve: Joint replacement surgery and recovery are very painful. Patients need to understand this. A surgeon will determine whether a patient is appropriate for joint replacement based on their ability to tolerate the rehabilitation (i.e., physical therapy).

The most common reason for failure of a joint replacement is not the surgical aspect but the recovery. If you're not willing to put in the painful work to rehabilitate the joint, it will become very stiff and painful postoperatively and then you'll wonder why you even did the replacement.

I tell my patients that in the first month you might question why you had a joint replacement. By the third month you begin to see a light at the end of the tunnel. By six months you're back to relatively normal function and mobility. Research evidence says it takes a year to fully regain all of your strength.

Colleen: Is PT always required post-surgery?

Steve: YES! 100%

Colleen: What kind of outcomes can a patient usually expect from the replacement? I'm sure there is a range of outcomes but what are the goals?

Steve: Good question. Getting a joint replacement is not like getting a joint like you had in your 12-year-old self. You are getting a replaced joint in an old body! Also, just to clarify, the joint is resurfaced rather than replaced. Patients sometimes get the idea that the end of their thigh bone and the top of their shin bone are cut off and replaced with a knee replacement. That is not the case. Those joint surfaces are technically resurfaced. If the joint is successfully replaced surgically and the patient completes their physical therapy successfully, they can expect a good outcome.



Colleen: What does "good" consist of?

Steve: We're looking for the following two outcomes:

- 1 Significant reductions in joint pain, the ability to walk community distances and to ascend and descend stairs with little to no pain.
- 2 Better range of motion post-operatively than before the surgery.

If a patient has successful surgery and rehabilitation outcomes, they are almost always pleased with their decision to have a joint replacement. If they "flunk" their physical therapy resulting in poor range of motion and stiffness they will invariably have residual pain and limitations in mobility.

Colleen: Thank you, Steve, for all of this helpful information!



If you would like more detailed information on joint pathology and management, view our presentation by either scanning the QR code or visiting CascadeHC.org/surgery.

