Local man gets devastating diagnosis, then a second chance at life

'I'm using my second chance to be an advocate in any way I can,' Steve Johnson said

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(SUBMITTED PHOTO)

Steve Johnson and his fiancée Melanie Fox pose for a photo while he undergoes treatment for the autoimmune disease primary sclerosing cholangitis (PSC).

It was just before the start of the Minnetonka High School boys hockey season in September 2024 when assistant coach Steve Johnson fell ill, leading to a diagnosis that would change his life forever.

Prior to his diagnosis, Johnson had come down with common cold symptoms — fever, chills, fatigue, lack of appetite — and originally mistook it for Covid-19. After a couple weeks had passed and his symptoms persisted, he sought professional medical care at the Mayo Clinic in Rochester.

After running several tests, doctors determined that Johnson had primary sclerosing cholangitis (PSC), a rare disease of the liver affecting up to 1 in 10,000 people, according to the Mayo Clinic. The autoimmune disorder is caused by inflammation of tubes in the liver, known as bile ducts, that scar and narrow, leading to the liver being unable to filter blood and support digestion.

"I was extremely jaundiced, very yellow everywhere.I was skinny. I was fatigued. ... I could barely eat.I was very tired, [had] headaches, things like that," Johnson said. "But I'm still pretty young, so I was still doing my best with trying to work out, trying to eat a lot of protein [and] do my best that I could."

PSC increases the risk of liver failure and cancers of the bile ducts, colon and gallbladder. It requires close monitoring of liver health and patient symptoms. While patients can undergo procedures to temporarily unblock affected bile ducts, the only cure is a liver transplant in advanced stages of the disease.

"So then [doctors] were like, 'listen, there's nothing that we can do. There's no pills. There's no regimen that we can do to stop this or to figure this out. This is a progressive disease. This could happen really quick, it can happen over time, but we need to get you on a liver transplant list because this is the only cure for this disease.It's the only thing that will allow you to live,'" Johnson said.

He recalls the day of his diagnosis being one of mixed emotions for both him and his loved ones. Shock, devastation and frustration kept him from falling asleep that night.

After taking the night to process his diagnosis, Johnson awoke with a renewed sense of determination. He was placed on the transplant waiting list for a liver and did what he could to ensure he was in good health for his future procedure. He credits his "athlete mentality" for helping him overcome the difficult challenges brought on by the disease.

Prior to his coaching days at Minnetonka High School, Johnson played for the school's team from 2010-12. He then received a full-ride athletic scholarship to the University of Minnesota — Twin Cities, and played four seasons with the Gophers from 2014-2018. He was drafted by the Los Angeles Kings in the 2014 NHL Entry Draft and played abroad professionally for three years.

While managing his chronic illness, Johnson continued coaching the local hockey team and went about his regular routine to the best of his abilities.

On Jan. 3, 2025, Johnson received a call from his medical team informing him that a liver was available for transplant.

"When I got the phone call, it was just an absolute rush of emotion. I was so incredibly excited," Johnson says. "I knew that my life [would] be changed forever.I knew that it'd be a whole different life. It's gonna be a whole new journey.It's gonna be a life journey. Nothing will ever be the same and so I totally just embraced it."

For nearly two months following the surgery, Johnson and his girlfriend temporarily resided in Rochester to complete the necessary post-operational care, receiving close monitoring to ensure a successful recovery.

Aside from an anti-rejection medication that must be taken twice daily, the now 31-year-old has returned to life as "normal." He continues to serve as an assistant coach for the boys hockey team, has a career in aviation as a commercial pilot for Sun Country Airlines, and even proposed to his then-girlfriend, Melanie Fox, in August 2025.

"My fiancée has just been a rock the whole time,"

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COMMUNITY BRIEF

Wings of the North Air Museum to unveil Minnesota Aviation Hall of Fame plaques

The Wings of the North Air Museum will host the unveiling of the plaques honoring seven new inductees into the Minnesota Aviation Hall of Fame at noon Saturday, April 11, at Flying Cloud Airport in Eden Prairie. The Class of 2026 includes:

- Eugene "Gene" DePalma, Navy veteran and aviation executive
- Charles "Chuck" Doyle, Jr., airline captain and airplane restorer
- Cora May Fuller, one of Minnesota's first female pilots
- Conrad "Butch" Maxwell, Air Force veteran and propeller expert
- James A. Olsen, founder of Sun Country Airlines
- Robert J. Pond, Navy veteran and vintage aircraft enthusiast
- John R. Sandberg, aviation mechanic, restorer, and designer

They will join almost 250 previous inductees.

The museum will also be unveiling the actual U.S. Navy Blue Angels flight suit worn by the first woman to fly fighter aircraft for the world famous demonstration team, Amanda Lee from Mounds View. She was inducted into the Hall of Fame in 2025.

Some of the inductees or their families are expected to be at the unveiling along with several past inductees and local dignitaries. The event is free and open to the public. Doors open at 11 a.m. and the public is welcome to enjoy the aircraft and displays of the Minnesota-themed Wings of the North Air Museum until 3 p.m. A formal induction ceremony and dinner will be held later that evening at the Mystic Lake Center.

Access to Flying Cloud Airport for the public is through Gate H, one mile west of Flying Cloud Drive on Pioneer Trail.

More information: wotn.org/museum/ and mahof.org/awards-banquet/

Both Wings of the North and the Minnesota Aviation Hall of Fame are IRS 501©(3) nonprofit educational organizations.



(SUBMITTED PHOTO)

Steve Johnson and his fiancée Melanie Fox shortly after getting engaged on Aug. 8, 2025.

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Johnson said. "I mean, the whole family too, but she was there at all the appointments and she was just an absolute rock during it. 'Whatever we got to do, we're going to do it,' type of thing."

The couple will be married this summer, with his medical team from the Mayo Clinic in attendance.

Johnson hopes his story teaches others about the importance of organ donation. "I'm using my second chance to be an advocate in any way I can," he said.

From a single donor, eight lives can be saved and more than 75 lives can be enhanced, according to organdonor.gov.

To learn more about organ and tissue donation and/or to register to become a donor, visit lifesource.org.