

Rolf Benirschke story

### **Alive & Kicking**

When Rolf Benirschke learned that he had become infected with hepatitis C from blood transfusions he had received in 1979, the deadly virus re-awakened the same passion and commitment to fight back as when he fought for his life and his budding NFL football career twenty years earlier. This new challenge was different, though, because he had a lot more at stake—his family.

After Rolf and Mary Benirschke's fourth child, Ryan, arrived in 1998, he did what any prudent father would: he sought the purchase of more life insurance to protect his family . . . just in case the unthinkable happened.

The insurance company set up the normal medical exam and blood test. All routine. But when the insurance carrier came back and said they wanted to do another blood test before they issued the coverage, Rolf inquired why. He was told that his AST and ALT liver enzymes were slightly elevated, probably nothing to be worried about, but they wanted to run another test to be sure.

Rolf was curious about this development but felt fine. He submitted to the follow-up test because he still wanted the extra life insurance. When the results came back, he was told to set up an appointment with his family doctor, who got down to business right

away. The news was not good, he said. “Rolf, it appears you have been infected with the hepatitis C virus.”

The doctor’s unemotional statement hit Rolf—a former kicker in the National Football league—like a blind-side tackle. His shock quickly turned to fear—not just for himself but also for what this news might mean for his family. He was the father of four children under the age of six—and two were adopted from Russia with special needs. Didn’t people die from having hepatitis C? How could Mary cope without him?

Rolf remembered reading something about the virus in the newspaper and the growing number of people suddenly discovering they were infected, but that was as far as his knowledge went.

“What does this mean?” he asked hesitantly, not sure if he was going to like what he was about to hear.

“Hepatitis C is a virus that gets into the bloodstream and attacks the liver,” his doctor explained. “It was formally identified in 1989, and a year later the first hep C antibody test was developed. Prior to that, physicians knew something was out there. They were calling it non-A or non-B hepatitis because it attacked the liver and acted like hepatitis. A more specific screen was developed in 1992, and that’s when most blood banks and testing facilities began thorough screening. Today, our blood supply is very safe, but before the implementation of that test, many people who received blood unknowingly became infected with the virus.”

Rolf buried his face in his hands. He must’ve been one of those who had become infected with hepatitis C accidentally. Back when he was kicking for the San Diego

Chargers, he had undergone emergency surgery during the 1979 season following a near-fatal battle with ulcerative colitis.

During the course of two major abdominal operations six days apart, Rolf needed 78 units of blood to keep him alive—blood that hadn't been screened for hepatitis C, or HIV for that matter. "The only bright side to this, Rolf, is that you didn't contract AIDS," said his doctor. "Remember, we weren't testing for the HIV virus back in the late 1970s either."

Rolf sat in the doctor's office, stunned at this new diagnosis, unable to fully grasp what he had just been told. He felt like he had just been handed a death sentence. He struggled to understand the significance of what it meant to him and his family. His mind began racing a million miles a minute.

*This must be a mistake. I feel fine, work out all of the time, and don't have any symptoms that anything is amiss. In a minute, the doctor's going to tell me they probably messed up the blood test and that I have nothing to worry about.*

But that scenario didn't happen. Instead, Rolf's doctor proceeded to tell him that hepatitis C was mostly associated with IV drug use, where infected blood is passed by the sharing of dirty needles. He also explained that emergency responders or military personnel working around blood and open wounds, as well as medical workers stuck by needles during operations, could also become accidentally infected. The other common way to get the disease was through blood transfusions.

"Listen, thank you for your time," Rolf told his doctor, still trying to process the grim news. "I'm going to have to talk with my family about where we go from here."

"I understand. Please let me know how I can help," his doctor responded.

### **Feeling Tired**

On the drive home, a wearying sense of dread fell over Rolf—the same dread that had dogged his steps twenty years earlier when he was first told he had ulcerative colitis . . . another disease he knew nothing about. His doctor had asked if he had been unusually fatigued lately, a common symptom sometimes associated with hep C. He had responded, “Of course, Doc. With all the needs of our young kids, I am fatigued, my wife is fatigued, but so are most of our friends trying to balance being good parents and working. That certainly isn’t a symptom that I would’ve noticed.”

When he got home and told Mary the difficult news, she was just as shocked and concerned as he was. Their future was suddenly very uncertain, and they needed some time to process this together. What they first read about the virus was not promising, so they decided the time was right to get away as a family and quickly build some memories with the kids since they weren’t certain what the future held.

So Rolf and Mary rented an RV and charted a six-week trip around the Southwestern U.S. They visited the Grand Canyon, Bryce and Zion National Parks, circled back through Utah and the Nevada desert, and motored down through the gold country of California back to San Diego. It was an emotional time, and Rolf and Mary shared a lot of hugs and tears but made a decision that they would take on this new challenge like they every other challenge they had faced before . . . *together*.

As they traveled, they voraciously read about the virus and what a couple should do when one was infected. They learned they should be especially careful *not* to share razors, toothbrushes, or even nail clippers. All three hygiene practices were no-no’s since

hepatitis C was passed “blood to blood.” Even though sexual contact with a monogamous partner was not considered a high-risk activity, they decided that Mary should get tested. When they returned home, Mary was tested and found to be free of the virus, greatly relieving the couple.

Rolf set a meeting up with a highly recommended hepatologist, Dr. Tarek Hassanein at the University of California at San Diego, to get educated, evaluate his options, and figure out what to do next. Dr. Hassanein recommended that Rolf should go on a new clinical trial that was being initiated with an interferon molecule that was the treatment of choice at the time.

The trial called for daily maximum dose injections of interferon that Rolf would self-administer for one year, as well as taking a daily antiviral pill. He was warned that the side effects could be quite difficult, so much so that he was strongly urged to go on an anti-depressant drug as well. There were studies indicating that some patients had such a hard time dealing with everything that they contemplated suicide.

The difficult side effects were as awful as advertised. Rolf experienced severe fever with violent shaking chills during the first week of treatment. This was followed by red skin rashes, his hair thinning out, eye sensitivity, nasal infections, and extreme fatigue and irritability over the next twelve months. But he was determined to see this through and not miss an injection while continuing to work.

Those brutal days left him exhausted. He’d often come home from work and fall into bed, telling Mary that he was sorry that he couldn’t help her with dinner or the kid’s homework.

Somehow, they endured and were encouraged when Rolf's viral loads kept coming back negative. But a year's worth of treatments left him physically and mentally worn out and 20 pounds lighter. When his blood was checked one month after finishing the treatment, however, Rolf and Mary received devastating news: the hepatitis C virus had returned.

Instead of being out of the woods, Rolf was deeper in the weeds.

### **The Silent Killer**

The Benirschkes were not going to give up. Dr. Hassanein encouraged Rolf to go back on treatment three months later with another interferon molecule that had also shown promise.

The second treatment was much like the first: the same physical side effects and the same emotional year-long roller coaster, but at least Rolf and Mary knew what to expect. Knowing how important it was to stay as active as possible and gain some weight, several close friends supported Rolf by meeting three mornings a week from 6-7 a.m. to work out with him and build up his conditioning and morale.

Unfortunately, another year's worth of treatment, though initially promising, netted the same result: the hepatitis C virus returned after going off the drugs.

The only bright side of two years of failed treatments was that Rolf at least knew where he stood . . . that he was infected and needed to be cautious about infecting anyone else. He knew that he could not even take a sip of alcohol or anything else that might further damage his liver.

Rolf learned that there were an estimated four million Americans and 170 million people worldwide infected with this serious form of liver disease. Most in the U.S. were Baby Boomers, and as many as 80 percent of them didn't know they had hepatitis C. Since many were fooled by the lack of symptoms, hepatitis C earned the label of the "silent killer."

Worn out from two rounds and two years of energy-sapping treatment protocols, Rolf needed to take a break. Four years later, a new form of interferon called pegylated interferon appeared on the horizon. This latest form of interferon was slower to break down in the body, thus keeping the treatment dose higher in the patient's blood. According to trials, the success rate for achieving a negative sustained viral rate (SVR) jumped from around 20 percent to mid-to-high 40 percent. Injections were needed weekly, not daily.

Even though four years had passed since Rolf's last treatment had failed, his need for a cure hadn't lessened. He still had a wife and four kids depending on him, and he still wanted to avoid the unpleasant prospect of reaching end-stage liver disease and needing a liver transplant to save his life.

The decision was made to again go on treatment for a year. Many of the unwanted side effects returned, but Rolf was familiar with ways to manage them. With optimism created by the knowledge of other patients who had become viral-free, a stronger body from four years of early morning workouts, and a supportive physician, Rolf stayed the course for another long year.

One month after finishing treatment, his blood test came back negative for hepatitis C, which was encouraging—but not a final resolution. When Rolf returned for

the all-important six-month test, he kept his expectations low, just in case. When the doctor's assistant called and explained that the lab had lost his results and that he had to be re-tested, his anxiety heightened.

*Did they really lose the test, or are they just trying to make sure before they deliver me bad news?* he wondered. It was a nerve-wracking time, but all he could do was wait. When the call finally came, Dr. Hassanein was on the line while Rolf was driving home from a meeting.

Rolf's initial thought when he heard his doctor's voice was whether this was a good or bad sign. Good news was usually relayed by his support staff; Dr. Hassanein would only call if there was bad news to explain. So Rolf was caught off guard when he heard his doctor declare, "Rolf, I've got great news. All of your hard work and persistence has paid off. You are virus free!"

The good news overwhelmed him; tears of relief streamed down his face, and he had to steer his car to the side of the road so that he could compose himself. "Thank you, Doctor. Thank you, Doctor," he repeated several times between deep-wrenching sobs.

Then he called Mary, and he broke down again, as she did, both so relieved that the burden they had been carrying for so many years was now lifted.

### **Addressing Hepatitis C Head-On**

Since that event in 2004, Rolf has remained virus-free, and today is committed to helping spread the word about hepatitis C and the need for people to get tested. He believes strongly that the fear of stigmatization or the absence of symptoms shouldn't keep people from addressing the virus head-on.



To help others who are infected with hepatitis C, Rolf has created a national patient-support and awareness program called “Kick Hep C.” The program is designed to reach high-risk groups where hepatitis C may be present and provide information, inspiration, and motivation to get tested and seek treatment if necessary. For more information on Kick Hep C, please visit [www.KickHepC.org](http://www.KickHepC.org).

“I’m so thankful that there are companies out there who are joining the fight against hepatitis C and spending time and research on finding new treatment options,” Rolf said. “There is too much at stake for us to just bury our heads and pretend the problem doesn’t exist. The cost to human life and to our health care system is going to be dramatic if we don’t come together to do something about this silent killer.”

“I can’t tell you what it means to me and my family to have a clean bill of health, and that’s something I want everyone with hepatitis C to experience.”

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### **Rolf Benirschke**

**Age:** 55

**Hometown:** Del Mar, California

**Family situation:** He and his wife, Mary, are the parents of Erik, Kari, Tim, and Ryan.

**Former occupation:** ten-year placekicker for the San Diego Chargers from 1977-86, where he was an NFL Pro Bowl player, winner of the NFL’s “Man of the Year” award and NFL Comeback Player of the Year, as well as being elected to the San Diego Chargers Hall of Fame.

**Present work:** nationally recognized author, speaker, and founder of Legacy Health Strategies, a company dedicated to creating patient support and awareness programs for pharmaceutical and medical device companies.

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