

Inside The Nation

Baseball/Softball News at Diamond Nation

Friday, November 1, 2019

FLEMINGTON, NEW JERSEY



COACH BEN FONSECA'S AMAZING RETURN FROM DEATH'S DOOR

By Bob Behre

It was August, the time of year Ben Fonseca loves, the dog days of summer, much of it consumed by baseball.

But in August of 2018, his doctors told Fonseca he had just days to live. Not years or months. Days.

Fonseca had already been to St. Paul's Church in Princeton months earlier to ask God to take him and release his wife, Toni, and the couple's three boys from the emotional torture of watching their husband and dad slip away.

"I called my brother to do a reading at my funeral," said Fonseca. "I wanted to get everything in order so Toni wouldn't have to lift a finger."

It had been a month since Fonseca lost the strength to lift his bed sheet off of himself to go to the bathroom. "I knew I was done at that point," he said. "I called Toni into the bedroom, we got a notepad and pen out and I started writing stuff down. I said, 'Look at me. I don't want to die. I have no intentions of dying. But look at my body.'"

Ben Fonseca had made a life in baseball, first as a player, then as a coach, and eventually progressing to the point where his expertise was best put to use in player development by the front offices of the independent Atlantic League and then the Somerset Patriots. He coached Division 1 college baseball at George Mason in Virginia, and affiliated ball, as well, with the Kansas City Royals' Single-A team. He worked as a scout with the Milwaukee Brewers.

As he and Toni raised their boys - Ben IV, 14, Mason, 11, and Sage, 7 - baseball became a huge part of their lives, too, and so family and baseball became the coach's singular focus.

Toni became Ben's partner in baseball crime, as one may describe it, transporting the boys from their South Brunswick home to Diamond Nation's facility in Flemington and any number of baseball venues throughout the east coast. The FONSECAS embraced the baseball life that had guided Ben for the better part of his 52 years.

Fonseca, at the same time, was busting his butt working overnight as a Federal Express yard switcher, moving semi-trailers to and from loading docks, all while coaching at Diamond Nation, guiding his boys and many other youngsters along the path to baseball excellence.

"Ben is such a high character guy," said one of his former Somerset Patriots players, Justin "JJ" Jensen. "He's an incredible coach and, of course, he was working overnight at FedEx to support his family. No one works harder."

Then Ben's body betrayed him.

The FONSECAS never heard of the disease scleroderma. Google the disease and read up on it a bit. It sounds like something from a science fiction movie. Worse, Ben learned he had a severe case.

"It started with a pinched nerve in my neck in July of 2017. It just never went away," said Fonseca. "I had it for three weeks. On top of that, I started getting really tired. I was working two jobs, FedEx overnight and the baseball academy. I'm the type of person who needs only four hours of sleep, but I was getting beat up. One day I couldn't catch my breath in the parking lot at Diamond Nation."

Toni suggested Ben go to the hospital. "I drove home from Diamond Nation on July 29 and didn't come back." The FONSECAS would soon learn that while they didn't know what was ailing Ben, neither did his doctors.

"The medical doctor and the gastrointestinal doctor had no idea what it was," said Fonseca. "They checked my blood for Lyme's Disease. That was the original thought. They checked me for Lupus and Multiple Sclerosis. Ten days later, I couldn't move and Toni took me to the emergency room at Princeton Medical Center."

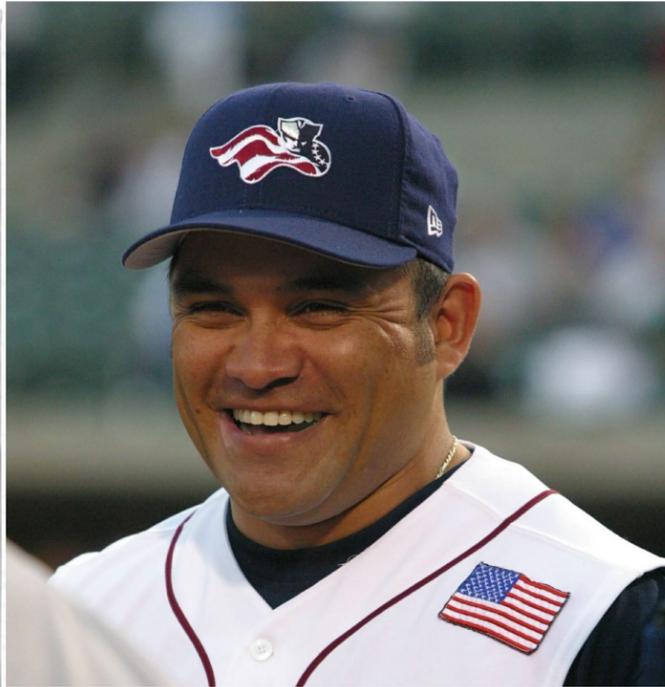
Ben was put on 600 milligrams of Tylenol for pain. The word scleroderma raised its ugly head for the first time a week or so later, after yet another blood test. "The doctor came in and said, 'You have the worst case of scleroderma you could have.' But there was no cancer. Zero. I was like, okay. Give me a couple pills and get me out of here," said Ben.

Ben's own body, however, would very quickly provide a very big reality check on the type of fight that loomed.

"Every one of my joints that is supposed to bend, would not bend," he said. "My skin turned to stone. We had to vacuum my bed sheets because my skin was flaking so bad."

The Enemy Within

Entering the battle with scleroderma, Fonseca had a major strike against him. He was being treated for a heart condition the previous 10 years.



Scleroderma is also referred to as systemic sclerosis, which is a chronic connective tissue disease. The word scleroderma combines two Greek words: sclera, which means hard, and derma, which means skin. Hardening of the skin is one of the most visible manifestations of the disease. The seriousness or intensity of the disease varies patient-to-patient. Essentially, Ben's immune system was attacking healthy tissue in his body.

Fonseca's case would soon qualify as the most serious of the serious scleroderma cases. His condition would quickly go from unsure to bad to much worse. The latter of which occurring seemingly moments after doctors finally understood what was ailing him.

"Ben was diagnosed in August of 2017 and with a prognosis of 3-5 years life expectancy," said Toni Fonseca in a heartbreaking Facebook post that detailed Ben's torturous battle with scleroderma. "The body overproduces collagen, causing a hardening of the skin and organs. In short, the human body begins to turn to stone." Collagen is the main structural protein in the body's connective tissue.

Toni, as you may have sufficed, was quickly becoming an expert on scleroderma, one of the most fatal of the autoimmune diseases.

"Unfortunately, scleroderma presents itself so differently in each patient it can be difficult to treat or understand," Toni said. "I learned, no two patients present symptomatically or respond to treatment the same. Of course, Ben was no exception. He could not catch a break. His body was truly at war with itself."

In her quest to find out what was wrong with her husband and how her family could find a way out of their nightmare, Toni would, very naturally, become Ben's No. 1 advocate and most reliable resource for everything, including, how to save his life.

"Two weeks after the initial diagnosis, scleroderma had completely taken hold of Ben and did not let go," said Toni. "It was truly as if a bomb went off inside Ben's body. Scleroderma was raging and there was no stopping it. Ben could no longer walk, breathe on his own, control bodily functions or absorb nutrients."

Fonseca's already compromised heart was under attack, too, and before Thanksgiving 2017 arrived - just three months after the initial diagnosis - he would require open-heart surgery to replace the mitral valve.

"As bad as things were, they turned worse," said Fonseca. "My specialist said I was too weak for heart surgery, that I would die on the table. The next thing I knew they were prepping me for surgery. I survived. My lungs cleared up and things were a little better. But now I couldn't eat."

A month later, Ben suffered a heart attack.

They fed me through a tube for the next eight months and fed nutrients straight to my heart."



Ben would gradually lose more than half his body weight, 117 pounds, from a rugged 225-pound frame. While his muscles swelled, became stiff, painful and weak, the disease had the same affect on his heart, lungs, kidneys and gastrointestinal system. The enemies were many and the FONSECAS weren't sure which one to fight first.

"When Ben was at his worst, the boys didn't go near him," said Toni. "They were afraid of him."

Plenty of scleroderma patients live with the disease, making assorted life accommodations to ease their struggle. But Ben Fonseca kept getting blindsided by very dark and depressing news about what the disease was doing to his body. He was diagnosed with congestive heart failure, interstitial lung disease, Sjogren's syndrome, Myositis and Raynauds, each an accompanying bonus of scleroderma.

In layman's terms, interstitial lung disease is a scarring that causes stiffness in the lungs, which makes it difficult to breathe. Sjogren's syndrome can more simply be described as dry eyes and dry mouth. Myositis is an inflammation of the muscles that causes muscle weakness. Raynaud's disease is a rare disorder of the blood vessels, usually in the fingers and toes. It causes blood vessels to narrow. When this happens, blood cannot get to the surface of the skin and the affected areas turn white and blue.

It was one body blow after another for the beloved coach, who had so embraced sharing the joys and intricacies of the game of baseball with professional ballplayers, college players, youngsters and his own boys.

"Every organ and joint in Ben's body was becoming fibrotic," said Toni. "The disease was moving at a rapid pace and each day another symptom presented itself. There were more twists and turns that I could process. The hits just kept coming."

Toni took charge of Ben's medical care, moving him eventually in March of 2018 to Thomas Jefferson University Hospital in Philadelphia, seven months after his initial diagnosis. It was a decision that would go a long way in saving Ben Fonseca's life.

"Toni talked to everybody she thought could help," said Ben. "Pete Schneider, a doctor in our neighborhood, would check on me when Toni was at school. Pete would educate Toni on the disease. He did research on his own. He'd come back with a professional opinion. When I was out of it, Toni was finding help." Toni continued teaching math at her middle school in South Brunswick when she wasn't helping her husband fight for his life.

Schneider was well aware of the fight Ben had ahead of him.

"It's a very complicated disease," said Schneider. "It affects every organ in your body. I don't think Ben knew a lot about his diagnosis, what he was facing. I tried to help, tried to give him the positives. As it progressed he was frightened, frustrated, but was not giving up." Schneider also witnessed Toni Fonseca at the very front of the fight for Ben's life.

"She kept fighting for him," Schneider said. "That was the thing. She went to the president of (one of the hospitals)."

Shortly after arriving at Thomas Jefferson Hospital, the FONSECAS received that grim update from their new doctors, that Ben would last perhaps 10 more days.

Ben's Jersey Girl

Ben was coaching the Somerset Patriots in 2001, a season he'd never forget. The Patriots would win their first Atlantic League championship and Fonseca would bump into the love of his life. Illinois boy meets Jersey girl.

"I was coaching the Patriots and Toni was on the field between innings trying to break water balloons with a bat to win a prize," said Ben. "We crossed paths when she was coming out of the tunnel. After she left the field, I got one of the groundskeepers and grabbed his walkie-talkie. I called the interns to look for her and get her phone number.

"There were 8,000 people at the game, so it wasn't easy to find her. She was with a bunch of girlfriends, but they found her."

FONSECA (continued on next page)

The story began there for the FONSECAS. Toni Lupo grew up in Colonia, a terrific sports town in New Jersey's Middlesex County. Her dad, Sam Lupo, was the football coach and athletic director at nearby Woodbridge High School and is now in the Woodbridge Sports Hall of Fame. Surely Ben knew he struck gold in finding a not only a gem and a soul mate in Toni, but a coach's daughter to boot. She would understand his baseball proclivities.

Ben grew up in Rock Island, Illinois, just across the Mississippi River from Iowa. "I ran away from home for baseball," he said. But his memories of Rock Island, a city of 60,000 or so in part of what is called the Quad Cities, are rock solid and heartwarming. "It was a small town but, to me, Rock Island was a cool place to grow up," he said. "We played football on the street and played all night under the streetlights. It was a blue-collar upbringing. I think it's part of what's kept me alive. I don't know anything other than to work hard."

Ben went to Alleman Catholic High School, a school that today boasts an enrollment of about 450 students. Fonseca played baseball, of course, and football.

Raising funds for Ben

By May of 2018, Ben's condition was slipping toward the abyss while the Somerset Patriots initiated a fundraiser in his name. So did Diamond Nation. His friends, family, the many he had touched over his years in baseball, as well as strangers, where coming through in the clutch for their coach and friend. Few realized how truly sick Ben was until they saw him on that July evening of the fundraiser at the Patriot's TD Bank Ballpark in Bridgewater.

It was no surprise to see those two organizations come together in a massive fundraising effort to soften the blow of the Fonseca family's medical bills. Fonseca had formed so many outstanding relationships during his years coaching the Patriots and instructing hundreds of young ball players both at TD Bank Park and Diamond Nation.



"The day of the fundraiser," says Marc Russinoff, the Patriots' vice president of public relations, "Ben wasn't doing well. He wasn't much more than 100 pounds. In the days after, people were talking about Ben not being around much longer."

Ben's frail appearance in a wheelchair certainly shocked many who hadn't seen him since he'd fallen ill.

"Keith Dilgard (Diamond Nation's president) came over and gave me a hug," said Ben. "I told him that this might be the last time we see each other. Keith said, 'don't say that.'"

Dilgard was certainly shaken by Ben's appearance.

"Seeing Ben that night in such a state of frailness was tough to come to grips with," said Dilgard. "Having known Ben for almost 20 years, he was always this upbeat, energetic and fit coach. It was incomprehensible how quickly this debilitating disease was taking the life out of him. I couldn't begin to imagine what Toni and his boys were going through."

The Patriots and Diamond Nation were very much enlisted in Ben's fight for life.

"Ben is and will always be a part of our family," Somerset Patriots president/general manager Patrick McVerry said during the planning stages of the fundraiser. "It is truly heartbreaking to see everything he and his family are going through. We want to do our part to bring our fans and community together to help them get through this difficult time and let them know they are not alone in this fight."

Toni, of course, would frame it best.

"Ben has spent his entire adult life helping others," she said. "He has coached baseball as high as the professional level and all the way down to the youth level, and everywhere in between. He has positively impacted the lives of hundreds. Coaches don't stay in baseball to get rich. They stay in it for the gratification of being an influence on the lives of their players."

Miracle Comeback

Coincidentally, Ben began a slow but remarkable rebound just a month or so after sitting in that wheelchair at TD Bank Park. He outlasted those 10 final days doctors had predicted, by a long shot.

While the fundraising and support that poured in helped Ben and his family tremendously, it was that little dynamo in the background, Toni Fonseca, who may have truly saved his life.



Toni had become frustrated in the early months of Ben's illness that his doctors were simply treating his symptoms and not attacking the disease itself. She was prepared to literally knock down doors to find a way to get her husband healthy.

"One doctor told Toni to be quiet, that she was asking too many questions," said Ben. "She left my room and burst through the door of the president of that hospital. She sat down and told him everything. A couple days later we left that hospital."

The FONSECAS' new plan was to go to Johns Hopkins in Baltimore. But, first, "someone recommended Thomas Jefferson Hospital in Philadelphia because their gastro doctors supposedly knew more about the disease," said Ben. "Looking back, things started going our way because two men took chances, two doctors at Thomas Jefferson found a way. And my wife went online looking for answers and called everyone she thought could help."

Dr. Fabian Mendoza, a rheumatologist, and Dr. Anthony DiMarino, a gastroenterologist, at Jefferson will forever be linked to Ben Fonseca's amazing rebound toward a healthier life.

It was Toni, though, who dug up an article online about experimental drug usage and scleroderma. Ben's doctors were willing to try. Ben, Toni and the boys had little hope otherwise on which to hang their baseball caps.

Hail Mary Answered

"We threw a Hail Mary pass that took us to Jefferson," said Toni. And not long after, that experimental treatment came to light. "What's amazing is that I couldn't even tell you where I found it online," said Toni.

Ben knew it was the bottom of the ninth and he was down to his last swings.

"They gave a specimen to a lab rat and two days later gave one to me," said Ben. "Still today, I am the only person in the world to have taken the intravenous cocktail. They are doing a study on it now hoping they can help other scleroderma patients."

Nothing would please the FONSECAS more. In fact, Toni is now actively involved in helping, through her family's experience, other scleroderma patients. "Our wish is for other scleroderma patients to find hope and eventually a cure," said Toni.

Ben described the IV drip as a chemotherapy type drug. "It was a concoction of three different drugs," he said. "It's a three-day process with three different IV drips. I was building my body and mind up to believe this was going to work. My mind always stayed strong."

Ben hadn't eaten solid food for months. At his lowest point, he was vomiting six-to-seven times a day. "Every time I vomited it felt like I just finished a marathon," he said.

The experimental treatment did not provide immediate results. As of mid-August, 2018, the FONSECAS felt nothing was working.

"The rheumatologist kept saying Ben needed to turn the corner," said Toni. "We kept asking, where's the corner. I was apprehensive about being hopeful."

Then Ben Ate A Cracker ... and a lot more

By late September, six weeks into the experimental treatments, the FONSECAS had a small but significant sign. Ben suddenly ate a cracker.

"The next day he ate a piece of toast," Toni recalled. "It was a mouthful here or there. I was so afraid at that point because there was nowhere else to fall back. Then out of nowhere, he started eating softer foods, and then, two weeks later, he ate a cheese steak. It was the most bizarre, intense fall from health and the quickest recovery."

The man, who needed nutrients to be pumped directly into his heart, was now eating real food.

"By late September, a month after his eating began, we stopped at Deli Works in Flemington on the way to a baseball game. We bought a Belly Buster and Ben ate all of it. I was so guarded, though. I thought we'd be back to the hospital at any point."

Ben's recovery

Ben continued his IV drips with the experimental concoction over the next six months. Each treatment required a hospital stay of four days at Thomas Jefferson. The treatments, amazingly, came without side effects. "None," says Ben.

"Once the treatments took hold, there were no setbacks whatsoever," said Toni.

Ben, miraculously, returned to Diamond Nation by late March to help out as a coach on young Ben's Diamond Jacks 15U Gold team. Every time he bumped into an old friend, colleague or acquaintances at the facility, jaws dropped. Fonseca looked like his old self. A few, it seemed, had thought he had already died.

"Right after Christmas, Ben showed up at Diamond Nation unannounced with a tin full of cookies and a card from the family, thanking us," said Dilgard. "I couldn't believe my eyes that day. He looked like a new man and, since then, Ben is back where he belongs, on the baseball field. A true testament to faith, family and determination."

Diamond Nation founder, Jack Cust, Sr. was equally taken by Ben Fonseca's brave fight back to improved health.

"All of us are so thankful for Ben's remarkable recovery," said Cust. "Ben is a fabulous person who strives to help others, be it on the field or off. Ben's remarkable strength has been an inspiration to all of us and we wish him continued good health and happiness for him, Toni, Ben, Mason and Sage."

Travis Anderson, Diamond Nation's On-Field Coordinator, played for the Somerset Patriots in 2006-'09, so spent a full season under Fonseca's tutelage. Ben was the Patriots' third base coach and hitting instructor in 2006.

"I hugged Ben at the fundraiser at TD Bank," said Anderson. "He was so brittle. I didn't know if Ben was saying goodbye that night. He had talked to me earlier about making a will. To see someone at death's door then come back, that's a miracle. Only one person can perform a miracle and that's God. To see it first hand is awesome."

If it was indeed God who intervened, it was Toni Fonseca who was His emissary.

"I'm here today because of Toni's courage," says Ben. "She was going to research everything until she was convinced otherwise. If it weren't for her being resilient, I would have died. A normal person would have trusted their (original) doctors. She never took anything any of them said as the answer."

Ben Fonseca is a proud man, an independent, self-reliant man, so the support that poured in from seemingly everywhere stunned the old coach.

"I was almost embarrassed that people I didn't know would reach into their pockets, cook a meal, just help out. It's so humbling," said Ben. "We couldn't have made it without the support of so many people. Like they say, it takes a village. We had the best team of doctors at Jefferson Hospital. Our doctors were just fighters. Our South Brunswick community, the Patriots, the Cust family and Diamond Nation and our local friends were amazing."

Living with scleroderma

The FONSECAS, however, still live in fear of scleroderma's return.

"It's still there," warned Toni. "We saw it before with the extreme weight loss, but we don't see it now. It's progressing inside. Every morning I come into the bedroom at 5 a.m. and wake Ben up to see if he is still breathing. I still have a fear this disease will come back around. We know it can. We live with that fear every day."

That does not stop the FONSECAS from counting their blessings and embracing each day as it comes.

"Through the grace of God, we had so many angels placed along our path to help us through this journey," Toni said. "God did not send us an angel in our worst hour, He sent us an entire army of angels. Each and every angel has been amazing and we could not have endured alone."

"Today we rejoice in all we have at this very moment. Scleroderma changed Ben. It changed our boys. It changed our entire family dynamic. But we are here. We are all here. Still a party of 5!"

