

# Patient Story

## Featuring: William Villanueva

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Anybody with the opportunity to experience a western or central New York winter is familiar with the unexpected flurries, blizzards that leave your car buried beneath feet of heavy snow and early mornings spent clearing the driveway. William “Will” Villanueva, a native of Rochester, is no stranger to the harsh snow fall and cold temperatures - until one winter something felt different. While shoveling he noticed that his hands were becoming numb and exceptionally painful with a peculiar coloring of his fingers. As winter turned to spring, his hands and ankles were puffy and swollen, which he attributed to warmer weather and it persisted through the summer despite changing to a low sodium diet. Another turn of the seasons brought more than the changing colors of the leaves on the trees for Will as he began to notice in the fall that doors were increasingly heavy, causing him substantial pain down to his forearms as he struggled to open them.

A year passed and Will decided it was time to seek answers. His primary care physician set him up an appointment with a rheumatologist in Rochester. After blood work and undergoing various tests there finally was an answer - Will was diagnosed with Scleroderma. For the next couple of years he worked with his healthcare team consisting of specialists spanning different cities and states to control his progressing symptoms. He had suffered significant weight loss, progressive weakness, various gastrointestinal symptoms and functional limitations from constriction in his hands and fingers. Several treatments were attempted ranging from oral anti-inflammatory agents and steroids to medication infusions, none of which were successful in slowing the progression of his condition. Imaging tests revealed there now was involvement of vital organs such as the heart and lungs, an indication that things were continuing to advance. It was in February of 2019 when Dr. Korman, his Scleroderma specialist in Rochester, recommended it was time to consider stem cell transplantation as a potential option for future treatment.

“I felt relieved and glad that he suggested it,” said Will as he detailed his initial reaction after being introduced to the idea of transplantation. “I had seen and heard of studies involving stem cell transplantation and followed up with stories of patients that experienced great improvements - this was the hope I needed.”

During transplant preparations Will underwent more extensive testing that is required to determine if he qualified as a candidate and to ensure it would be safe to move forward with the process. In August 2019 there was a setback as his journey towards a transplant at Northwestern in Chicago came to a halt.

“It was like the rug got pulled out from under me and it was the worst news I had heard in a long time,” says Will as he recalls the moments after the plans for transplantation fell through. “I had already gone through all this testing and was just waiting for my insurance to approve the treatment. I was just floored - I felt hopeless.”

Dr. Korman remained a consistent source of guidance, working to establish care with a new institution willing to do the transplant. A few months later in October, Will was with Duke University, admitted to the hospital and ready to receive his stem cell transplant. He spent months in North Carolina following the treatment, first receiving full body radiation and chemotherapy and then following up in an outpatient clinic for fluids and daily blood draws to ensure he was moving in the right direction. Although the process was extensive and in an unfamiliar city, the compassionate care he received by the healthcare staff at Duke provided a sense of comfort.

"I just can't say --", as Will pauses to find the right words to express his gratitude. "Duke, they were just awesome and on the ball. I was impressed with how well and how smoothly it went. Everything was great; the staff, the nurses. My doctor at Duke was such a great guy and very personable - he made you feel like a human and not just a number."

Life for Will following the transplant has been filled with improvements that give him with hope and enthusiasm for the future. The first noticeable change occurred in his fingers within the first week following treatment, which had become softer and he regained some of the sensation. He is now able to bend to the ground to pick up objects he drops and can reach above his head to close the tailgate of his car. Limitations from pain and stiffness in his joints left him barely able to walk half of a mile, but now he finds himself able to complete five-mile hikes with his family. There has been increased mobility in the skin of his face, making it easier to open his mouth to eat and speak. When those closest to him interact with him now they have noticed that he sounds better, is more energetic, less worn down and acting more like his usual self.

During the course of our conversation I was impressed with the level of optimism and resilience that he has maintained throughout his journey. Plenty of times he could have dwelled on the disappointments and setbacks, but he chose to look forward to the future with a positive mindset. He attributes his unwavering strength to his wife Jenny and his children, his brother and his two dogs for always being in his corner to make the tough times more bearable. Another source of support has been the Tri-State chapter of the Scleroderma Foundation, which he became involved in two years ago after his wife stumbled across a post on Facebook advertising the annual fundraising walk. Will also was able to provide his unique perspective of not only being a patient, but also can draw on his experiences as a patient care technician as well as a nurse. To end our conversation, I asked Will to leave me with a piece of advice and something that he would want a future healthcare professional to know.

"I know you can't spend 30 minutes with each patient, but also when someone feels you are trying to inch out of the door that is not a good feeling either. Everyone wants to feel that they matter and want to be able to trust that they are in good hands," says Will. "The most important thing is to be a good listener." It was an honor to have the opportunity to dive into Will's story, pick his brain for advice to help me connect to my future patients and most importantly, to listen to his story.