When friends and family accompany Jeannette Marty on her appointments at Smilow Cancer Hospital, they usually have the same reaction. "They say, 'You know everyone here," Ms. Marty shared.

Ms. Marty is a familiar face at Smilow. Over the past 15 years, a multidisciplinary care team of Yale specialists has helped Ms. Marty through a myriad of chronic medical challenges caused by a rare autoimmune disease called antisynthetase syndrome. Ms. Marty's resolute faith, resiliency, and optimism continually inspire those at Smilow who have traveled alongside her on her long and difficult health journey. Kristin Rattini writer Peter Baker photographer

A DIFFICULT DIAGNOSIS

Her journey began in 2003, during her third pregnancy. Ms. Marty developed a bacterial infection in her blood, then clots in her lungs landed her in the ICU at a New York hospital. Her son, Josiah, was born two months premature, and both baby and mother struggled after the delivery. Ms. Marty had high fevers and trouble breathing; her health did not improve as time passed. She received several conflicting diagnoses over the next couple of years. It wasn't until she moved from New York to Connecticut in early 2006 and had a consult at Yale Cancer Center that she was correctly diagnosed.

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Antisynthetase syndrome is a rare chronic autoimmune condition that affects multiple parts of the body. For Ms. Marty, it has been linked to diagnoses of both breast and cervical cancer. It has caused myositis, a painful inflammation of the muscles used to move the body, especially her legs. It has affected her esophagus, making it difficult to swallow, and impacts her liver and lymph nodes. It has made her highly susceptible to infections from even minor things, such as a bug bite or cut on her finger. And it has especially impaired her lungs. She has been on oxygen for eight years and has been pursuing a double lung transplant for even longer.

"My diagnosis is difficult because I don't fit in anywhere," she said. "There are support groups for specific cancers or autoimmune diseases, but I have a multitude. I'm grateful that Yale and Smilow have been able to treat me for all of them."

A COMPREHENSIVE CARE TEAM

Ms. Marty's care team spans multiple specialties: immunology, pulmonary, liver, oncology, and pain management. Hari Deshpande, MD, Associate Professor of Medicine (Medical Oncology), was among the earliest members of Ms. Marty's care team. In fact, his initial consult with her predated the opening of Smilow Cancer Hospital by three years. "Unfortunately, Jeannette's condition doesn't have a cure, so we're trying to slow the disease down and stop it from progressing as long as we can," he explained.

Chemotherapy has been part of her treatment regimen from the beginning. However, after many failed trials of various chemotherapy treatments, the combination of the immunotherapy IVIG and chemotherapy rituximab is the regimen that finally helped stabilize her condition. "It helps me function and be able to do things with my family," she said. With her portable oxygen concentrator in tow, she has hiked in New Hampshire and visited friends in New York City and Puerto Rico. She was able to take her dream trip, a Caribbean cruise, with her husband, Angel, and their three children. "I orchestrated adventures for them to have together," she said, "and I found a nice corner in the spa where I could just sit and stare at the ocean. I felt very much alive."

But when her condition flares, it can be too painful to even get out of bed. "My muscles get so inflamed that my legs feel like lead pipes," she explained. At times, she has needed to use a wheelchair to get around. Andrew Putnam, MD, Assistant Professor of Medicine (General Medicine), has long been the pain specialist on Ms. Marty's care team. He has worked with her over the years to find the right medications to reduce her pain. "Jeannette has persevered through major disappointments and hardships and continued with good humor," said Dr. Putnam. "She never gives up and is always hoping that something better is coming around the corner."

FAITH THROUGH LIFE'S STORMS

As a pastor, Ms. Marty credits her faith in God as the anchor that helps her "rise above the ongoing raging life storms," as she wrote in a reflection that she contributed to a Yale New Haven Health publication titled, *Spirituality Through Our Struggles: Patient Stories, Reflection and Prayers.*

"With a poor prognosis like mine, it feels like a clock is over your head saying, 'Time is ticking.' There is so much uncertainty," she said. "It's important to keep living in spite of all of that and to have faith, because without faith the alternative is bitterness, anger, and frustration."



Ms. Marty and her husband had already discussed a future that she might not be a part of. But then the greatest storm yet raged into her life: Angel died suddenly in January 2019. Ms. Marty's care team rallied around her. "They cried with me, which is very telling," she said. "People can offer empathy, but to have someone cry with you and step into that pain with you is beautiful."

She found tremendous support from Dwain Fehon, PsyD, Chief Psychologist for Psychiatric Services at Yale New Haven Hospital and a longtime member of her care team. "With Dr. Fehon, I have a place and person where I can share my emotions," she said. "He has been such a big help to me."

"Jeannette is an amazing person," Dr. Fehon said. "She has such a generous spirit, to give of her time so that others can understand and be more knowledgeable and empathetic with their own patients."

Ms. Marty continues to receive a combination of immunotherapy along with chemotherapy while looking for more resources to remain stable or halt progression. Every time she enters Smilow, she's comforted knowing that familiar faces are there to greet and treat her. "The support I receive at Smilow is a gift. I would not have come this far without this team."