

Janet M. Ocasio-Stiffler

Janet M. Ocasio-Stiffler is the outgoing co-president of the Transplant Support Organization (TSO). Under her leadership, TSO expanded its base of support to include partnerships with organizations including the New York Blood Center, Westchester Medical Center, the Putnam Department of Health, and the Acocella Foundation. By providing education, support, and outreach through TSO, Janet embarked on a public policy campaign in cooperation with local and national organizations to address the many issues that make NYS 50th in organ donations in the country, a reality about her home state she finds unacceptable.

Always seeing the value of education and service, Janet attended Fordham University with a scholarship for her undergraduate studies. She later attended Hunter School of Social Work and earned her master's degree in social work.

Despite academic successes, Janet struggled through most of her adult life with Primary Biliary Cirrhosis and its implications for her life in the future. It was a progressive, potentially fatal illness for which there was no treatment and no cure. She also had her growing family to consider; her youngest son was 2 years old when she received this devastating diagnosis. After she began to research her condition and seek out treatments and interventions, she was led to her only option: transplantation. However, she quickly learned one very hard fact... organs for transplantation were scarce because of the lack of donors, causing people to die every day waiting for a transplant. She learned about the hardest, uncontrollable aspects of transplant procedure, like waiting lists and scoring systems. For 13 years, she learned to wait.

In the meantime Janet committed herself to living a full life with her disease. She continued to work in her profession, eventually becoming vice president for ambulatory services at a progressive long term care facility. She chaired committees and presided over professional organizations, serving on the Governor's Task Force on Aging, and worked on a National Council on Aging Committee to help to develop a framework for the President's Task Force on Aging under the Clinton Administration. She made professional presentations, wrote papers, and devoted herself to serving the disabled, frail, and elderly. All the while, not a day went by where Janet did not consider the limitation of her time and what awaited her. She hid her illness as much as she could because the stigmas attached to liver disease and cirrhosis, misconceptions which were born out of ignorance. Janet's children and family were her primary obsession in life. During her illness she strove to make every moment count, wanting them to have every opportunity that life could offer. She took countless photos, went to every ball game and concert, talked, played, and learned to cherish every moment with them. Throughout all of this there was always a dark and ominous cloud that hung over her head, and despite her best efforts she thought about her illness every day. She knew life was not a given for anyone, but her illness offered certain predictions on the progress of her life without receiving a transplant, making the unknown seem uncomfortably clear. Still, her family life thrived. She was proud to see her children go on to earn degrees from West Point, New York University, and the Wharton School of Business at the University of Pennsylvania.

In 1997 Janet's condition worsened dramatically and she began to have bleeding episodes, severe headaches and fatigue, encephalopathy, ascites and jaundice. She was forced to go on disability and walk away from her career.

By the time Janet received her transplant, she was told that she only had months left, experiencing onset liver and kidney failure during a case of pneumonia. Strangely enough, her insurance company deemed her too sick to qualify for a transplant, since they expected that she would not survive the procedure. Thanks to legal intervention her company changed its mind. On October 8th, 1998, Janet received a liver transplant. She walked out of the hospital 2 ½ weeks later and went home.

Janet's transplant experience taught her many lessons, among them how to have faith and that she was much stronger than she had ever imagined. Her new understanding of life and herself set the groundwork for what would become her new passion, paying it forward. She began to provide support to other pre and post-transplant patients while receiving support herself. She accepted responsibility for the public education and outreach necessary to increase awareness and registrations for organ donation. She joined the New York Organ Donor Network as a volunteer and, returning to her cultural heritage, began efforts to reach the Hispanic community, which has been incredibly responsive and thoughtful. She wrote two Spanish language articles for Westchester Medical Center's Transplant Living Center, led a Spanish language support group, and other individual support services. Most recently, she assumed the position of Co-President of the Transplant Support Organization in Westchester.

Working on behalf of the transplant community and raising awareness of the need for organ donation are her primary missions in paying it forward. Janet has grown to understand why she survived and accepts what she owes to her donor and her family, a woman with whom she shared so much common, including age, family life, and career. She sees the worth of carrying her donor's DNA and liver along with her; she carries her soul in her heart. Janet believes her donor's sacrifice is the debt she's always learning how to repay, and not one day goes by when she does not think of her. Janet knows her donor watches over her and wants her to be proud of her work so that her gift of life is not taken for granted. That gift is cherished and revered, as well as the drive that propels Janet to continue her work until every person who needs a transplant will be able to receive one.

In addition to maintaining a scholarship fund for high school seniors who have made it their mission to promote organ donation, Janet is currently working on new initiatives through TSO to help raise awareness. The group is planning the first 5K walk on behalf of organ donation in Westchester County next spring and a celebration honoring liver transplant recipients in conjunction with the American Liver Foundation. She hopes to replicate these events with the Kidney Foundation in the future.

Janet currently lives to enjoy graduations, weddings, and the birth of her two grandchildren.