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Collaboration of Care to Battle a Rare Cancer

Serving in the Army during the Vietnam War, Tom Jacquot faced many dangers, but he had no idea one of his greatest battles would come decades later, fighting an unfamiliar foe; cancer. After moving from Connecticut to North Carolina, Tom developed a purple, itchy spot on his back that his doctor thought might be a cyst. After a biopsy and several tests, it was confirmed that what he had was blastic plasmacytoid dendritic cell neoplasm (BPDCN), a rare cancer involving his skin, bone marrow, and lymph nodes. Since the first case of BPDCN was reported in 1994, only a few hundred cases have been recorded. Having received a diagnosis of an extremely rare and aggressive cancer, Tom knew two things for certain; he wanted to be treated at a world-class cancer center, and he wanted to be near family. This led him to The Veterans Affairs (VA) Comprehensive Cancer Center in West Haven under the direction of Michal G. Rose, MD, and to Smilow Cancer Hospital, under the care of Iris Isufi, MD, Assistant Professor of Medicine (Hematology).

Tom would come to refer to Dr. Isufi as his ‘life-saver’ and she got right to work on a treatment plan. Due to the rarity of his disease, there was not much data available on the best treatment options. It was up to Dr. Isufi and her team to come up with the best care plan for Tom. Knowing there is a high risk of recurrence, it was suggested that Tom undergo an allogeneic

stem cell transplant, where cells are transferred from a donor. Tom was treated with an aggressive leukemia chemotherapy regimen shortly after he arrived at Smilow. Treatment was challenging, requiring several hospitalizations; however, he responded very well to chemotherapy.

“Tom’s cancer and treatment plan were very complicated and he underwent an aggressive treatment regimen. This required constant communication between myself and Dr. Rose’s team at the VA to make sure he was receiving the correct prescriptions, tests, etc.” said Dr. Isufi. “This is a disease that moves fast, and we had to be faster.”

Following a one-month hospitalization under the care of a specialized stem cell transplant team, Tom’s care continued in the Smilow outpatient transplant clinic. A few months after the transplant, Tom lost the donor stem cells, and arrangements were made for his donor to give more stem cells, and he underwent additional chemotherapy. This attempt was successful, and he has had 100% donor blood cells since then. Five years out from his transplant, and again living in North Carolina, Tom encountered other unrelated health issues. He was scheduled for a routine endoscopy to monitor his Barrett’s esophagus, when he was dealt another blow—a diagnosis of stomach cancer.

“I say that God kept changing his mind about me,” said Tom. “After receiving the first diagnosis and learning what my

prognosis was, I thought it might be the end for me, but then I met Dr. Isufi and that all changed. When I was diagnosed with stomach cancer, I knew there was no other place I could go for care; the team at Smilow had saved my life once, and there was no one else I trusted to do it again.”

After discussing Tom’s case at their weekly tumor board, and taking into account his current health and the fact that he had received a transplant, his care team again set to work creating a personalized treatment plan. He started chemotherapy with Dr. Rose, but when the side effects became too much, they discussed his case with Charles Cha, MD, FACS, Associate Professor of Surgery at Yale School of Medicine and determined he was a candidate for surgery. Tom underwent a laparoscopic gastrectomy. After removing 70% of his stomach and some surrounding lymph nodes, Dr. Cha was confident he had removed all of the cancer and that Tom would not need further treatment.

Dr. Rose commented, “Tom’s first diagnosis was a rare and aggressive one, and required the expertise of a high quality and specialized transplant center. His second cancer was not as rare, but treating it was more challenging given his prior transplant. Without the careful collaboration with Drs. Isufi and Cha, Tom would have faced a different outcome.”

Dr. Rose often collaborates with Smilow physicians to coordinate care for veterans. She commented that on average veterans have higher burdens of comorbidities and environmental exposures. Although it cannot be confirmed as a cause in Tom’s case since his cancer is so rare, Agent Orange, a powerful herbicide used during the Vietnam War to eliminate forest cover, is an established risk factor for many conditions including several cancers such as lymphoma, myeloma, lung and prostate.

Throughout his treatment and travel, Tom’s girlfriend Margaret remained by his side. She travelled every few weeks to be with him while he received treatment and cared for him at their home in North Carolina. His family was also a constant, with him every step of the way, at every appointment and when he was in the hospital. He moved in with his sister Catherine for two years so that she could care for him, and his brothers Richard and Frank stepped in when she could not be there, along with his brother-in-law and sisters-in-law. His sister, Miriam, also helped when she could, and his three children were always checking in. Tom commented that the added support from his family made all the difference and made it possible for him to continue with the aggressive treatments.

From the beginning, Tom commented that he never had to worry about a thing and that his care between the VA and Smilow was seamless. “Every mile was worth it to be at a center so dedicated to me and to my care. They are the reason I am here today,” said Tom. “Every doctor, PA, nurse, everyone I encountered, knew about my case and genuinely cared for me and my family.”

Shortly after leaving the Army in the late 1960s, Tom joined a bowling league, and it later became a way for him to bond with his daughter. They would spend every Sunday morning at the bowling alley, after having coached his son’s baseball teams. He now looks forward to sharing his passion for the sport with his grandchildren and great-grandchildren, of which he has many. Being able to spend more time with his family has made everything Tom has gone through worth it. He is also now feeling well enough to enjoy golf and travel again.

As much as Tom credits his doctors for their dedication, they have learned from him as well. Dr. Isufi has since treated patients with similar diagnoses and was able to use what she learned from treating Tom to provide more comprehensive care. The knowledge and expertise provided by both the VA and Smilow gave him a fighting chance, not once, but twice. ↻



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