

SAE BROTHER GIVEN A SECOND CHANGE AT LIFE BY A BE THE MATCH DONOR

BY: ERICA SEVILLA



IN 2018, FRANK GINOCCHIO (NORTHWESTERN '66) KNEW JUST A FEW THINGS ABOUT HIS DONOR: SHE WAS A 23-YEAR-OLD WOMAN FROM GERMANY. ALL BETTINA RIPPEL KNEW WAS THAT SHE AGREED TO DONATE SOME OF HER BLOOD STEM CELLS TO AN ANONYMOUS PATIENT FROM THE U.S. SO THAT HE COULD ENJOY MORE TIME WITH HIS LOVED ONES.

Patients such as Frank, who battle leukemia, lymphoma, and other blood cancers, can be cured if they receive stem cell transplants from matching blood donors. Halfway across the world, a young woman named Bettina received word that she was a 12-for-12 match for Frank. That's 12 of 12 matching human leukocyte antigens, genetic markers passed down in a person's DNA – half from mom and half from dad. A 12-for-12 match is the best possible scenario for a marrow or stem cell transplant. It is so rare that most patients only find a matching donor among their siblings just 25 percent of the time.

Bettina would have to wait two years before she could find out more about the patient whose life she would save. She only knew he needed her to give him the precious gift of time – time spent enjoying retirement, traveling, simple pleasures like boating, and seeing his grown children raise his nine grandchildren.

A SECOND CHANCE AT LIFE



Frank and his grand daughters

14 MONTHS TO LIVE

Frank’s journey over the years has been one focused on family, success, brotherhood, and laughter. He graduated from the prestigious Northwestern University in Evanston, married his college sweetheart, Nancy, and began a family. He and his brother spent 20 years working together building a wholesale food business.

In 1993, he became the Director of Operations and eventually General Counsel for Sigma Alpha Epsilon, the brotherhood he joined in college, which he cherishes for all the relationships –old and new – that he continues to enjoy.

“I realized how many of my oldest friends are fraternity brothers, and I enjoy the chance to make new friends and connect with young people because we become like family,” Frank said. “If you go to a university of 30,000 students, having someplace you belong like SAE makes a big difference.”

He spent 25 years in leadership for SAE before fate took him on a harrowing journey. In January 2018, Frank went for his annual physical exam and his primary medical doctor discovered some irregularities. After months of blood tests, doctors gave Frank a life-altering diagnosis: Two aggressive and rare blood diseases – myelodysplastic syndrome (MDS) and myeloproliferative neoplasms - unclassified (MPN-U). Doctors predicted Frank would live just 14 more months.

Frank’s only hope for a cure was a stem cell transplant from a matching donor. Blood disorders and cancers originate from the marrow of the bones, a spongy center that contains stem cells, which are the building blocks for infection-fighting white blood cells, oxygen transporting red blood cells and clot-forming platelets. A stem cell transplant replaces a patient’s unhealthy blood-forming cells with a donor’s healthy ones.



Frank and his wife, Nancy at Sigma Alpha Epsilon’s 165th Anniversary Convention.

Many hospitals are hesitant to order a transplant for older patients in their 70s. But Frank didn’t have any comorbidities, and he was in great shape physically and mentally. Every ounce of health was needed because a marrow or blood stem cell transplant is complex for patients, requires an aggressive regimen of chemotherapies, and has potentially lethal complications if an ideal match is not found.

A SWAB FOR A WILLING STUDENT

Bettina remembers the day she joined the German stem cell registry. It was August 21, 2016 – her 22nd birthday – and she was visiting an amusement park in Germany, dressed as Belle from “Beauty and the Beast.” She and her boyfriend enjoy cosplay - dressing as movie or cartoon characters. Little did she know that by swabbing her cheek on this day, she would be able to tame the beast of blood cancer that threatened to ravage an SAE brother’s body.

“There was a table set up at the entrance and I didn’t think much about it,” Bettina said. “I was just going to do it – everyone who registered was given a free ticket to return another time, so I didn’t think much about the decision to swab my cheek.”

Two years later, in 2018, she received a call. She was a match for a man in the United States. Bettina readily agreed to the donation, which would end up being delayed twice over several months because back in the states, Frank was battling serious infections as a result of his immunocompromised body. She donated in 2019; her blood stem cells were hand carried by a courier onto an airplane and flown to Moffitt Cancer Center in Tampa Bay Florida, arriving just hours before they would be infused into Frank via a catheter on September 5, 2019 – his re-birthday!

“The one thing I always thought about is if I was sick or I was suffering from cancer I would want someone to save my life,” Bettina explained. “I would hope for someone to donate for me – so if I can do it, if I can get registered and donate, that’s what I should do because that’s what I would want if I was sick.”

The donation process was simple, according to Bettina, who gives blood several times a year.

There are two ways to donate blood stem cells. The most common process, ordered by a patient’s doctor 85 percent of the time, is a peripheral blood stem cell (PBSC) extraction through a nonsurgical process called apheresis, which resembles a plasma donation. The donor receives a series of injections five days in advance of donating to stimulate the production of stem cells. The donation process itself is not painful; it simply requires a few hours for the volume of stem cells to be collected from the donor’s blood stream. About 15 percent of the time, doctors will order a marrow extraction, which is a

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Frank’s Donor, Bettina Ripple and her fiancé

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surgical procedure performed under anesthesia. Liquid marrow is extracted from behind the hip bones, and donors report soreness following the procedures for approximately three weeks. Marrow donation is most frequently requested for pediatric patients to help reduce complications for the youngest cancer warriors.

Bettina donated PBSC via the nonsurgical process. “I felt quite good,” she said. “It was a long day – it took about six, seven hours, but I was back to work the day after.”

Bettina teaches kindergarten and serves as her school’s headmaster – a position she loves. Today she is four years post-donation, and while she considers Frank’s cure from disease a miracle, she doesn’t consider herself a hero. Bettina says she didn’t do anything significant that required much effort on her part – and she doesn’t expect anything in return.

PRECIOUS TIME

Learning you have cancer is a life-changing experience, according to Frank. He and his family were no strangers to tragedy. Frank lost his first wife Nancy to lung cancer on Mother’s Day in 2014; six months later, one of his young sons died; he was 37. Having witnessed the fragility of life made Frank want to fight harder to enjoy more precious time with his children, grandchildren and his new wife, also named Nancy.

Frank’s family rallied around him, recognizing the long odds of a cure. He brought his sense of humor to the fight. Before his 75th birthday in December 2018, he had custom rubber duckies created and floated 250 of them in a pool with the words “Happy Frank” imprinted on them. Frank would later award these rubber ducks to staff at Moffittm, because Frank realized these were the people whose care and decisions gave him the best chance at surviving.



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“The percentages weren’t in my favor, but it was the only opportunity I had to continue to see my family and enjoy sunrises and sunsets, which I wanted to do,” Frank said. “When you go through this transplant experience, it’s a trip and challenges your stamina. I had to live day to day and not worry about the eventual outcomes – I put my life in the hands of my doctors.”

Frank admits that during such an uncertain time, he didn’t spend much time thinking about the donors who give life to patients like him. Frank needed 57 blood transfusions to keep him alive during his battle. He now reflects with gratitude on the selflessness of blood donors who helped his fight, as well as the young woman who would eventually save his life.

Frank has slowed down his pace of life, but he continues to support his SAE brothers by attending conferences and continuing to mentor young men. He remains grateful for the lifelong friendships he has made through the fraternity. He realizes relationships are more important than achievements, sunrises and sunsets marking each extra day he has been gifted with his family a blessing.

“I spend more time talking to people instead of worrying about my golf game,”



Frank said. “I enjoy riding my bike, swimming in the pool, reading, boating and fishing. When I was younger, I was focused on my business; my wife handled everything at home. But now I’m learning how to be a partner in the kitchen and the garden.”

Frank’s appreciation for life is contagious – and he sees beauty in each new day. He and Bettina exchange correspondence regularly, and the two hope to meet in person one day.

SAE BROTHERS BECOMING LIFESAVERS

In July 2021, SAE partnered with Be The Match to engage members of its national chapters in registry drives to add more young, healthy, and willing donors to the national registry.

Doctors most often request younger donors to help patients like Frank because younger donors lead to more successful outcomes for patients. In addition, young men produce a higher volume of stem cells, which also contributes to the success of the transplant.

SIGMA ALPHA EPSILON AND ITS LEADERSHIP ARE PROUD OF THE RESULTS OF THE PARTNERSHIP; IN ITS FIRST YEAR, THIS HAS LED TO MORE THAN 2,604 NEW DONORS BEING ADDED TO THE REGISTRY THROUGH DRIVES HOSTED BY 42 SAE CHAPTERS NATIONWIDE TO LEARN HOW YOU CAN SUPPORT BE THE MATCH, VISIT MY.BETHEMATCH.ORG/SAE