

WHY WE GIVE, OUR JOURNEY WITH MDS



Joshua, David, Fred and Stephanie Vendig

We support the Aplastic Anemia and MDS International Foundation because they helped our family as my husband, Fred, struggled with MDS. Until his passing, they were part of our support system as we fought the disease together.

Fred was diagnosed with Myelodysplastic Syndromes, MDS, at a routine physical when he was 60. They told Fred that he would only live 18 months to 5 years, and there was no cure. We received little information about the disease or possible treatments since the disease is so rare.

The MDS diagnosis was earth-shattering. Fred had no collection of symptoms that would have prepared us for the life-threatening condition. We had planned a retirement full of travel and hobbies instead of rocking chairs, and suddenly those plans evaporated. We both had enjoyed good health all our lives, so we were shaken.

We decided not to mark time as Fred's condition progressed, but instead to take action, no matter the outcome. Because our children were grown, we could concentrate on fighting MDS.

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We thought, "If we could do something, we should do something!"

As a survivor of the Holocaust, my husband learned early that he shouldn't only rely on himself alone. First, I ran to the local library to gather all the information I could, but I only found listings of academic papers in this preinternet era. Next, we sought a second opinion, which confirmed the diagnosis. The doctor did help with a recommendation of a clinical trial that featured a drug targeting MDS.

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As we searched for answers, we found the Aplastic Anemia and MDS International Foundation (AAMDSIF) to be a source for information and other resources. As the internet became a fixture in our lives, AAMDSIF's web-based help because a valuable part of our support system.

AAMDSIF gave us the chance to meet other people "in the same boat" at their patient and family conferences. At one conference, I met a man whose wife also had MDS. He had a listsery for patients and families all over the world, who shared their information on MDS as well. Through these patient conferences and the listserv, we began to feel that we were not helpless victims of the disease.

Fred participated in two more clinical studies with the NIH. We learned that he could have a bone marrow transplant as a possible solution. When his brother was tested, we were disappointed that he was not a match for Fred. (After his death, we discovered that Fred's brother was also diagnosed with MDS. If he had been a match, then Fred would have received cells contaminated with the disease.)

Through the Foundation we learned about donor registries, and we found a match. We moved to Seattle, Washington, to take advantage of the bone marrow transplant program at Fred Hutchinson Cancer Care Facility there. The procedure was successful.

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Then Fred's condition took a turn for the worse. With a reduced immune system from the transplant and an antibiotic-resistant bacterium, the infection quickly overwhelmed his system.

After 17 days of a successful transplant and 8 years of fighting MDS, Fred lost his battle on September 14, 2001 of methicillin-resistant Staphylococcus Aureus, or MRSA.

Even after losing my beloved husband, our family continues to give to AAMDSIF in support of other MDS patients and those with other bone marrow failure diseases. Join me in providing support for these invaluable patient support services, including patient and family conferences, health professional resources, and scientific research.

> Sincerely, Stephanie Vendig

Stephanie Vendig Spouse of MDS Patient, Fred Vendig

