

Parents, University Establish Aplastic Anemia Foundation

A child's death from a usually incurable blood disease—aplastic anemia—has spurred his parents, Bart and Margaret Fisher, and Johns Hopkins to join forces to establish the Aplastic Anemia Foundation of America (AAFA), in the hope of saving others from the little-known killer.

Seven-year-old Ivan Fisher died last year after unsuccessful experimental treatment at the Johns Hopkins Hospital. Ivan's father, Bart S. Fisher, founder of the AAFA and a member of the Washington, D.C., law firm of Patton, Boggs & Blow, recalls his own first reaction to the disease: "When the doctors told us that Ivan didn't have leukemia, but instead had aplastic anemia, we were relieved, feeling our son had been spared one of the worst forms of cancer.

"Our relief was based on ignorance. Leukemia, especially in children, is treatable and frequently curable. Aplastic anemia is less well known but much more lethal."

Through the AAFA, Mr. and Mrs. Fisher hope to raise money for research and patient care and educate the public about aplastic anemia. They already have convinced Congress that the nation needs a bone marrow registry. Legislation for the registry passed October 2 as part of the National Organ Transplant Act. The registry would help patients locate unrelated donors for bone marrow transplantation, a treatment for aplastic anemia, leukemia, sickle cell anemia, and other blood diseases. Such a registry was established in Britain years ago and has saved many patients, including some in the U.S.

Research funded by the AAFA will concentrate on understanding the causes of the disease, improving bone marrow transplantation techniques, finding new treatments, identifying susceptible individuals, and classifying individuals who might be prospective donors of bone marrow.

Aplastic anemia is the unexplained failure of bone marrow to produce blood-clotting platelet cells, infection-fighting white blood cells and oxygen-carrying red blood cells. The absence of these cells causes uncontrolled bleeding, infection, and symptoms of anemia—fatigue, weakness, and shortness of breath.

Without treatment, aplastic anemia is one of the most rapidly fatal diseases known. Even with excellent medical care, most patients with severe aplastic anemia generally live only a few weeks or months.

dangerous, can cure the disease because it repopulates the bone marrow with a donor's stem cells, immature cells that give rise to red cells, white cells, and platelets.

Although the disease is little known, doctors diagnose approximately 2,000 new cases of aplastic anemia in the U.S. each year. The cause of these cases is rarely discovered.

Massive radiation exposure, however, is known to cause aplastic anemia. After a nuclear war or nuclear power plant accident, aplastic anemia would be one of the major radiation-induced illnesses. Thus a cure for the disease could be essential for many more people than those who develop it from "natural" causes.

"We expect the Aplastic Anemia Foundation to serve as a resource for all Americans suffering from this disorder, which has caused tremendous suffering for its victims and their families," states University President Steven Muller. "The University is pleased to provide the Foundation with a medical and academic home."

The Aplastic Anemia Foundation of America will be located in Washington, D.C., and at the Johns Hopkins Oncology Center. A national group dedicated to the systematic research and study of aplastic anemia, the Foundation will operate as an affiliate of Johns Hopkins under its own board of directors headed by Lyle L. Sensenbrenner, associate professor of both oncology and medicine at the School of Medicine. Dr. Sensenbrenner is director of the Division of Experimental Hematology within the Johns Hopkins Oncology Center and is a former president of the International Society for Experimental Hematology.



Ivan Fisher