[illegible]oy's death spurs donors of marrow

By Sue Miller
Evening Sun Staff

Bart S. Fisher says he "tried to take a disaster and turn it into something good for somebody else."

So, after his 7-year-old son Ivan succumbed to severe aplastic anemia—a little-known and usually incurable blood disease—Fisher, a Washington lawyer and lobbyist, plunged into a project he contended could save the lives of an estimated 1,500 patients a year.

Fourteen months after his personal tragedy, he has set in motion a process for the establishment of a national bone marrow registry, which would help patients locate [illegible]ed donors for bone marrow transplantation, a treatment for aplastic anemia, [illegible]ia, sickle cell anemia and other blood diseases.

Details of the registry, which also involves Johns Hopkins Hospital, were announced today at a Washington press conference.

Unrelated donors are needed, Fisher said, because a national registry in England has shown they work if a good or close match can be obtained and because the yield from the traditional sibling donors is low, due to the trend of smaller families, and may be drying up while the demand for bone marrow transplantation is rising.

Legislation for the U.S. registry passed Oct. 2 as part of the National Organ Transplant Act and was signed into law by President Reagan Oct. 19. Fisher said he believed the registry would be in operation by February 1986 as a two-year demonstration project.

Fisher, 41, of Great Falls, Va., has teamed up with Johns Hopkins to form the Aplastic Anemia Foundation of America to underwrite the [illegible]try and raise money for research into aplastic anemia and to educate the public.

"Every year there are 10,000 new patients with leukemia and aplastic anemia that could benefit from bone marrow transplantation," Fisher said.

Twenty-five bone marrow transplantations using unrelated donors with good or close matches from England's registry had been done in this country with 16 successes, he said. The work is being done primarily at the University of Washington in Seattle, the University of Iowa and at Sloan-Kettering Memorial Cancer Institute.

One objective of the Aplastic Anemia Foundation is to underwrite the national bone marrow registry in this country, which would amount to $7 million a year to obtain 100,000 names, Fisher said.

"The bottom line is that out of those 10,000 people, 1,443 could be benefiting from an unrelated bone marrow transplant. So, if we had the registry, 1,443 lives could be saved each year—and that's a lot of lives."

Bone marrow transplantation is the treatment of choice for victims of aplastic anemia. Even though the therapy is dangerous, it can cure the disease because it repopulates the bone marrow with the donor's stem cells—immature cells that give rise to critical red cells, white cells and platelets.

In aplastic anemia, the bone marrow of siblings can be used—if it closely matches the patient's bone marrow. This happens in one of four cases.

Ross Fisher, 6 at the time and the only other child of Margaret and Bart Fisher, was not a good match for his brother.

Hopkins cancer specialists then turned to an experimental therapy to decrease Ivan's immune suppressive response to try to save the youngster, who had been healthy and active until April 1983, four months before he died.

Ivan was treated with an anti-lymphocyte globulin, a serum made from horses, which had shown "a significant response" in about 10 of 20 patients, said Dr. Lyle L. Sensenbrenner, director of the division of experimental hematology at the Hopkins Oncology Center. But the therapy failed.

"Gradually, his platelet count fell," Fisher said. "He had a stroke at the end of July, was in a coma for a week and then died on Aug. 6.

"The stroke was the result of his not having blood-clotting platelet cells and without the bone marrow making platelets you will bleed through the veins. He bled into his brain through the veins."

Aplastic anemia is the unexplained failure of bone marrow to produce the 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.

Fisher said a bone marrow registry in England had identified 50,000 potential unrelated donors.

"That's not nearly enough, that's not big enough, although they do say they can match 30 percent of what they get sent over from Sloan-Kettering and Hopkins," he said. "But it just seems to me outrageous that Americans would have to go to England.

"To date, there have been around 2,000 bone marrow transplants performed in this country, practically all from siblings. And now, we are at the stage of doing them with unrelated donors."