

## VP leads team effort

By Bart S. Fisher

Since Al Gore has been skewered for his claims to have founded the Internet, it seems only fair to recognize his contributions. Did you know he was the member of Congress to propose a bone marrow transplant registry?

This year, more than 1,500 Americans will receive the living gift of life, a bone marrow transplant, largely because Gore took the lead in educating the Congress about marrow transplantation in 1983.

The National Marrow Donor Program provides Americans with leukemia, aplastic anemia and other life-threatening blood-related diseases with the chance to obtain a marrow transplant from an unrelated donor. The program was established partly due to Gore's pioneering efforts in 1983.

In 1983, while canoeing with my young son Ivan, I tapped him on the shoulder. The next day, I noted a large bruise where I had tapped Ivan. Our doctors said that Ivan had aplastic anemia, a life-threatening disease that occurs when the bone marrow stops producing blood cells, and that he would need a bone marrow transplant. Since Ivan's brother was not a marrow match, doctors said Ivan would need an unrelated marrow donor. The odds are about 10,000 to one against the chance of any two people matching marrow types.

Unfortunately, there was no bone marrow transplant registry in the United States in 1983, although there was one in England. The small registry had about 50,000 marrow donors.

Knowing that time was short for Ivan without a transplant, we did try to find a donor for Ivan through the English registry, but I also vowed to establish a registry in the United States regardless of the outcome for Ivan.

My first step was to contact Gore, who had sponsored a path-breaking bill then moving through the House, the National Organ Transplant Act. This bill established Organ Procurement Organizations to facilitate the transplantation of solid organs such as the heart, lung, liver, kidney and pancreas.

I had discussions with Jerold R. Mande, then in charge of health care issues for Gore, and Peter Bouxsein, who was the chief staffer for Rep. Henry Waxman's Subcommittee on Health and the Environment of the House Commerce and Energy Committee. I explained that marrow is a fluid organ that can be transfused into a vein and that a marrow registry could save thousands of lives annually.

Accompanied by Ivan's doctors from Johns Hopkins, I made the same argument to Rep. Barbara Mikulski who agreed to sponsor the bone marrow transplant registry amendment to the National Organ Transplant Act.

With Gore, Waxman and Mikulski in support of a registry, the drama began. To my disbelief, the Reagan administration opposed establishing a national bone marrow registry, calling it "premature" and "highly experimental." At that point, Mande explained Gore's dilemma. While Gore supported the bone marrow transplant registry, he could not risk a veto and the failure of the entire legislation over this single issue. His challenge was to keep the marrow transplant registry alive and not see the rest of the bill die. Gore triumphed as the House passed the National Organ Transplant Act by a vote of 396 to 6. On the House floor, Gore said, "Bone marrow transplantation is yet another example of a rapidly improving technology that will help save thousands of lives."

Undaunted by the failure of the "trigger" mechanism established by Gore's legislation to launch the registry, Robert Graves, whose daughter received the world's first unrelated marrow transplant in 1979, approached Sen. Paul Laxalt, who then managed to secure a \$1.2 million appropriation as a line item in the Navy budget to establish the first nationwide bone marrow registry. The rationale used by the Navy was that the Navy might need access to a pool of marrow donors if there were a serious accident at a nuclear power plant or aboard a nuclear-powered Navy ship.

I later was told by Captain Robert J. Hartzman, head of the Navy's marrow transplant registry, that the Navy line item would never have been approved had the earlier legislation effort not been undertaken by Gore. The earlier failure was the fertilizer of future success.

Today, there are more than five million voluntary donors of marrow worldwide and over three million in the United States alone. Over 150 unrelated marrow transplants occur monthly due to the registry.

The point is not whether Al Gore "started" the bone marrow transplant registry, any more than whether Al Gore was the "father" of the Internet. The lesson is that it is rare for any one person to achieve matters of great consequence in Washington, D.C. It takes a team of dedicated individuals.

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