

Gifts From Perfect Strangers

For Some Patients, Death Can Be Defeated With a Marrow Transplant—If They Can

Find a Donor

By William Hines
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Each year, thousands of Americans sicken and die of blood-related disorders that could be set right with a gift from a stranger.

The gift is bone marrow, from which oxygen-carrying red cells and most of the body's disease-fighting weapons are manufactured.

But today, the national registry established two years ago to match unrelated donors and recipients is far short of meeting the need.

For an estimated 9,000 Americans who are desperate for marrow transplants, the odds against finding a suitable match from an unrelated donor are something like 20,000 to 1. To give them a realistic chance at getting a transplant, health officials estimate that 250,000 donors must be on the roster.

So far, the registry counts only 70,000 willing would-be donors nationwide. The shortage of black donors is particularly

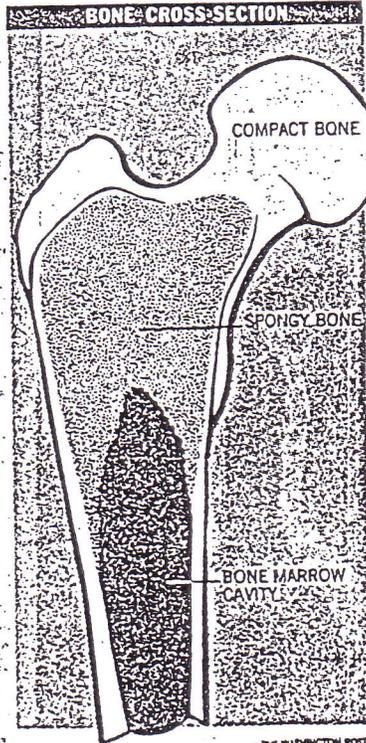
at the same time, the registry has proved its worth and to date about 250 unrelated transplants have been performed. The name bank of potential donors is growing, appeals for both marrow and cash are getting a warm reception in widely separated parts of the country.

While the idea of using marrow to treat otherwise fatal blood diseases has been around for 20 years, only in recent years has it attained a real potential for broad application. What made bone marrow transplants a realistic option for people desperately ill with certain blood cancers and anemias was the discovery 10 years ago that unrelated people could sometimes be matched for an exchange of marrow from one to the other.

Marrow transplants had been done off and on for a decade before that, but only between very close relatives.

Typical of efforts to expand the registry are appeals in the Washington area on behalf of Allison Atlas, a 20-year-old Bethesda woman suffering from a form of leukemia for which no cure except marrow transplant exists. Typical, too, is a less well-organized effort for Judie Davis, a 45-year-old mother of three from Oakland, Calif., who also has an otherwise untreatable type of leukemia, a cancer of the blood.

Both women have been unable to find suitable donors among their relatives and have gone public with urgent appeals. Though different in genetic background, they have one complicating factor in common: both are members of minorities: Atlas is Jewish and Davis is African-American. Their best chances of getting a lifesaving marrow match lie with people of back-



grounds similar to their own. Yet most such potential donors are unaware of the women's needs or their own ability to help.

Only an estimated 200 persons on the registry are African-American, according to Rudolf Brutoco of Covina, Calif., the physician who started the registry. There would need to be 100 times as many potential donors as there currently are to give Judie Davis a reasonable chance for a new lease on life, Brutoco said.

Atlas and Davis are not isolated cases. While 9,000 Americans are candidates for marrow transplants, finding a donor is very much like beating the odds in a lottery.

Out of the desperation of people like Atlas and Davis and their families and friends has come the national fund-raising and networking organization called Lifesavers Foundation, which has led to the national registry. It was established by Brutoco for an intensely personal reason. His wife Diana contracted leukemia and was saved by a timely transplant from an unrelated donor who was found for her by Lifesavers.

A lobbying effort for federal funds and government support got its start when Washington lawyer Bart Fisher watched his 7-year-old son Ivan die of aplastic anemia for want of a marrow match. "I said I'd never rest until a bone marrow registry was established so Americans requiring a marrow transplant would never again bear that death sentence," Fisher said recently.

Out of these and other endeavors, the national roster of potential donors has grown to about 70,000 names. Some 50,000 of these were collected in drives by Lifesavers and other interested groups. Encouraged, backers of the marrow campaign are aiming now for a quarter million names of tested and typed donors.

As things stand, no segment of the U.S. population is adequately represented on the registry, which the National Heart, Lung and Blood Institute (an arm of the National Institutes of Health) maintains at St. Paul, Minn. Unlike blood, which can be matched well within about eight general groups, the many variables that it takes to make a close bone marrow match require a donor of very similar genetic heritage.

Davis's husband Calvin, an accountant, is trying to do for his wife what Brutoco did for his and what relatives of Allison Atlas are seeking to accomplish for the Bethesda woman. But the task is daunting because of the complexity of the diseases involved and the money and effort needed to conquer them.

For example, disorders such as chronic myelogenous leukemia (CML, a form of cancer) and aplastic anemia require very aggressive and rugged treatments, of which bone marrow transplantation is only a part. In the case of CML, for example, the stricken person has to be brought to the brink of death with powerful medications and massive radiation doses and then "rescued" with marrow from another individual. The treatment is not only difficult and risky for the patient, it is also extremely expensive—averaging \$150,000 or more and going up as high as \$400,000.

There are also misconceptions about bone marrow transplants. When most people hear the word "marrow," they probably think of a pale, buttery substance from inside a soup bone. But that is far different from the material given in transplants. The latter is a red fluid that circulates inside the bones and can be drawn out of a healthy person and injected into an ailing one—if the tissue types of the two individuals are compatible. If not, a transplant would be worse than useless, it would be disastrous.

Giving marrow is rather like giving blood for a transfusion, and indeed the fluid nature of the life-giving substance makes the procedure seem more like a blood donation than an organ transplant. But the need for extremely precise typing makes marrow donation far more like giving a kidney than giving blood.

Selection of donors starts with a preliminary blood test that ordinarily costs about \$200 but is done for \$75 under special arrangements by Lifesavers Foundation with testing labs all over the country. This is only the start of a lengthy screening procedure to end up with a sufficiently close

match that makes an actual transplant feasible.

As far as donation of marrow is concerned, the experience for the donor is far closer to that involved in giving blood than in parting with a vital organ like a kidney. About 5 percent of the marrow in the donor's body is taken from a series of needle punctures into the hip bones, which are performed under anesthetic. After an overnight recuperative hospital stay, the donor is tired but otherwise in good health, except for some soreness.

One donor who had helped a Seattle patient described the experience as "like after the first day of football practice." Within a fortnight, typically, the once depleted marrow is back to normal levels.

People become marrow donors for different reasons—some as kinfolk called to help a relative in need, some as public-spirited citizens responding to a donor-testing appeal and some in other ways. David Staudt of Arlington, a government scientist, found his through the Red Cross, for which he had given blood on many occasions. He was asked to join a specialized donor program, and from this he drifted into the then-new bone marrow registry.

"They told me at the time there was very little likelihood that I'd ever be matched," Staudt recalls, "and darned if first shot out of the bag it wasn't me."

Staudt's marrow closely fitted the requirements of a man near death from chronic myelogenous leukemia. He was asked to check into a Washington hospital where something over a liter of marrow was drawn, chilled down and packaged for transportation by air to Milwaukee, where it was administered to the ailing man.

The recipient, Staudt said, made a full recovery from his leukemia but died 18 months later of causes not connected with that disease. At autopsy, "his bone marrow count was excellent," Staudt said he had been told.

Good "takes" after transplantation are not the invariable rule. Many marrow recipients lose their battle, some to pneumonia or other communicable diseases and some to a rejection phenomenon called graft-vs.-host disease.

Still, studies show that about 70 percent of patients respond well to a bone marrow transplant if the operation is done early enough. Because unrelated donor transplants have been performed only recently, there is no meaningful data on survival rates, but with related donors some patients have survived for nearly 20 years.

According to physicians, there is no reason to suppose there would be any difference in acceptance rates between well-matched related donors and well-matched unrelated donors.

How You Can Help

Two essential elements for building a bone marrow donor registry of adequate size for the United States (250,000 enrollees) are blood and money. The two go hand-in-hand.

Under present circumstances, virtually no federal funds are available for typing would-be donors; out of \$3.7 million that Congress appropriated in 1989 for the national bone marrow program, only about \$100,000 went for actual testing, while the rest went for operating costs and administrative expenses. At regular rates, this sum would buy about 500 preliminary screening tests. Lifesavers Foundation, the national fund-raising and networking organization founded by Rudolf Brutoco, a California physician whose wife's life was saved when an unrelated donor was found for her, has negotiated a special price of \$75 with laboratories in all parts of the country.

Individuals interested in possibly becoming donors can call Lifesavers at a toll-free number, 1-800-999-8822, where an interviewer will ask preliminary questions and send the applicant a consent form and a list of nearby cooperating labs. The selected lab sends Lifesavers the bill and a report on the test results. Then it's a matter of "don't call us, we'll call you" until more definitive screening and a possible match-up with a suitable recipient is found. There is no charge to the donor, and all information is confidential, according to Lifesavers.

Suitable prospects for donor status are between 18 and 55, in general good health, free of AIDS and hepatitis viruses and without a history of cancer (except for cured skin cancer).

People in the Washington area who prefer to donate money to help pay for someone else's screening may send checks to Lifesavers Foundation, 8314 Meadowlark Lane, Bethesda, Md. 20817. \$75 will pay for one test, but any size contribution is welcome.

Those particularly interested in augmenting the small number of blacks on the national donor registry may call Ward Martin at 1-213-517-5185 or write to Lifesavers Foundation at 529 S. Second Ave., Covina, Calif. 91723.

There is, of course, no objection to exercising both options and volunteering both blood and money.

— William Hines