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July 16, 1998

STATEMENT OF VICE PRESIDENT GORE ON THE NATIONAL BONE MARROW REGISTRY REAUTHORIZATION ACT OF 1998

Message Creation Date was at 16-JUL-1998 18:46:00

THE WHITE HOUSE

Office of the Vice President

For Immediate Release: Contact: Thursday, July 16, 1998 (202) 456-7035

STATEMENT OF VICE PRESIDENT GORE
ON THE NATIONAL BONE MARROW REGISTRY REAUTHORIZATION ACT OF 1998

Giving all Americans access to life-saving therapies is not only a high priority of our Administration, it has been an important personal priority of mine since I served in Congress. That is why I am pleased that President Clinton signed into law today the National Bone Marrow Registry Reauthorization Act of 1998.

For thousands of Americans facing life-threatening illnesses, a bone marrow transplant is their best hope for recovery. By working together, the Administration and Congress have taken an important step to expand the availability of this life-saving treatment. I especially want to acknowledge the leadership of Congressman Bill Young, who has been working on this issue from the very beginning; Senator Bill Frist, who helped write the original transplant law as a physician and who has continued his leadership role in the Senate; Senator Ted Kennedy, with whom I had the privilege to work in writing the law that created the marrow program; and Congresswomen Anna Eshoo and Juanita Millender-McDonald, for their invaluable help. I also want to thank Admiral Bud Zumwalt, who has championed this cause from the start and who has had much to do with the success of the program.

The National Marrow Donor Program is a unique national resource. When this federal program began, many doubted such a registry could attract enough volunteers willing to go into the hospital and donate marrow for a complete stranger. I am pleased to say the doubters were wrong. Today, the National Marrow Donor Program□,s registry lists an astounding 3.2 million volunteers, and the program has facilitated more than 7,000 transplants. As the author of several laws that helped establish the registry, I am particularly gratified to see this program□,s record of success.

The bill that President Clinton signed today will ensure the continued success of the nation□,s marrow program. I am especially pleased that the new law focuses on improving the chances for patients of racial and ethnic minority heritage to find a matched donor. By working together, we can continue to help families in need.

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NATIONAL MARROW DONOR PROGRAM
EASTERN REGIONAL OFFICE

7910 Woodmont Avenue, Suite 1103
Bethesda, MD 20814-3015

Fax Number: 301-951-5526
Telephone Number: 800-57-DONOR

DELIVER TO: Mr. Jerry Mande (ASAP)

ORGANIZATION: White House

FAX NUMBER:

FROM: Paul S. Egan ~~951~~ 951-5512 x30

DATE: 7/14/98

Pages including cover sheet: 2

COMMENTS: Jerry:

As requested the attached is a draft statement for the Vice President's possible use upon enactment of the National Marrow Registry Reauthorization Act tomorrow.

Please give me a call if I can be of any assistance in providing further information.

Paul S. Egan

Bill Summary & Status for the 105th Congress

NEW SEARCH | HOME | HELP | ABOUT DIGESTS

H.R.2202
SPONSOR: Rep Young, C. (introduced 07/17/97)

SUMMARY:

(REVISED AS OF 05/19/98 -- Passed House, amended)

National Bone Marrow Registry Reauthorization Act of 1998 - Amends the Public Health Service Act to set forth the purpose of the National Bone Marrow Donor Registry and impose requirements regarding its board of directors.

Sets forth program functions, including regarding collection, analysis, and publication of data on donor searches.

Mandates implementation of a plan to effectuate efficiencies between the Registry and donor centers.

Requires the Registry to: (1) recruit donors; (2) give priority to recruiting populations underrepresented among potential donors; and (3) consider racial and ethnic minority groups underrepresented.

Requires the Registry to maintain an office of patient advocacy meeting specified requirements, including providing case management. Allows the office to provide information on the process of receiving a bone marrow transplant, including the posttransplant process.

Mandates maintenance of a scientific registry regarding patients who have received marrow from an unrelated donor.

Authorizes appropriations to carry out the Registry provisions.

Mandates a study of the Registry and report to the Congress by the Comptroller General regarding specified aspects of the Registry.

Directs the Secretary of Health and Human Services, by a specified period after the effective date of this Act, to ensure that the office of patient advocacy (mandated by this Act) is in compliance with certain requirements.

Providing all Americans access to life-saving therapies is a high priority of our Administration. That is why I am pleased that today the President has signed into law the National Bone Marrow Registry Reauthorization Act of 1998. For thousands of Americans facing life-threatening illnesses, a bone marrow transplant is their best hope for recovery. By working together, Congress and our Administration have taken an important step in expanding the availability of this life-saving treatment. (I especially want to acknowledge the leadership provided by Congressman Bill Young who has been at this from the very beginning and Senator Bill Frist who helped write the original transplant law as a physician and who has continued his leadership role in the Senate.)

delete sentence

~~The National Marrow Donor Program is a unique national resource that is saving lives.~~ Only thirty years ago, scientists successfully performed the first bone marrow transplants in two children with damaged immune systems. Today these children are healthy adults with immune systems derived from their siblings. The key to success was donor bone marrow that almost exactly matched the children's bone marrow.

30

donated

Most patients, however, do not have a family member who is a good match. Only a few short years ago, patients in this situation had little chance of survival. Today, because of the National Marrow Donor Program, their chances are greatly improved. As the author of several laws that helped establish the registry I am particularly gratified to see this program's record of success.

registry

When this federal program began, many doubted such a registry could attract enough volunteers willing to go into the hospital and donate bone marrow for a complete stranger. I am pleased to say the doubters were wrong. Today, the National Marrow Donor Program's registry lists an astounding 3,200,000 volunteers, and the program has facilitated more than 7,000 transplants.

As successful as this program has been, some patients needing unrelated bone marrow transplants still face daunting challenges. Minority patients are particularly at risk. A significant disparity remains between the likelihood of finding a matched donor for Caucasian patients and the likelihood of finding a matched donor for patients of racial and ethnic minority heritage.

We must correct this disparity. The bone marrow program has done an excellent job recruiting racial and ethnic minority volunteers, particularly in the last several years, but we can do more. We must encourage the greatest possible number of volunteers of minority heritage to enroll in the bone marrow registry. We must also promote awareness within the medical community about marrow transplantation as a clinical option and encourage early referral of patients who could benefit from unrelated bone marrow transplants.

& continue their commitment to

The legislation signed today will help meet these challenges and ensure the continued success of the nation's bone marrow transplant program. Among other things, the new law will require the registry to: give priority to recruiting underrepresented populations; maintain an office of patient advocacy; and maintain a scientific registry to track the progress of patients who have received marrow from an unrelated donor. It also authorizes Congressional spending for the program through 2003.

1ST STORY of Level 1 printed in FULL format.

The Washington Post

December 19, 1989, Tuesday, Final Edition

SECTION: HEALTH; PAGE Z10

LENGTH: 2916 words

HEADLINE: New Era in Transplants

SERIES: Occasional

BYLINE: Sandra G. Boodman, Washington Post Staff Writer

BODY:

It was the second operation, nearly 15 hours long this time, in which a portion of a healthy liver from a live donor was transplanted into a dying baby. Six days later the donor, Robert Jones, a 20-year-old drywall finisher from Tennessee, felt well enough to hold a press conference, and his 16-month-old daughter was free of one of the classic signs of liver failure: the jaundice that had yellowed her skin since birth.

Surgeons at the University of Chicago Medical Center, who performed the delicate double surgery December 8, were delighted with his progress but astounded by hers. Sarina Jones, who weighs less than 15 pounds, had been removed from a ventilator weeks ahead of schedule. Her liver function was basically normal, and doctors were planning to move her out of intensive care.

"This is the best graft ever in the history of [this] transplant program," proclaimed Peter F. Whitington, chief of pediatric gastroenterology and a member of the transplant team. "She is doing better than anyone ever could have hoped."

Just three weeks earlier, the same doctors had performed the same operation -- the nation's first liver transplant involving a live donor -- on 29-year-old Teresa Smith and her 21-month-old daughter Alyssa. Previously, transplant surgeons had used only livers obtained from cadavers.

The operations on the Smiths, which took place November 27, did not go as smoothly. During the laborious and exacting 13 1/2-hour operation, surgeons accidentally nicked Teresa Smith's spleen, requiring its removal, and her bile duct, which had to be surgically rebuilt. Alyssa Smith underwent five hours of emergency surgery to stop postoperative bleeding.

Chicago surgeons plan to perform 18 more of these operations in the next year. Despite the enormous anxieties surrounding the pioneering procedure, what was not lost on either the transplant team or on other surgeons, medical ethicists or the estimated 31,000 Americans who die every year of end-stage liver disease was the prospect that transplants involving living donors might provide a vital new source of organs. It is far too soon to tell whether the Chicago procedure could be adapted for the 700 adults who last week were on the federal government's liver transplant waiting list.

Nor is it certain how useful the procedure might be for the 700 children who need new livers every year. Half of them die awaiting the death of another

child whose parents agree to donate a liver. Like Alyssa Smith and Sarina Jones, most of these children suffer from biliary atresia, a birth defect that results in blockage of the bile ducts, eventual liver failure and death.

Although the future of living donor liver transplants depends on how well the Smiths and Joneses do, the historic operation has already raised serious ethical questions: Should doctors subject healthy people to a high degree of risk in an experimental procedure that will benefit someone else? How truly informed is a consent given by parents who would willingly risk their lives to save their children? Who pays for such expensive, experimental surgery? Transplant Boom

Despite a continuing shortage of donors, transplantation has been one of the most stunning medical advances of the 1980s, largely because of the development of cyclosporin, a potent drug that prevents the body from rejecting the transplanted organ.

Statistics compiled by the federal Health Care Financing Administration show that the number of heart transplants performed annually increased nearly 16-fold between 1982 and 1988, from 103 to 1,646, while liver transplants jumped from 62 to 1,680 during the same period.

At the same time, the pool of donors has not increased. Some experts say the use of seatbelts and infant car seats has reduced the number of fatal accidents in which victims could be potential donors; others say that hospitals remain reluctant to ask relatives of dead patients to donate their organs.

One-year survival rates for all types of transplants range between 70 and 80 percent; federal statistics for five-year survival rates are sketchy but are believed to hover around 50 percent. Although the condition of patients following a transplant -- especially a liver transplant -- varies considerably, many people do well for several years.

Among them is Jamie Fiske of Bridgewater, Mass. Fiske underwent a transplant in November 1982, shortly before her first birthday, after her father made a desperate and highly publicized plea for a new liver. She recently celebrated her eighth birthday and has had a relatively normal childhood.

Another development has occurred recently in the field of transplantation. Now that single organ transplants are common, some surgeons are experimenting with multiple organ transplants in conjunction with a new anti-rejection drug, FK 506, developed by the Japanese. Two weeks ago, Pittsburgh surgeon Thomas E. Starzl led a team that spent 22 hours transplanting a heart, liver and kidney from cadavers into a 26-year-old woman.

Liver transplants are still relatively rare, a reflection of the enormous skill involved in performing them, especially when the recipient is a child. That fact alone, some ethicists speculate, will probably limit how many of the nation's 249 transplant centers attempt to follow Chicago's lead.

Because the organ, which is shaped roughly like a boxing glove, is composed of so many intricate veins and ducts, surgeons say that it is much harder to transplant than a heart. Liver transplantation is "the most complex technical procedure of all the organs that we transplant," said Ronald Busuttil, chief of liver transplantation at the University of California at Los Angeles Medical School. "And if one considers the complexity and difficulty [in splitting a

liver] that is going to be used to be implanted in the recipient, that even adds more difficulty."

The liver is the largest internal organ in the body and, like the heart, is essential for life. It is composed of several lobes and extracts waste from the blood, stores sugar, vitamins and minerals and produces bile, the digestive juice.

It is only because the liver has an extraordinary capacity to regenerate -- unlike most other organs -- that living donors are possible. The livers transplanted into Alyssa Smith and Sarina Jones will grow along with them, while their parents' livers are expected to look almost normal within a year.

"There aren't many organs you can take just a piece of," said surgeon James S. Wolf, chairman of the division of transplantation at Northwestern University School of Medicine. "Could this be done with older children, say with a 90-pound girl? It's hard to say. The limiting factor in dividing the liver is the size of the bile duct."

In the Chicago procedure, surgical teams spent almost as much time cutting and preparing the parents' livers as they did implanting the healthy pieces into the bodies of their sick children. First they made a splayed, three-pronged foot-long incision running from the ribcage to the navel of each parent. Getting to the liver, which is nestled behind other organs, and clamping it off took nearly 2 1/2 hours. The most dramatic and anxious moments involved cutting and removing one third of the adults' livers. The severed piece was then bathed in solution, gingerly placed in a small metal basin and spirited to a second operating room. A trio of surgeons wearing amplifying glasses hunched over what was to become the new liver, meticulously checking grafts and arteries and the functioning of the organ that would be transplanted into the baby, replacing the diseased liver.

Two years ago, Christoph Broelsch, the surgeon who led the Chicago team, pioneered the use of adult cadaver livers that were cut to fit children. Last year, he performed the first "split liver" transplant, using one adult cadaver liver to save two children.

The difficulty of liver transplantation is magnified when it involves live donors, whose livers are softer and tougher to handle than a chilled organ obtained from a cadaver. One of the reasons Alyssa Smith required emergency surgery for postoperative bleeding is that a hematoma, a small pool of clotted blood, had formed under a layer of skin covering her mother's liver. Chicago surgeons speculate that the hematoma probably occurred when the team handled the organ. There were no such complications in the second transplant involving Robert and Sarina Jones.

Ethical Questions

The Chicago transplants have revived a longstanding debate about human experimentation. "There are several key issues," says Arthur Caplan, director of the Center for Biomedical Ethics at the University of Minnesota. "One is that the procedure really raises some serious questions about the validity of informed consent. I find it very difficult to credit consent when you're asking the parent to assume a risk to save the life of his or her child. I think most parents would do nearly anything, including killing themselves, to save their

child's life."

George Annas, professor of health law at the Boston University School of Medicine, agrees. "The second question is one of the magnitude of risk to which you can subject healthy people," said Annas. "Generally, doctors don't put healthy people at risk at all. This is clearly an issue with liver donation which is a lot more dangerous than donating a kidney," since people are born with two healthy kidneys but need only one to survive.

"And the next question," Annas adds, "is that if it works and we let parents do it, why not uncles, cousins, brothers or, for that matter, strangers?"

Given the advances in transplantation, the questions are not far-fetched. Until recently, bone marrow transplants -- used to treat leukemia and other potentially fatal blood disorders -- were performed only on members of the same family. Because the chance of an exact tissue match is only 30 percent, except in cases involving identical twins, the federal government established the National Marrow Donor Program in 1987, designed to match strangers as donor and recipient. Recently the family of 20-year-old Allison Atlas of Bethesda, who suffers from a rare form of leukemia, launched a highly publicized drive to find a donor that matches her unusual tissue type.

Organ transplants pose considerably greater risk to the donor than giving bone marrow, which quickly regenerates. Although federal law forbids the sale of organs, a common practice in some countries, most ethicists doubt that permitting living strangers to donate pieces of their organs will become acceptable. "We don't permit non-relatives to donate a kidney," Annas says. "There's no particular reason for it, except that doctors think it's just too weird and refuse to do it."

Ethical questions about using live donors are not unique to liver transplantation. Many of the same questions were raised in the early days of kidney transplants; the debate intensified after several donors died. Surgeons acknowledge that in some cases the coercive nature of family relationships can cause serious problems, something hospitals try to guard against.

"This is not a purely rational decision," said Annas. "The early research with kidney transplants showed that the family members made the decision immediately; it's sort of a gut decision. But as a basic rule, it seems to me that parents should never designate that one kid donate an organ to the other," which has occurred.

Mental health workers who evaluate transplant candidates and prospective donors try to screen out those with obvious psychological problems. But they acknowledge that the subtler, and sometimes more insidious, dynamics within families are harder to read.

"There are problems with some people being afraid to say no because they'll be viewed as disloyal or uncaring," said James L. Levenson, a psychiatrist at the Medical College of Virginia in Richmond, a major transplant center. "Then there are people who say no and mean yes and people who say yes and mean no. And in some cases a relative wants to donate, but their spouse doesn't want them to."

Although most parents say they would gladly donate parts or entire organs to save their children's lives, some recognize that the decision is not so simple.

"I would hate to see parents feeling pressured to do this," said Susan Watson of Fairfax, whose 6-year-old daughter has had an operation to correct biliary atresia and someday may need a transplant. "Let's say it's a young couple and there are other young children. I can see parents saying no, that it's just too risky to lose two members of the same family at the same time. The other thing is that a lot of families are very marginal in terms of income. If there's a risk that the breadwinner might die or lose a lot of time from work or a job, that's got to be a major consideration."

The Chicago team went to unusual lengths to grapple with the ethics of using live donors, a move applauded by ethicists and other surgeons. Last August, the team outlined its plan to perform a series of 20 transplants in the New England Journal of Medicine.

Unlike traditional medical policy, which stipulates that transplants should be reserved for the sickest children who have no other hope of surviving, the team announced that it planned to attempt the procedure on those who are not critically ill but are expected to need a transplant within six months.

The team also said that minors would be barred as donors, to minimize possible family coercion; in most cases, the donor would be a parent who would receive extensive psychiatric and physical evaluation and then be required to wait two weeks before deciding. In addition, the consent form explicitly states, "The operation your child will have . . . has never been performed."

"By approaching parents early, we've really given them a real choice, which we think sort of minimizes the coerciveness," said John Lantos, a pediatrician and ethicist who is a member of the transplant team. "We say, 'In three to six months, it looks like your kid is going to die without a transplant, and if you wait, there's still a chance a donor's going to come along, so you can try this experimental procedure or opt for the standard therapy.' That's different than saying, 'Look, your kid has got only a week or a month to live, what do you want to do?' " he adds.

"The Chicago procedure was telegraphed a long time ahead, and I don't think you could ask for anyone to try harder than they did" to consider the ethics of the procedure, says Jerold Mande, senior legislative aide to Sen. Albert Gore (D-Tenn.) and an expert in transplant policy. "Obviously if this works, there will be enormous pressure on other hospitals to start doing them."

Some surgeons are reserving judgment until more live liver transplants are performed but say the procedure seems promising. "From a physiological and anatomic standpoint, it's very reasonable," said Northwestern's Wolf, who is vice chairman of the United Network on Organ Sharing. "I think it's certainly a worthy experiment, and the people who are doing it are very good."

Soaring Costs

While using portions of live livers from parents may help solve the problem of the organ shortage, it doesn't ameliorate one of the most pressing problems confronting medicine: spiraling costs that have sparked serious discussions about rationing care.

Most major insurance companies now cover many of the costs of transplantation, according to a recent survey by the Health Insurance Industry Association. But the Chicago procedure, which officials say costs at least $ 150,000, is experimental and few insurance companies pay for experimental treatment. Humana Healthcare Plans, which insures Teresa Smith, a fourth-grade teacher from a San Antonio suburb, has agreed to cover most of her transplant.

The situation for Robert Jones and his family is far different. The Joneses are among the 37 million Americans who lack health insurance. He and his supporters raised $ 160,000 from friends and neighbors in their native Tennessee to cover the cost of a transplant for Sarina, who had been on the waiting list for nearly a year. They must raise another $ 10,000 annually to cover related medical expenses, including the medications necessary to keep her alive.

Chicago officials say that financing each of the live transplants will be handled on an individual basis. If the procedure is as successful as it initially appears and if it can be adapted for adults, the financial ramifications are significant.

"If you look at the fact that at least 30,000 people die of liver failure annually in the U.S. and the fact that this operation costs about $ 150,000, well that saves a lot of lives," Lantos observes. "But it costs a lot of money."
DONOR ORGANS: STILL IN SHORT SUPPLY

The following chart depicts the number of transplants performed in 1988 and the number of people on the federal government's waiting list on one day, Dec. 11, 1989. Officials who compile the figures say that the one-day snapshot of the waiting list understates the actual number of people who need transplants. It reflects only those people who reach the waiting list by meeting the medical and financial criteria established by each of the nation's 249 transplant centers. Patients who died while awaiting a transplant, who need a re-transplant because of rejection problems or who are too sick to receive a transplant have been omitted.

GRAPHIC: PHOTO, ALYSSA SMITH, 21 MONTHS OLD, IS PREPARED BY SURGEONS AT CHICAGO MEDICAL CENTER TO GET PART OF A LIVER FROM HER MOTHER, TERESA, 29. AP; CHART

LANGUAGE: ENGLISH

20TH STORY of Level 1 printed in FULL format.

The Washington Post

January 20, 1987, Tuesday, Final Edition

SECTION: HEALTH; PAGE Z14; COVER STORY

LENGTH: 3503 words

HEADLINE: Transplants: Who Lives? Who Decides? Doctors Can Make Them Work-But Can Society Make Them Fair?

BYLINE: Don Colburn, Washington Post Staff Writer

BODY:

Two patients have irreversible liver disease. Their only hope is a liver transplant. One, nearly comatose and breathing on a respirator in the intensive care unit, will die within days. The other, sitting at home watching television, is still employed but will die within a year. Given a liver transplant, the first patient -- the sickest one -- has a 30 percent chance of walking out of the hospital, while the second has an 80 percent chance. But only one liver is available.

Who gets it?

"The patient in the ICU, because that's what society dictates," said Brian Broznick, director of organ procurement for the Pittsburgh Transplant Foundation.

"Which one should get the liver? Nobody wants to touch that question." ? ? ?

Almost unthinkable a generation ago, human organ transplants have become practically routine in many medical centers, epitomizing both modern medicine's technical prowess and the no-easy-answer questions that medical progress raises for society. In barely 30 years, doctors have learned to transplant an array of vital human organs -- kidney, heart, liver, pancreas, lung -- into patients who often have no alternative but to die.

But transplantation may also be a victim of its own success. Limited less and less by technical obstacles and more and more by the shortage of organs, the life-saving procedure poses hard questions of fairness and cost.

Who lives? Who dies? Who decides? And, increasingly, who pays?

Experts say transplantation offers a glimpse of the troubling ethical issues that may eventually confront the rest of the health care system in a time of burgeoning technology, growing demand and limited resources.

"Transplants are a sort of early warning system of the problems involved in allocation of scarce resources," said Arthur Caplan, associate director of the Hastings Center, a New York think tank specializing in study of ethical issues in medicine. "It looks like the classic rationing case: Who gets the organs, and what rules do we follow?"

Most decisions about how to spend medical resources, Caplan said, haven't reached the rationing stage yet because "there's still a lot of fat and waste out there. But the rhetoric of rationing is all over the place -- we're talking as if we're in a lifeboat.

"In transplants, we are in the lifeboat."

Transplant Boom

On any given day, more than 10,000 Americans are on waiting lists for a new heart, kidney or liver. Many of them will die before a suitably matched donor can be found.

" 'Rationing' is a frightening word," said Dr. William B. Schwartz, professor of medicine at Tufts University Medical School and author of "The Painful Prescription." "As a physician, I certainly find it frightening, and I would if I were a patient. But transplantation is one of the few areas of health care where true rationing is taking place."

"For the first time in the United States, we have to ask in a big way: How do you ration an expensive medical technology?" said George Annas, professor of health law at Boston University and former chairman of the Massachusetts Task Force on Organ Transplantation.

For the nearly 80,000 Americans with kidney failure, thrice-weekly dialysis treatments that filter wastes from the blood can keep them alive. But patients with heart failure or liver failure have no such alternative.

"You either get a transplant," Annas said, "or you die."

Fifteen years ago, only two U.S. medical centers -- Stanford University in California and the Medical College of Virginia in Richmond -- performed heart transplants. Today, 90 centers around the country do them, and that number could double in the next five years.

The annual number of heart transplants in the United States has increased 20-fold since 1981. Liver transplants have increased more than 30-fold. On average, U.S. doctors perform 30 transplants a day of hearts, livers and kidneys.

The explosive growth is the result of many factors, including improved anesthesia and surgical techniques, advances in tissue-matching and the accumulation of experience. But perhaps the biggest factor is an anti-rejection drug called cyclosporine. It was approved by the Food and Drug Administration in 1983 after dramatically increasing survival rates during experimental use.

A major risk in transplantation is rejection: the tendency of the body's immune system to fight off viruses and other "foreign" organisms -- including a transplanted organ -- that it doesn't recognize as its own.

"That's wonderful for immunity," said Dr. Clive Callender, director of the transplant center at Howard University Medical Center, "but when we come to transplants, this great protector is also the transplant surgeon's greatest

enemy."

Cyclosporin, which suppresses the immune system, has pushed back the limits of transplantion.

Stanford, which pioneered cardiac transplants, announced recently it would begin transplanting hearts in babies under 6 weeks old. The oldest recipient of a heart transplant at Stanford was 64; the youngest, a 5-month-old boy released from the hospital this month.

At the University of Pittsburgh, the world's leader in liver transplants, Dr. Thomas Starzl performed 344 liver transplants last year in patients who ranged in age from a weeks-old baby to a 76-year-old woman.

"It's an almost irresistible technology for hospitals," bioethicist Annas said, "because they get such nice publicity from it, and because both doctors and patients feel like second-class citizens if their medical center can't do transplants."

The Washington area, where six hospitals now do kidney transplants, is on the verge of a transplant boom. The area's first heart transplant took place at Fairfax Hospital late last month. Five District hospitals also have applied for a permit to perform heart transplants.

Georgetown University and Children's hospitals have applied for permits to perform bone marrow transplants; George Washington expects to soon. Georgetown also has filed a letter of intent to do pancreas transplants. Washington Hospital Center and Howard University Hospital intend soon to apply for permission to do liver transplants. The Hospital Center will also try for pancreas transplants.

But will there be enough organs to transplant?

Even with increases in the supply of donor organs, said Tufts' Schwartz, growing demand will lead to "a considerable shortage of at least some organs indefinitely."

And even in the unlikely event that the organ shortage were suddenly "solved," experts warn, the natural rationing now imposed by a sheer lack of transplantable organs could turn into economic rationing. Insurers, including the federal Medicare and Medicaid programs, would suddenly have to ask a question they have largely sidestepped in the past: Should the U.S. pay for an expensive but potentially life-saving treatment for thousands of patients?

Every 1,000 additional transplants a year, at an average cost of $ 100,000, could add $ 100 million to the nation's health bill.

"We're going to be at a cross- roads in a few years," said Schwartz. "Cost containment is not the benign and happy thing it has been described as by many politicians and organizations. I think we should do all these things to cut out the waste, but that's not rationing.

"The problem comes when you say, okay, we're not going to have that device or that operation available for everybody who needs it."

Many insurance companies still refuse to pay for adult liver transplants, for example, on the grounds that they are "experimental."

"That's a great way of rationing," Schwartz said. "Another way is to say the patient is too old."

Transplant patients at most medical centers must also pass what has been dubbed "the green screen."

"In other words," said Jon Gold of the federal Office of Organ Transplantation, "you either have to have insurance coverage, or pay $ 50,000 or $ 100,000 up front. That's a pretty effective screen."

Transplant recipients also must take cyclosporin for the rest of their lives at an annual cost of $ 5,000.

Such financial restrictions exclude minorities disproportionately from the transplant pool, Howard's Callender pointed out: "The overriding thing is, if you don't have any money and you don't have any coverage, then you're not going to be transplanted."

Fairfax Hospital said it will not charge its first heart transplant patient, a 20-year-old District woman whose Medicaid coverage is not transferable to Virginia.

"We're pretty much committed to doing that at first," said hospital spokesman Lon Walls. "Whether the patient can pay or not, we'll go ahead and do them.

"As we get more referrals, that's going to turn around."

'The Only Chance We Had'

Kiran Ahooja, a 36-year-old woman with acute leukemia, became the first bone marrow transplant patient in the Washington area in an operation Nov. 25 at Georgetown Hospital. She arrived here from India in August with her husband and three children. She was rejected by seven other centers -- three in the U.S. and four abroad -- because of her critical condition and because she could not pay for the operation in advance.

"Without $ 100,000 down on the table, in advance, they would not even see the patient," said Dr. Vinod K. Sachdeva, the patient's brother-in-law, a physician at Andrews Air Force Base.

Georgetown, which had applied for a permit from health planners to start a bone marrow transplant program but had not obtained approval, initially refused to operate on Ahooja. But the family insisted, and, without notifying District health planners, Georgetown agreed to try the unauthorized operation.

"It was the only chance we had," Sachdeva said.

Unlike organ transplants, the bone marrow procedure does not involve waiting for a well-matched donor to die. But as with any transplant, a match is required, and the risks are high.

Georgetown demanded $ 35,000 in cash up front, with the rest to come later. Sachdeva spent most of the fall gathering loans from relatives and friends, and used $ 20,000 of his own savings to meet the down payment, which was exhausted within 20 days. Sachdeva paid the hospital another $ 25,000 after the operation.

Eight weeks after the transplant, the patient is still in the hospital, in stable condition, hoping to be discharged by month's end. Her medical bill is mounting by nearly $ 2,000 a day, Sachdeva said, and may soon reach $ 200,000.

Searching for Donors

"The good news about transplants," said Dr. Jimmy A. Light, director of transplantation services at the Washington Hospital Center, "is that they're succeeding extremely well. The bad news is that the demand for organs is increasing faster than the supply. Our waiting list went up by 50 percent last year, and the number of available organs only went up 15 percent."

Organ donors are not just people who die. They are young, healthy people who die unexpectedly -- usually from a violent accident, suicide or crime, such as a motorcycle crash or a gunshot wound to the head. Transplant surgeons sometimes refer to motorcycles as "donorcycles."

The potential supply of donors is essentially the estimated 20,000 otherwise healthy Americans a year who become brain dead. Their brain function is totally and irreversibly destroyed, but their other vital organs can be kept alive temporarily with artificial life support, including mechanical ventilation of the lungs.

But of those 20,000, only about 3,000, or 15 percent, become organ donors.

The reasons vary: geography, logistics and a reluctance -- on the part of physicians, families or both -- to broach the subject.

Surveys show that most families agree to organ donation if they're asked -- but most never are. For many reasons -- consideration for the family's grief, fear of a possible lawsuit or mere oversight -- doctors often don't ask the family if they would consider donating their dead relative's organs.

"No matter what anybody tells you," said Brian Broznick of the Pittsburgh Transplant Foundation, "there is not a shortage of organs for transplant in the United States. There is a shortage of donor referrals. That's a big difference."

A 1985 Gallup poll revealed widespread public support, but considerable ambivalence, about organ donation. Though 93 percent of Americans were aware of organ transplants and 75 percent approved of organ donation, only 17 percent said they carried an organ donor card. And while 73 percent said they were "very likely" to give permission to donate a loved one's organs, only 27 percent said the same about their own organs.

Of those very likely to donate their organs, only half had told their families, which is important because doctors almost invariably ask for a family's permission before removing a brain-dead patient's organs.

"These organ donor cards mean just about nothing," Annas said. "There isn't a doctor or a hospital in the country that will take a person's organs on the basis of that card without talking to the family first."

In one study, less than 3 percent of the organs transplanted came from people carrying a donor card at the time they were admitted to the hospital.

That's why more than half the states recently have passed "required request" laws. These require hospitals to raise the possibility of organ donation with family members of any brain-dead patient who is a potential donor. The decision whether to donate remains with the family.

To many, however, brain death continues to be a troubling concept.

"Is it morally acceptable to move parts from a dead person to a living person, or even from a living person to another living person?" said the Hastings Center's Caplan. "A lot of people think we've gotten over that. I'm here to tell you we haven't. It makes us feel squeamish. It makes us feel weird, especially when we see a dead donor who still looks warm and pink even though he would stop breathing if the respirator were turned off."

"Imagine trying to explain to a family: Look, your son is dead even though he's in the next room breathing, and we'd like to take his organs out for transplant," said bioethicist Annas. "That's very tough."

Almost every successful transplant begins with a human tragedy, the sudden death of a young healthy person.

"You've got one family that's in joy, you've got another family in sorrow," Evans said. "There's no easy way to reconcile it. That's why medicine has such a hard time dealing with all this. The people who practice medicine are basically scientists, but the issues we're dealing with are social, ethical and moral questions that don't often have any right or wrong answers."

Technology's Mixed Blessing

Barring a major advance in artificial organs or animal xenografts -- such as transplantation of a baboon heart into a human -- the growing demand for transplants is likely to outstrip the number of available organs.

"I don't think we'll get to the point where we have enough organs to meet the demand," said Batelle's Evans.

"We don't really know how many people could benefit from a heart transplant," Light said. "What we do know is that when you provide the technology, somehow a lot of patients appear."

In 1982, when Barney Clark became the first person to receive an artificial heart, he was 61 and the upper age limit for a transplant at Stanford was 50.

"Now there are probably a dozen centers around the country that would transplant Barney Clark," said Boston University's Annas.

Use of the artificial heart as a "bridge to transplant" in dying patients until a human heart is found doesn't affect the shortage. It doesn't reduce the number of people on the waiting list; it merely changes the name at the top. The artificial heart recipient in effect jumps ahead in line for the next available heart.

"That is a heart that someone else could have had," said Tufts' Schwartz. "It's a very nice thing to do and it's very dramatic, but it doesn't add to the pool of human beings that benefit from heart transplant."

Life-and-Death Choices

In the face of a persistent shortage of organs, most transplant centers have set up waiting lists, specifying "objective medical criteria" that in effect are ways of rationing available organs.

The criteria include age, tissue and blood types, prognosis and general health.

Tissue match is key. Usually an available organ matches no more than one person on a center's waiting list, said Dr. John Makoviak, a heart transplant surgeon at Washington Hospital Center.

Every patient on every transplant waiting list, Makoviak said, is "identical in two ways: they're all human beings, and they're all going to die without a transplant in a relatively short time.

"When human life is the bottom line, there is no authority -- moral, legal or ethical -- that could say that transplanting one person over another is the wrong thing to do at a particular moment."

The Massachusetts Task Force on Organ Transplantation, chaired by Annas, concluded that organs should go first to those likely to survive "for a significant period of time with reasonable prospects for rehabilitation."

"As you can see," Annas said, "there are a lot of weasel words in there."

The task force ruled out several other possible ways as unfair or unworkable: the open market; a lottery; "first come, first served," and "social worth."

The last was tried with disastrous results during the 1960s in the early days of kidney dialysis, when a citizens committee in Seattle met in secret to decide which patients should be put on the limited number of dialysis machines and which should die. The harrowing selection process, two experts observed, ruled out "creative nonconformists" and made the Pacific Northwest "no place for a Henry David Thoreau with bad kidneys."

Even "objective medical criteria," Annas said, can be tantamount to "back door" social worth criteria if, for example, drug addicts or alcoholics are ruled ineligible.

Congress banned the sale of bodily organs for transplant when it passed the National Organ Transplant Act in 1984, sponsored by Sen. Albert Gore Jr. (D-Tenn.). The act provided for a national computerized registry linking the 110 agencies that procure hearts, livers, kidneys, pancreases, lungs and corneas.

But the Reagan administration has been reluctant to fund the registry. It waited until the final hours of the fiscal year before awarding the contract for it last Sept. 30 to United Network for Organ Sharing (UNOS) in Richmond, Va. And funding for the registry was wiped out of the administration's proposed budget for fiscal 1988.

In a letter to Reagan earlier this month, Gore criticized the president for "turn[ing] your back on a commitment our society has made to respond to the needs of patients on transplant lists."

The act also set up a 25-member task force that issued a report last spring concluding that a patient's financial status "should not limit the availability of this medical treatment" and that criteria for organ placement must be "objective, medically sound and publicly stated."

But as the transplant boom gains momentum, even those "objective medical criteria" don't answer some of the most excruciating dilemmas about who should or should not get organs.

For example, should a patient whose first transplant fails go back to the top of the waiting list for a retransplant, or should someone else be given a chance?

Meghann LaRocco, a 7-month-old girl born with a fatal liver defect called biliary atresia, recently received four liver transplants in 31 days. She is in "serious" condition on a ventilator in Wyler Children's Hospital at the University of Chicago, where her medical bill has been estimated at $ 300,000 to $ 350,000.

Should U.S. citizens be given priority over foreign nationals? Should drug addicts be allowed on the waiting list? What about mentally retarded patients? Alcoholics? Convicted felons?

"Take liver transplants," said Jack Meyer, a health economist and president of New Directions for Policy, a small Washington consulting firm. "You can transplant a 2-year-old child with a fatal disease. It's hard to think of a more valid cause. On the other hand, you could also transplant a 20-year-old alcoholic with cirrhosis, who by dint of his own behavior has destroyed his own liver.

"Is society going to do that? And if they do, who should pay for it? We feel very funny about discriminating against people in these ways.

"The Hippocratic Oath doesn't say, 'I will do all I can to help those who haven't abused themselves, or all those who have a middle-class social support system at home.' "

Medicine has been wrestling with these issues since the first kidney transplant in 1954. Others -- insurers, lawyers, social workers, philosophers, judges, policymakers, patients themselves -- are increasingly drawn into the fray.

"These are political and ethical questions," said Hastings Center's Caplan. "People keep dumping them into the doctors' laps, but they're questions for the whole society."

GRAPHIC: ILLUSTRATION, A KIDNEY TRANSPLANTONE OF THE WORLD'S FIRSTTHE MECHANICAL ALTERNATIVE, (HANDS & ARMS), RICHARD DOWNS-TWP; PHOTO, (KIDNEY TRANSPLANT OPERATION); ILLUSTRATION, (TRANSPLANT STATISTICS), JO ELLEN MURPHY-TWP; PHOTO, (BARNEY CLARK)

LANGUAGE: ENGLISH

THE WHITE HOUSE

Office of the Vice President

For Immediate Release:

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STATEMENT OF VICE PRESIDENT GORE

ON THE NATIONAL BONE MARROW REGISTRY REAUTHORIZATION ACT OF 1998

Giving all Americans access to life-saving therapies is not only a high priority of our Administration, it has been an important personal priority of mine since I served in Congress. That is why I am pleased that President Clinton signed into law today the National Bone Marrow Registry Reauthorization Act of 1998.

For thousands of Americans facing life-threatening illnesses, a bone marrow transplant is their best hope for recovery. By working together, the Administration and Congress have taken an important step to expand the availability of this life-saving treatment. I especially want to acknowledge the leadership of Congressman Bill Young, who has been working on this issue from the very beginning; Senator Bill Frist, who helped write the original transplant law as a physician and who has continued his leadership role in the Senate; Senator Ted Kennedy, with whom I had the privilege to work in writing the law that created the marrow program; and Congresswomen Anna Eshoo and Juanita Millender-McDonald, for their invaluable help. I also want to thank Admiral Bud Zumwalt, who has championed this cause from the start and who has had much to do with the success of the program.

The National Marrow Donor Program is a unique national resource. When this federal program began, many doubted such a registry could attract enough volunteers willing to go into the hospital and donate marrow for a complete stranger. I am pleased to say the doubters were wrong. Today, the National Marrow Donor Program's registry lists an astounding 3,200,000 volunteers, and the program has facilitated more than 7,000 transplants. As the author of several laws that helped establish the registry, I am particularly gratified to see this program's record of success.

The bill signed by President Clinton today will ensure the continued success of the nation's marrow program. I am especially pleased that the new law focuses on improving the chances for patients of racial and ethnic minority heritage to find a matched donor. By working together, we can continue to help families in need.

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THE WHITE HOUSE

Office of the Vice President

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The National Marrow Donor Program is a unique national resource that is saving lives. For almost three decades, marrow transplantation has been a valuable tool in treating disease. The key to its success has been an available family member whose marrow almost exactly matched the patient's marrow. Most patients, however, do not have a family member who is a good match. Only a few short years ago, patients in this situation had little chance of survival. Today, because of the National Marrow Donor Program, their chances are greatly improved. As the author of several laws that helped establish the registry I am particularly gratified to see this program's record of success.

When this federal program began, many doubted such a registry could attract enough volunteers willing to go into the hospital and donate marrow for a complete stranger. I am pleased to say the doubters were wrong. Today, the National Marrow Donor Program's registry lists an astounding 3,200,000 volunteers, and the program has facilitated more than 7,000 transplants.

As successful as this program has been, some patients needing unrelated marrow transplants still face daunting challenges. Minority patients are particularly at risk. A significant disparity remains between the likelihood of finding a matched donor for Caucasian patients and the likelihood of finding a matched donor for patients of racial and ethnic minority heritage. We must correct this disparity.

The bone marrow program has done an excellent job recruiting racial and ethnic minority volunteers, particularly in the last several years. More than 800,000 of the volunteers on the registry are of minority racial heritage. Each year unrelated transplants facilitated by this program have increased by 25 percent. Each year, higher proportions of minority patients have received unrelated marrow transplants.

But we can do more. We must encourage the greatest possible number of volunteers of minority heritage to enroll in and continue their commitment to the marrow registry. We also must promote awareness within the medical community about marrow transplantation as a clinical option and encourage early referral of patients who could benefit from unrelated marrow transplants.

The legislation signed today will help meet these challenges and ensure the continued success of the nation's bone marrow transplant program. Among other things, the new law will require the registry to: give priority to recruiting under-represented populations; maintain an office of patient advocacy; and maintain a scientific registry to track the progress of patients who have received marrow from an unrelated donor. It also authorizes Congressional spending for the program through 2003. By working together, we can continue to help families in need.

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FACSIMILE

DATE: 7/15/98

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FAX #: 456-6027

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Office of the Chief of Staff
Department of Health and Human Services

Phone: 202/690-7431 Fax: 202/401-5783

COMMENTS:

Some comments on the VP's statement.

[redacted]

I'll call you to discuss. Thanks.

_____Pages [including this cover]

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TALKING POINTS

Marrow transplantation is a life-saving treatment option for patients with leukemias and other blood disorders. Although transplants that use the patient's own marrow are appropriate for some diagnoses, in other cases a patient's immune system must be replaced with that of another person. About 30% of these patients have a family member whose blood matches sufficiently to provide marrow. But, 70% of patients needing a marrow transplant must depend upon unrelated donors.

In response to this need, the National Marrow Donor Registry was authorized by Congress in 1984 to facilitate unrelated bone marrow transplantation by matching patients and donors and maintaining a Registry of volunteers willing to donate marrow. With more than 3 million volunteers worldwide who are willing to provide marrow for an unrelated patient, the success of the Donor Registry has exceeded all expectations.

The National Marrow Donor Program® (NMDP) manages the Registry and is a network of 100 donor centers, 114 collection centers, 122 transplant centers, 12 recruitment groups, and a coordinating center which assists patients find matching volunteer unrelated bone marrow donors for transplants. The NMDP is also a research organization that studies the effectiveness of unrelated marrow transplants and related treatments. Federal funding for the NMDP is essential to address five goals: (1) to increase the number of unrelated marrow transplants through physician education; (2) to provide equitable access for all racial and ethnic population groups; (3) to address the financial, social, and psychosocial barriers to transplantation; (4) to assure that the network of donor, collection, and transplant centers operates in an efficient, responsive,

and cost-effective manner; and (5) to expand efforts to conduct analyses and disseminate data concerning outcomes and scientific research.

The first goal is to increase the number of unrelated marrow transplants through physician education and other strategies. Since family practice physicians most frequently refer patients to hematologists and oncologists for evaluation of treatment, a professional education program for family physicians and related specialties may result in increased numbers of transplants. The Federal Government funds physician education to reduce the number of patients who are never referred to the Registry or not considered for an unrelated transplant.

The second goal is equitable access to transplantation. There are now over 700,000 minority volunteers on the Registry, a growth of almost 150% since 1994. Although the number of transplants for minority populations has increased by over 115% since 1994, minority transplants a still represent only 18% of all transplants. Because of the diversity of blood types, particularly for minorities, patients are more likely to find matched donors within their own racial and ethnic background. The likelihood of finding a matched volunteer on the Registry available to donate marrow remains considerably lower for a minority patient than for a Caucasian. One of the Federal Government's priorities is to increase the number and availability of minority donors on the Registry in order to increase the number of life-saving transplants for minority patients. Recruitment efforts include complete typing of minority volunteers so they are more readily identified as matches for searching patients and more education of potential donors about the need to be available if they match.

By the end of 1997, the number of African Americans on the Registry numbered over 235,500; Hispanic or Latino volunteers totaled almost 220,000; Asian/Pacific Islanders represent over 175,000; and American Indian/Alaskan Natives were over 41,000. The number of minorities grew by about 12,000 donors each month in 1997. Recruitment goals call for a continued increase in the number of minority volunteers recruited from 123,000 to 146,000 per year.

Not only has the number of minority donors increased, but access to transplantation by all population groups has improved. The number of transplants for minorities exceeded 18% of the total number of transplants in 1997. The likelihood of finding at least one suitable match at the preliminary search for a Caucasian is 85%; while it is 61% for an African American; and 66%, 76%, and 50% for Asian/Pacific Islander, Hispanic/Latino, and Native American/Alaskan Native populations, respectively. Barriers such as the difficulty of donor-recipient matching, patient and physician education, genetic heterogeneity, cultural differences, and financial issues must be overcome.

In order to increase access for minorities, the Federal Government funds typing of potential minority donors. All donors are typed at recruitment. To date, over 1 million donors have been fully typed. Analysis of data from search activities indicates that 90% of transplants are performed using donors who were fully typed prior to the current search. Federal funding is needed to ensure that donors are fully typed at recruitment.

The third goal is to address the financial and psychosocial barriers for patients and family members considering transplantation as a treatment option. An Office of

Patent Advocacy was established within the NMDP to respond to over 5,000 calls in 1997, 21% of which were search-related; to send out materials which cover all aspects of search, donation, and transplantation; and to perform a case management role to work with patients, families, and physicians to make difficult decisions and financial arrangements.

The fourth goal is to assure the network of donor, collection, and transplant centers operates in an efficient, responsive, and cost-effective manner. The Federal Government has established a fee-for-service reimbursement system for the donor center network, including financial rewards or penalties dependent upon performance. Consolidation of centers and other streamlining measures are under consideration. The Office of Inspector General evaluated the network with respect to several factors that affect efficiency, cost, and performance. These issues are being addressed currently.

The fifth goal is to expand efforts to conduct analyses and disseminate data concerning outcomes and scientific research. The field of transplantation is constantly expanding; peripheral blood stem cells and umbilical cord blood are treatment options unavailable just a few years ago. Continued clinical and outcomes research are needed to continuously improve the treatment of patients diagnosed with life-threatening diseases. Blood samples are collected from donors and patients for scientific research and stored in a sample cell repository for research concerning HLA typing, histocompatibility, and marrow and peripheral blood stem cell transplantation. In 1998, the Federal Government provided limited funds to support investigator-initiated

research grants, with particular emphasis on minority populations.

Physicians, patients, families, and researchers need complete and accurate information about transplantation, and the performance of transplant, collection, and donor centers. Assuring that timely clinical, scientific, and demographic data are available is an important objective of the NMDP. The Federal Government is working with the Registry to disseminate and publicize information otherwise unavailable to the public.

In closing, the success of establishing and expanding a Donor Registry from volunteers in 1987 to over 3.1 million today is commendable. However, many patients continue to have difficulty finding a match that can lead to a transplant and many more patients would have a better chance of success if a better match were found. The NMDP's Office of Patient Advocacy, the emphasis on minority recruitment, the expansion of research, continuing development of DNA-based HLA typing, the maintenance of a database of donors and patients, and provision of access to transplantation ensure that this life-saving therapy will be available for people of all racial and ethnic backgrounds. We are pleased to reauthorize support for this national resource for all people.

Questions and Answers on Marrow Transplantation

THE LAW ON MINORITIES

Question: What does the law state regarding minority recruitment?

Answer: The law states: *the registry shall increase the representation of individuals from racial and ethnic minority groups in the pool of potential donors for the registry in order to enable an individual in a minority group, to the extent practicable, to have a comparable chance of finding a suitable unrelated donor as an individual not in a minority group.*

FEDERAL FUNDING OF ACTIVITIES

Question: What activities are carried out with Federal funds?

Answer: The National Marrow Donor Program® (NMDP) is funded for a three-year contract supporting donor recruitment; tissue typing and matching; physician education; collecting, analyzing, and distributing data and research findings; an Office of Patient Advocacy and case management activities; and research and special studies of the optimum registry size and composition, donor retention, search and waiting times, activities to increase the number of transplants, and donor and patient safety monitoring. The largest percentage of funds is used to support activities that recruit and tissue type donors, particularly minority donors, and to maintain the Registry. The contract includes funding for a repository of blood samples for donors and recipients and the development of cell lines that are available for scientific and clinical research activities.
Specific activities that support these objectives include:

- Emphasis on increasing the number of transplants, including a major initiative on physician education;
- Increasing minority donation;
- Donor center restructuring and consolidation;
- Consideration of optimal registry size and configuration;
- Evaluation of donor retention; and
- Development of a research plan and publication of outcome studies.

The NMDP develops and maintains a Registry of volunteer donors for marrow and stem cell transplantation; conducts searches of the Registry for patients considering transplantation; and conducts research related to HLA typing, outcomes of unrelated marrow/stem cell transplantation, and related issues.

LIKELIHOOD OF A MATCH

Question: What is the likelihood of a match?

Answer: A large diversity of HLA types in a population makes it less likely that two unrelated individuals will match each other. Consequently, data show that minority patients, particularly African Americans, have a more difficult time finding an HLA-matched donor who is available for transplant.

Using 1997 data, the following indicates the percent of patients who identified at least one HLA-matched volunteer on the preliminary search:

Caucasians	85%
African Americans	61%
Asian/Pacific Islanders	66%
Hispanics/Latinos	76%
American Indians/Alaskan Natives	50%

COMPLETELY TYPED DONORS ON REGISTRY

Question: How many donors on the Registry have been completely typed?

Answer: By the end of 1997, over 1 million of the 3 million donors were fully typed, of which over 66% were minority donors and over 33% were Caucasian. All donors have been typed for HLA-A and B.

NUMBER OF TRANSPLANTS

Question: Have the number of transplants increased over time?

Answer: The number of transplants have increased -- from 555 in 1992 to almost 1,300 in 1997. The percent of transplants for minority populations also increased, from 14% in 1992 to 18% in 1997.

SURVIVAL RATES

Question: What are the survival rates?

Answer: The success rate depends on the disease, the stage of the disease, and the age and condition of the patient being treated. Overall, survival rates are generally between 30% and 60% for diseases that would be fatal without marrow transplants.

Unrelated donor transplants represent a successful therapeutic option for selected pediatric and adult patients with chronic myelogenous leukemia, acute myelogenous leukemia, acute lymphoblastic leukemia, severe aplastic anemia, myelodysplastic disorders, histiocytic disorders, inherited ethythrocyte abnormalities, inherited immune system disorders, Hodgkin's and non-Hodgkin's lymphomas, and certain other malignancies and blood disorders.

MINORITY EFFORTS

Question: What are the minority efforts in the NMDP?

Answer: Minority populations have been under represented within the potential donor pool and among the individuals who undergo transplants. The NMDP has targeted minority populations to increase the number of potential donors. Barriers such as the need for donor-recipient matching, patient and physician education, genetic heterogeneity, cultural differences, and financial issues must be overcome.

There have been major changes in the number of minority donors since 1992. The number of minority donors increased by almost 560,000 donors from 1992 through 1997, a 10% increase. African American donors represent 9% of this increase with over 200,000 additional donors recruited from 1992 through 1997. Hispanic/Latino donors increased by 8% and over 180,000 donors; and Asian/Pacific Islanders increased by over 6% and 145,000 from 1992 through 1997.

By the end of 1997, there were over 665,000 minority donors, 22% of the Registry.

The racial and ethnic diversity is reflected in the following tables:
(Data source: National Marrow Donor Program, 12/31/97)

VOLUNTEER DONOR REGISTRY:

RACE	As of 12/31/92	As of 12/31/93	As of 12/31/94	As of 12/31/95	As of 12/31/96	As of 12/31/97	% of total
African-American	34,248	59,104	98,052	136,462	193,396	235,559	7.8%
Asian/Pacific Island	28,203	46,877	68,466	93,555	140,712	173,183	5.7%
Caucasian	546,459	748,194	960,626	1,161,462	1,536,185	1,783,799	58.8%
Hispanic	35,453	64,408	91,576	122,929	174,375	216,102	7.1%
American Indian/Alaskan Native	8,245	13,079	17,606	23,483	33,580	40,543	1.3%
Declined information	1,736	2,038	2,478	2,867	3,496	4,081	0.1%
Other	4,799	6,325	8,174	9,970	23,196	36,839	0.4%
Unknown	91,763	175,923	251,663	395,907	480,016	545,787	18.0%
Cumulative total	740,906	1,115,948	1,498,641	1,946,635	2,584,956	3,035,893	—

DISTRIBUTION OF TRANSPLANTS

RACE	Before 1992	End of 1992	End of 1993	End of 1994	End of 1995	End of 1996	End of 1997	Current Total	% of total
African-American	13	15	16	24	42	66	64	240	3.7%
Asian/Pacific Island	2	7	6	21	19	33	46	136	2.0%
Caucasian	815	475	589	714	828	966	1,011	5,412	83.2%
Hispanic	34	16	30	46	51	61	106	346	5.2%
American Indian/ Alaskan Native	2	6	2	2	9	8	6	33	0.5%
Declined information	122	28	14	6	1	0	0	170	2.7%
Other	17	8	18	18	19	12	14	106	1.7%
Unknown	0	0	5	9	1	15	33	63	1.0%
Yearly Total	1,005	555	680	840	972	1,172	1,282	6,506	—
Cumulative Total	1,005	1,560	2,240	3,080	4,052	5,224	6,506	—	—

COORDINATING CENTER UPDATE

"Celebrating Second Chances" — awareness theme with a new perspective

National Marrow Awareness Month 1997, held in September, was a time of change. A new theme was developed to replace the previous theme, "Share Life." The phrase "Celebrating Second Chances" was developed through the efforts of Awareness Month employee and network committees. These groups provided the groundwork and ideas for new themes, which were then voted on by the network and Coordinating Center staff.

WHY CHANGE?

As the retention of donors and increasing patient services are added to the NMDP priorities, the communications and special events need to reflect these changes. Awareness Month is an event designed to continue carrying the important messages of the program and link our program to the services we provide. The new phrase and logo were part of the linking process and will be used in future events.

WHAT DOES "CELEBRATING SECOND CHANCES" MEAN?

The NMDP has many reasons to celebrate second chances. We celebrate the volunteers who give of themselves through marrow donation. We also celebrate the patients who receive the marrow and a second chance at life. By setting aside a special month, all centers are able to participate and plan local events during September. In this past year, transplant centers and patients celebrated the commitment of the current and new donors on the Registry along with the technology that makes matching and transplants possible. Donor centers celebrated the new people willing to join the Registry and honored those who already had made the commitment. Events included donor–recipient meetings, special marrow drives, fundraising events and other activities.

1998

Plans are underway for the upcoming Awareness Month in September. "Commitment" to the program will be the main message throughout the month. New activities include a public service announcement print campaign focusing on "commitment" and a special button initiative, encouraging everyone to show their involvement with the NMDP.

If you have any ideas for activities or ways to "Celebrate Second Chances," it's not too late! Please call 1-800-526-7809 and ask for either Andrea Carter or Tanya Zmuda to share your thoughts.◆

Minority issues addressed through new partnership

As one of the key partners in the National Organ and Tissue Donation Initiative, the Congress of National Black Churches, Inc. (CNBC) joined with The Department of Health and Human Services to sponsor a leadership meeting on May 12 - 13 in Washington, D.C. The meeting focused on opportunities and barriers related to organ/tissue and marrow transplantation. Twelve NMDP Donor Centers and two NMDP Recruitment Groups participated.

An organ recipient and organ donor family spoke on behalf of the solid organ program. Eugene Boyd, a marrow donor, spoke on behalf of the NMDP. Also, Jackie Cooper, who has been searching for an unrelated marrow donor for five years, shared the reality of what it's like to wait every day for that one special person to come up as her match.

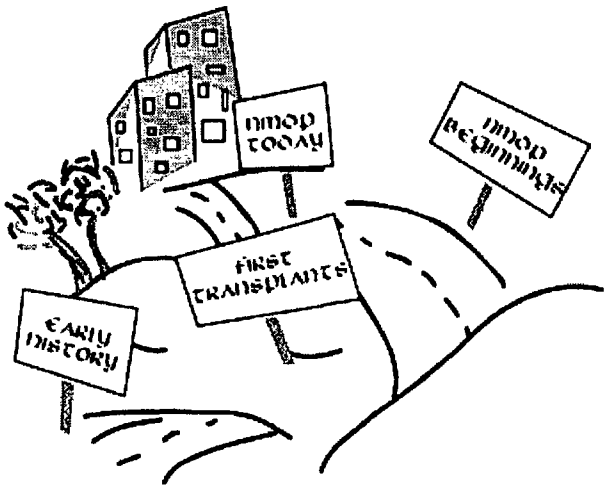
Charlene Drew Jarvis, Ph.D. spoke on real and perceived barriers to donation such as minority mistrust in the medical field, and clinical studies and reluctance to donate any part of the body because of cultural beliefs. Julia Cruz, M.D. discussed understanding organ/tissue and marrow transplantation issues. Issues included the need for diversity on the Registry, background information on diseases treated by a bone marrow transplant and how the tissue typing of donors is handled.

Representatives from the CNBC, Health Resources and Services Administration and the NMDP also met in breakout sessions to brainstorm ways the three organizations could collaborate. The final recommendations are being tallied and were not available at the time of printing.

Future plans include having several of the NMDP donor centers work with CNBC affiliates and organ representatives to develop models for recruitment and awareness activities to use with CNBC groups throughout the NMDP network.◆

NMDP History

Today's Date: Jul 14, 1998



Click on Mileposts to follow history

It's been an interesting road for the NMDP. Earlier this century, scientists had some different ideas about using bone marrow for treatment -- Needless to say, treatments today using bone marrow transplantation have proven to be much more successful. Follow the milestones and learn about the history of this lifesaving treatment.

[Early History] [First Transplants] [NMDP Beginnings] [NMDP Today]

Early History

Nearly a century ago physicians administered bone marrow by mouth to patients with anemia and leukemia. While such therapy was unsuccessful, it stimulated multiple attempts over the ensuing years, to replace or regenerate bone marrow in patients with marrow failure or malignancy. Among early attempts to transplant bone marrow from one individual to another (allogeneic transplantation) were those carried out in France following a radiation

accident in the late 1950s.

Discovery of HLA System

In 1958, a French scientist named Jean Dausset described the first of many human histocompatibility antigens. These proteins expressed on the surface of essentially all cells were found to be the targets for graft rejection and graft vs. host disease (GVHD). With knowledge of these human leukocyte antigens (HLA) came the ability to match potential donors with recipients. It was learned that an individual inherited three antigens designated HLA-A, B and DR from each of his/her parents thereby requiring that a total of six antigens of a potential donor match with the six antigens of the recipient. While antigens other than HLA antigens are known to play a role in bone marrow transplantation, the HLA-A, B and DR determinant are a part of the "major histocompatibility complex" -- those antigens most important in determining transplant outcome and therefore requiring the most stringent matching.

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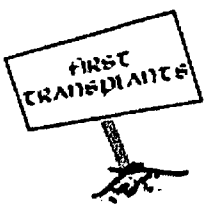

First Bone Marrow Transplants in U.S.

In 1968, the first two related transplants occurred both for children suffering from immunologic deficiencies, severe combined immunodeficiency and the Wiskott-Aldrich syndrome respectively. These patients remain healthy to this day with immune systems derived from their siblings.

First Unrelated BMT

In 1973, a team of physicians at Memorial Sloan Kettering Cancer Center in New York performed the first unrelated bone marrow transplant on a five-year-old patient suffering from severe combined immunodeficiency syndrome. The donor was found in Denmark through the Blood Bank at Rigshopitalet in Copenhagen. The patient received multiple infusions of marrow. Each successive transplant was performed to improve or correct the patient's blood counts and after the seventh transplant, engraftment was achieved and hematologic function rapidly became normal.

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The Formative Years

The need for a national registry of volunteer donors hit the spotlight when a young patient from Fort Collins, CO was diagnosed with acute leukemia in 1979. The family was referred to the Fred Hutchinson Cancer Research Center, in Seattle, for ongoing treatment of the child's disease and, facing the lack of any suitably matched family donor, the family requested the staff at the Hutchinson Center to search all possible registries of typed platelet donors to find an unrelated donor for their daughter. A match was located within the laboratory staff at the cancer center and Laura Graves was the first patient with leukemia to be treated with an unrelated bone marrow transplant. The donor marrow engrafted without complication, she suffered no GVHD, and after 100 days Laura went home with her family as a healthy child. Although the transplant was initially a success, Laura died two years later from recurrent leukemia.

By the early 1980s, with a crusade begun by the Graves family and others, registries of HLA-typed individuals had been established in Milwaukee, St. Paul, Seattle, and Iowa City. These registries were established by approaching previously HLA-typed platelet donors. However it was not long before some of the families of patients in need of an unrelated donor transplant began organizing efforts in their communities. These donor drives were usually quite small because of cost considerations and allowed only a modest growth in the regional registry sizes.

Transplant Acts and Amendments

In 1984 the National Organ Transplant Act was passed by Congress. It discussed among other things the feasibility of establishing a national registry of voluntary bone marrow donors.

In 1985 Robert Graves, DVM, along with other physicians and families, made a plea to Congress for the funding of such a program. The group of physicians and concerned families were successful in gaining an audience with members of Congress. They were able to show that if donors could be located quickly, and marrow transplants could be performed early in the disease process, the patient outcomes would improve dramatically. In July 1986 U.S. Representative William Young helped to secure a $1.3 million Navy appropriation the Office of Naval Research then awarded the first contract to establish the National Bone Marrow Donor Registry.

The Organ Transplants Amendment of 1988 brought changes to the original statute to support the marrow program by stating a registry would be established no later than October of 1988. The statute also contained comments about the already discussed confidentiality and consent issues. The Transplant Amendments Act of 1990 wrote into law the network of centers, addressed the need for diversity, and covered the consolidation needs of all the registries. These laws formalized what had already been developed by a community recognizing a need.

100-607
S.1433
AG spon
separate bill

101-616
S.2946
AG coop.

First NMDP Facilitated Transplant

In 1987 a patient from Raleigh, NC who had been diagnosed three years earlier with acute lymphoblastic leukemia, began the first search of the national registry. A six-of-six match

was found. The first transplant of the National Marrow Donor Program was performed with the donated marrow of Diane Walters of Milwaukee, WI, a 49-year-old grandmother. The marrow was grounded in Milwaukee amidst snow and high winds. A pilot from the Flight for Life International met Cindy Cook of the Milwaukee Donor Center at the airport. Despite the questionable weather, the flight made it to Minneapolis and from there on a commercial flight to Seattle within the allotted time.

Nobel Prize for Medicine

In 1990 Dr. E. Donnall Thomas was awarded the Nobel Prize in Medicine for his pioneering work in transplantation. During the early to mid-1970s Thomas performed more than 100 transplants for patients with aplastic anemia and leukemia with HLA-A, B and DR identical siblings. He was awarded the prize because of his many successful endeavors in both clinical and experimental bone marrow transplantation.

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Today

Throughout the early 1990s there have been many advances in the field of bone marrow transplantation and hematopoietic stem cell transplantation in general. Unrelated transplants are now being performed using umbilical cord blood obtained at birth and peripheral blood stem cells derived through the process of apheresis. There have also been many improvements in HLA-typing, moving toward more accurate DNA-based methods, and in procedures to reduce GVHD.

Currently, the NMDP Registry is made-up of more than 3 million potential volunteer donors and the Program has facilitated more than 7,000 transplants. The NMDP's primary goal continues to be providing the best possible source of hematopoietic stem cells from unrelated donors for patients who could not otherwise receive a transplant.

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STATEMENTS ON INTRODUCED BILLS AND JOINT RESOLUTIONS (Senate - June 09, 1998)

Mr. FRIST. Mr. President, I rise today to introduce the National **Bone Marrow** Registry Reauthorization Act of 1998. Transplantation of **bone marrow** is a procedure that offers hope to patients and their families and has saved the lives of many patients with leukemia and other life threatening conditions. As a physician, I know first-hand the heartache of waiting for a donor, and how the gift of **bone marrow** can change a patient's life. Of patients needing **bone marrow** transplants, 70% do not have a family member with matching **bone marrow** . These patients must rely on an unrelated donor. The National **Marrow** Donor Registry helps patients needing a **bone marrow** transplant find that unrelated donor with matching **bone marrow** .

Since its inception in 1987, the National **Marrow** Donor Program has grown to include more than 3 million volunteers willing to donate **bone marrow** to an unrelated patient. The program has facilitated over 6,500 **marrow** transplants around the world. The annual number of transplants rose from 840 in 1994 to over 1,280 in 1997.

This bill is companion legislation to H.R.2202, introduced by Congressman **Bill Young** which has 218 co-sponsors. Congressman **Bill Young** helped found the National **Marrow** Donor Program and has long been a champion of **bone marrow** transplantation. The companion House bill was unanimously voice voted out of the House Commerce Committee on May 14 and was unanimously passed by the House of Representatives on May 19, 1998. This kind of bipartisan support stems from the enormous need for this program. In this short legislative year, it is a must-pass bill.

The statutory authority for the legislation expired in 1994. An Act reauthorizing both the solid organ and **bone marrow** programs passed the Senate in 1996, but failed to pass the House.

This bill is the result of a collaborative effort by the House and Senate to reauthorize the National **Bone Marrow** Registry. In April, during National Organ and Tissue Donor Awareness Week, the Senate Labor Subcommittee on Public Health and Safety and the House Commerce Subcommittee on Health and Environment held a joint hearing on increasing **bone marrow** donation and transplantation. During the hearing, we heard from patients and their families, including testimony from Robert Wedge, a young man who continues to wait for a matching donor to be found. Robert's brother, Cornell, is a member of my staff. Our office has partnered with his loving family and the Congressional Black Caucus to hold a **bone marrow** drive here in Congress. We also heard from a father whose son's life was saved by a **bone marrow** transplant. We heard from professionals involved in the operation of the program, and the message throughout the hearing was consistent. The need for **bone marrow** donation is urgent, and we must continue to address the unique issues surrounding recruitment and transplantation of **bone marrow** among minorities.

The National **Bone Marrow** Registry clearly helps save lives. However, there is room for improvement in recruitment of donors and in the services provided to patients needing transplant.

Racial and ethnic minority populations are underrepresented in the Registry. The registry is working to increase the number of racial and ethnic minority donors. Today, the Registry includes more than 700,000 minority volunteers, a growth of almost 150%. However, more potential donors are needed before the probability of a match for a minority patient is comparable to that of a patient who is not a minority. This bill addresses the need for increasing the number and availability of minority donors. By directing special attention to informational and educational activities to recruit minority donors, including African Americans, Hispanics, Asians, Native Americans, and those of mixed racial heritage, the registry will increase the number of potential donors and help save lives.

To help patients and their families with the search for a **bone marrow** donor, the bill also establishes an Office of Patient Advocacy. The office will provide information to patients about the search process, the costs of the transplants, and patient outcomes at different transplant centers, and will also help resolve difficulties with the transplant process.

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