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HIV's Startling Spread Among Hemophiliacs

By Randy Shilts

Chronicle National Correspondent

Americans afflicted with hemophilia have the highest HIV infection rate of any population in the world and face serious problems ranging from health care costs as high as \$100,000 a year to the largely unabated spread of the AIDS virus to their wives and children.

An estimated 60 percent of the nation's 20,000 hemophiliacs carry the human immunodeficiency virus, which they

SPECIAL REPORT

unknowingly injected into their veins during routine treatments for the life-threatening blood disorder. Already, more than 1,100 hemophiliacs have been diagnosed with full-blown AIDS.

In spite of this astounding rate of infection, government agencies and private organizations have been slow to confront

the AIDS problem, leaving hemophiliacs to suffer from substandard health care.

"It's so ironic," said Larkey De Neffe, 27, a hemophiliac and program chair of the Oregon chapter of the National Hemophilia Foundation. "Of all the groups who got AIDS, we were the ones who could have done the best. We are used to dealing with a medical system, relying on new medical techniques. And look what's happened."

What has happened is a chain of medical, psychological, social and economic problems that have converged to make hemophilia the darkest part of the AIDS epidemic:

■ New technologies have enabled researchers to develop pristine blood products for hemophiliacs, but costs are so high that patients are quickly exhausting insurance limits and

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Deadly Spread of AIDS Virus in Hemophiliacs

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sinking into poverty to pay for the products.

■ Some hemophilia centers have refused to prescribe new, purer blood products to HIV-infected patients in apparent violation of federal civil rights laws. At one center in Portland, Ore., a high-ranking physician has refused to prescribe an important new medical product because he is opposed to marketing techniques used by the firm that manufactures it.

■ Although AIDS clearly represents the most serious health problem for these patients, some hemophilia specialists have refused to acknowledge the AIDS threat and have resisted gaining expertise on HIV, putting their patients' health in greater peril.

■ Hemophiliacs, who are more assimilated into the general population than other high-risk groups, have been subject to some of the cruelest discrimination reported in the AIDS epidemic. Dozens of hemophiliac children have had to go to court just to be able to attend school. One family in Florida was burned out of its home.

■ Cleaner blood products stopped new HIV infections of hemophiliacs four years ago, but the disease continues to spread because the hemophiliacs — all of whom are male — generally have been slow to adopt safe-sex guidelines, infecting their wives, who then transmit the infection to their offspring during pregnancy.

"People are dying left and right," said Dr. W. Keith Hoots of the Gulf States Hemophilia Center in Houston. "I can't stand it."

Young Victims

What makes the problems even more tragic is that they are so often played out in the lives of the young, as hemophilia strikes thousands of children and teenagers.

As these youths attend their hemophilia clinics around the country — with brightly colored posters of "Garfield" and "Teenage Mutant Ninja Turtles" hanging on the walls — the cheerful decorations mask the severity of their predicament.

The Oyler family of Carmel



BY CATHY CHENEY/SPECIAL TO THE CHRONICLE

Larkey De Neffe, a leader of the Oregon chapter of the National Hemophilia Foundation, injected himself with Factor VIII

cases, of Factor IX, proteins that allow blood to clot normally, stemming the flow at the site of an internal or external injury. In about one-third of all cases, hemophilia appears spontaneously in a family with no history of the disease.

Passed From Mother to Son

Usually, the disorder is passed from mother to son, as it was through many generations of European royalty. (Only men can contract hemophilia; women can suffer from an even rarer condition dis-

ankle caused internal bleeding that often left hemophiliacs with crippling pain. Surgery as innocuous as a tooth extraction or a tonsillectomy could cause a fatal hemorrhage.

But the treatment of hemophilia was revolutionized in the late 1960s with the release of concentrated forms of Factors VIII and IX.

To make the new products, pharmaceutical companies pooled the blood of thousands of donors and then extracted just the clotting factor that the hemophiliacs lacked

established lifelong relationships with doctors who provided everything from Factor VIII to dental care.

As Hoots of the Gulf States Hemophilia Center puts it, "We were in the golden age, and we were the golden boys."

This golden age, however, came to a quick end on June 11, 1982, when the first case of AIDS-related pneumonia in a hemophiliac was reported to the federal Centers for Disease Control.

The CDC dispatched an investigator to the University of Colorado Medical Center where the patient, a janitor, lay dying. The man was not gay or a drug user — the two groups that had so far been identified as being at risk for AIDS.

Rude Awakening

Investigators concluded that there was only one way the man could have contracted the disease: through his Factor VIII infusions.

"I still remember the day the CDC called and told us not to panic but that there were three people with hemophilia who had been diagnosed with pneumonia," recalled Alan Brownstein, executive director of the National Hemophilia Foundation. "That was our rude awakening."

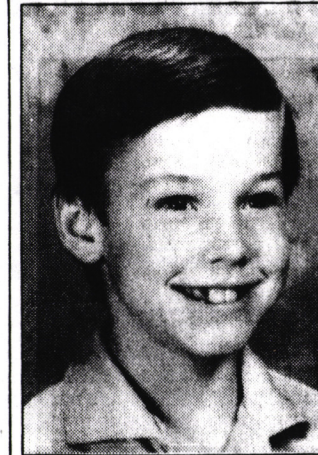
Given the fact that just a few years of infusions of Factor VIII exposed a hemophiliac to the blood of as many as 1 million donors, experts were quick to realize that a blood-borne virus was an enormous hazard. At hemophilia centers around the country, patients began showing up with immunological problems, often minor at first.

And then they began to die.

In Pittsburgh, Dr. Margaret Ragni, who treats 200 people at the Hemophilia Center of Western Pennsylvania, had long been collecting the blood of her patients. When she later went back to test the dated samples, she found that her patients had started becoming infected with HIV as early as 1978.

By 1983, tests showed that 75 percent of her patients were HIV positive.

"The cat was already out of the bag before AIDS was even found," Ragni said with a sigh. "We're in the



'We didn't expect the rejection... We needed love and support'

Benjamin Oyler wasted away to 34 pounds before he died of AIDS in 1986

The use of heat-treated Factor VIII largely stopped new infections by 1985, but huge numbers of hemophiliacs already were infected with HIV by that time.

Most estimates put the rate of HIV infection among the nation's 7,000 to 9,000 severe hemophiliacs at about 95 percent. Among moderate hemophiliacs, who required fewer infusions, infection rates hover between 40 percent and 50 percent. Few of those with mild hemophilia are infected with HIV.

The devastating tales of untimely death, particularly among young hemophiliacs, are often made worse by the social ostracism inflicted on these youths.

In Carmel, it was only when young Ben Oyler was about to begin the third grade that his mother learned the school board had decided to ban him from classes.

"We had moved to a new house, so Ben had no friends around — he so counted on going to school so he could have contact with other children," said Christine Oyler, who runs a remodeling business in Monterey with her husband.

Isolation

With Ben's health failing, his family found itself increasingly isolated from others in the affluent community. "There were close friends we didn't hear from any

more," Oyler recalled. "It was too much. We didn't expect the rejection at all. People didn't seem to realize we needed love and support. It took me a long time to get over it."

Ben was one of at least 170 hemophiliac children across the nation who have been excluded from schools because of HIV infection, according to the hemophilia foundation. News reports on some of these celebrated children, such as Ryan White in Kokomo, Ind., often led to more expulsions when parents in other states realized that hemophiliac children attending their own schools could be HIV-positive.

Three years ago in Arcadia, Fla., a family with three HIV-infected hemophiliac boys was burned out of its home after protesting the local school board's decision to bar the boys from the classroom.

"Many of our constituents began to tell us to take the quiet road because of this," Brownstein said. "They told us they did not want us to do anything to reinforce the connection between AIDS and hemophilia in the public mind."

It was this pressure that led the NHF to take an extraordinarily low profile in dealing with AIDS. Because of its clout with the federal government and its hemophiliac members, this private, nonprofit foundation occupied the central

Portland Doctor Withholding New Version of Clotting Factor

Portland, Ore.

Barry Kurath was ecstatic when he learned that researchers had devised a pure new version of the clotting factor he needs to treat his hemophilia.

The new Factor VIII product, he knew, would drastically reduce his exposure to hepatitis viruses — a major development, given that liver disease is the second-highest cause of death among hemophiliacs.

But when Kurath went to ask for the new treatment, his doctor told him he would not give him a prescription.

The physician, Dr. Everett Lovrien, medical director of Hemophilia Center at the Oregon Health Sciences University, concedes that the product is "very fine medicine" but refuses to give it to Kurath, in part because he does not like the company that makes it.

The company, Armour Pharmaceuticals, has been contacting patients directly to sell the new Factor VIII. To discourage such direct marketing, Lovrien is simply refusing to prescribe much of the product.

"We don't want to lose control of our patients," he says bluntly.

Complicating the issue is the



DR. EVERETT LOVRIEN
He disapproves of marketing

high cost of Factor VIII and other treatments in general. Lovrien says he will not give expensive new treatments to patients who, like Kurath, are HIV-infected.

Safer Treatment

"If you take some patient who's HIV-positive and put them on a medication that costs \$50,000 a year — and the reason to do it is that it's safer, but they've already got (HIV)

— that doesn't make sense to me," he says. Lovrien controls financing for Oregon's Hemophilia Assistance Program, which is what pays for Kurath's Factor VIII treatments.

As for the treatment's effect on protecting immune-deficient patients from further liver disease, he says such benefits are yet to be definitely proved.

Jonathan Botelho, a hemophiliac and a staff member with the office of civil rights of the Department of Health and Human Services, said such decisions violate federal laws banning discrimination against people with disabilities, such as HIV infection.

But Lovrien says, "I don't pay attention to the law. I try to do what's logical — sometimes that's illegal."

At the U.S. Department of Health and Human Services in Washington, Sharon Barrett, who administers the federal program that finances the Portland center, says she is "a little disturbed" by the problems patients face in obtaining monoclonal Factor VIII. "It is definitely an area I'm looking into this year," she said last week.

Many hemophiliacs say they feel restricted in their ability to protest, because they worry about los-



PHOTOS BY CATHY CHENEY/SPECIAL TO THE CHRONICLE

Computer programmer Barry Kurath said he is afraid to pressure his doctor about the treatment

ing their access to treatment altogether. Kurath is reluctant to pressure Lovrien because he is the chief of the only hemophilia treatment center within 600 miles of Kurath's Portland home.

"You don't want to sue your doctor when he's the only one who's got the medicine you need," says the computer programmer.

Lovrien's apparently capricious ill will toward Armour Phar-

maceuticals has denied patients millions of dollars in free Factor VIII. He refused the company's offer of free monoclonally produced Factor VIII for his patients, saying he "doesn't believe in rebates." Patients who wanted the factor were simply refused a prescription.

To make matters worse, patients who have obtained prescriptions from other doctors often find themselves thwarted later when

they ask insurance companies for reimbursement. Third-party payers often seek the advice of the region's foremost hemophilia expert before paying for the product. That expert is Dr. Lovrien, who advises them not to pay for the factor.

"You end up feeling like you're hitting your head against a brick wall," Kurath says.

— Randy Shiltz

How Medical Success Story Turned Into a Nightmare

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role in all policy related to HIV and hemophiliacs, sometimes to the frustration of public officials.

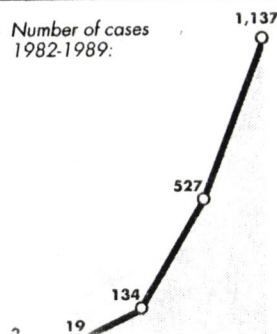
"I never felt it was the role of the U.S. Public Health Service to defer to (a private foundation)," said a staff member of the Centers for Disease Control who worked with hemophiliacs in the early years of the epidemic. "It really slowed things down."

Already Integrated

The NIH decision to temper its response to AIDS continues to haunt the organization today and is seen as the source of a central irony

AIDS AMONG HEMOPHILIACS

Number of cases
1982-1989:



there's a lot of Monday morning quarterbacking today about our actions then," Brownstein said. "We thought AIDS was a significant new event that would cause death, but we had no idea it would be as much of a problem as it was today."

Early AIDS denial also slowed the response of other populations, such as the gay community. In contrast to other groups, however, denial among hemophiliacs persisted long after the early, confusing years of the epidemic.

Today, in no area is the continued denial of HIV more poignant than in the difficulty in persuading hemophiliacs to adopt safe-sex practices.

about 47 percent of HIV-infected hemophiliacs consistently used condoms.

Psychological Reasons

Part of the resistance stems from deep psychological reasons, hemophiliacs say, because sex has traditionally been one of the few physical activities they could enjoy.

"I remember when I found out about sex. I thought, here's finally a sport I can do," said Botelho, of the Northern California Hemophilia Foundation. After years of having to avoid vigorous physical activity, he said, "it was a place where I could feel macho."

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As blood specialists, few hemophilia experts had much experience with either immunology or the diseases that follow HIV infection.

"They'll be the first to admit they're lost with this," said Jason from CDC. "They don't have a clue as to what they should do. They're not giving appropriate care, but it's out of ignorance, not maliciousness."

With some doctors woefully uninformed about advances in new HIV-related treatments, hemophilia patients have been left without the benefit of the medical break-

carrying the burden of HIV infection in severe isolation.

The unmitigated despair wrought from the loneliness has also led to growing reports of suicides among hemophiliacs, particularly among HIV-infected teenagers who feel they have nothing to live for.

In Portland, suicide is now the second leading cause of death among hemophiliacs — after AIDS. One man jumped off a bridge, took overdoses of phenobarbital three times and was on his way to leap from the city's tallest freeway bridge except that his car ran out of gas before he could reach the central section of the span.

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Already Integrated

The NHF decision to temper its response to AIDS continues to haunt the organization today and is in part the source of a central irony in the problem of HIV among those with hemophilia. In virtually every way, hemophiliacs were a population that was better prepared than any other to face the challenges of a new chronic disease.

They already were integrated into hemophilia centers, giving them unparalleled access to specialized medical care. With the NHF, they also had a well-respected national organization with chapters in every part of the nation that could champion their interests. But by most accounts, rather than working to help hemophiliacs in the crisis, these factors sometimes impeded an effective response to the disease.

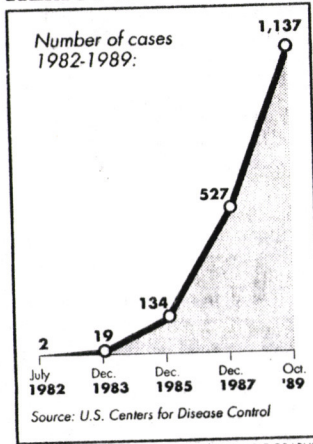
"The attitude from national (the NHF office) was to not get involved," said Jonathan Botelho, president of the Northern California Hemophilia Foundation. "They said, 'Don't talk about it out loud.'"

"To this day," he said, "there are chapters that won't print the word AIDS in their newsletters."

Along with fears of discrimination, national foundation leaders in New York City worried that too much attention on AIDS might frighten patients away from using Factor VIII, leaving them to suffer from the debilitating effects of untreated hemophilia.

However, NHF critics among hemophiliacs, researchers and

AIDS AMONG HEMOPHILIACS



CHRONICLE GRAPHIC

health officials cite another, simpler reason for the lack of a strong NHF response: denial.

The Denial Factor

"The NHF wants to please its group, and the truth is not going to make them happy," said one federal official who worked extensively with the organization and asked not to be named.

This denial factor had disastrous effects nationally because most federal money for AIDS education and studies is coordinated through the National Hemophilia Foundation.

NHF officials counter that nobody could have predicted in the early years the grim new threat that HIV posed. Even critics credit NHF with being an effective lobbying group to Factor VIII producers and with wielding influence in more conservative quarters of Congress.

Six months ago, the group decided to begin to adopt a more forthright public relations policy in regard to the problem of AIDS among hemophiliacs.

"Yes, there was denial, but

there's a lot of Monday morning quarterbacking today about our actions then," Brownstein said. "We thought AIDS was a significant new event that would cause death, but we had no idea it would be as much of a problem as it was today."

Early AIDS denial also slowed the response of other populations, such as the gay community. In contrast to other groups, however, denial among hemophiliacs persisted long after the early, confusing years of the epidemic.

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Use of Condoms

The CDC was first alarmed by the threat to hemophiliacs' spouses in 1984 when an early study showed that 10 percent were already HIV positive, said Dr. Janine Jason of the CDC, who worked on the research.

Although the NHF began publicly recommending safe sex, some of the group's most outspoken members have continued to have children — even though they risk infecting both wife and unborn child.

One federal official, for example, was shocked when one of the NHF's most prominent spokesmen rose at a 1987 conference to point proudly to his pregnant wife.

"He said that they decided to take the chance," the official recalled. "It was appalling. On paper, the NHF is talking about safe sex, but at their meetings, they still tell people how to check for ovulation."

When Pittsburgh's Dr. Ragni tested sexual partners of her patients, 13 percent were infected. Other studies have found that as many as 25 percent of hemophiliacs' spouses are now HIV positive. Some of these women have gone on to have children who were born with the virus.

A recent study by the CDC and Stanford University found that only

about 47 percent of HIV-infected hemophiliacs consistently used condoms.

Psychological Reasons

Part of the resistance stems from deep psychological reasons, hemophiliacs say, because sex has traditionally been one of the few physical activities they could enjoy.

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Last year, Brownstein said, NHF and federal officials designated the halting of sexual transmission as a top "national goal" for AIDS prevention efforts among hemophiliacs. He conceded that the programs met with "substantial resistance" at first, in part because many of the hemophilia doctors were uncomfortable discussing sexual issues.

Brownstein said that NHF chapters are now increasing their AIDS education. Last month, the group launched a Women's Outreach Network in chapters nationwide to educate sex partners of HIV-positive men with hemophilia.

Yet another problem continues to plague hemophiliacs, often with life-threatening consequences. Because some of the doctors who staff the hemophilia centers remain uncomfortable about AIDS, many hemophiliacs are receiving substan-

dard medical care for the HIV-related ailments, patients say.

As blood specialists, few hemophilia experts had much experience with either immunology or the diseases that follow HIV infection.

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With some doctors woefully uninformed about advances in new HIV-related treatments, hemophilia patients have been left without the benefit of the medical breakthroughs that have marked clinical management of HIV infection during the past two years.

Along with the medical problems are profound social problems being suffered by a group that has created few of the support networks that have marked the response to HIV among gay men.

"More than anything else, hemophiliacs wanted nothing more than to assimilate into American culture — to be just like anyone else," said De Neffe, who has AIDS-Related Complex. "They are afraid to be identified with something like AIDS. They don't want to be associated with gay people or the drug culture."

When De Neffe tried to organize a support group for HIV-positive hemophiliacs in Portland recently, only one other patient showed up. The result is that many are

carrying the burden of HIV infection in severe isolation.

The unmitigated despair wrought from the loneliness has also led to growing reports of suicides among hemophiliacs, particularly among HIV-infected teenagers who feel they have nothing to live for.

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"The doctors are crazed by this," said Dr. Louis Aledort, director of the Hemophilia Center at Mount Sinai Medical Center in New York. "We gave it to them. We didn't put the virus in their bottles, but we were the instruments of their death."

For the 500 babies born with hemophilia every year, HIV will no longer be a threat. New technologies for manufacturing Factor VIII and Factor IX through recombinant DNA and gene insertion processes will also provide pristine infusions.

Without effective, long-term treatments for HIV, however, the short-term prognosis for the hemophilia population is bleak.

In the end, for experts and people with hemophilia themselves, there is a lingering sense of betrayal over how a medical story that once was so bright has fallen into such disaster.

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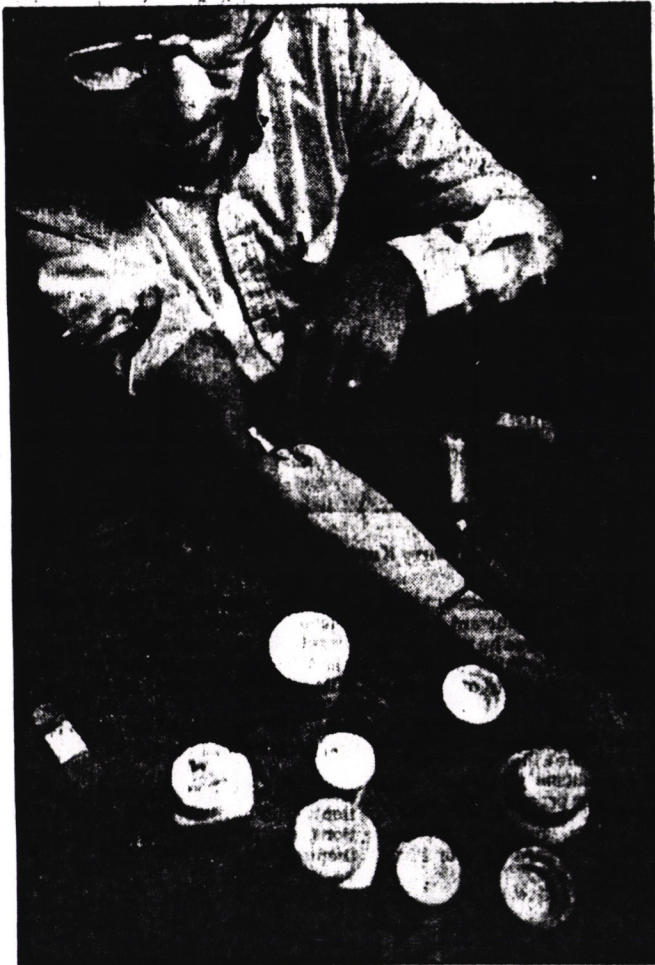
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