Childhood, hemophilia, HIV

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As a hemophiliac, Terry Chisholm’s life is a battle against pain and internal bleeding.

His weapon against hemophilia is something called Factor VIII, which helps his blood coagulate.

Unfortunately, the medicine he depends on to keep him well is believed to have been the cause of another great battle.

Terry has the human immunodeficiency virus, or HIV, which as many as 10,000 other hemophiliacs may have contracted from Factor VIII.

In school, Terry’s classmates picked on him because he has the virus that causes AIDS.

But Terry didn’t let name-calling and mean words stop him from telling people about his condition.

He has spoken about AIDS to students at a Baton Rouge school. He talks openly about AIDS with people who want to learn about the disease.

“I wanted to help kids understand what it was in case other kids have it, so they wouldn’t pick on them,” said the 11-year-old Walker boy.

“You can’t catch it by being somebody’s friend.”

Things are improving somewhat: His schoolmates aren’t so mean, he said.

“They used to treat me a lot differently. Now it’s getting a lot better.”

Terry is like many young boys: He loves to fish, hunt rabbits and hit fly balls to his little brother.

He anxiously awaited a week-long trip last month to Disney World, a gift from Dreams Come True, a Baton Rouge-based group that tries to fulfill the wishes of children with life-threatening illnesses.

Terry tested positive for the virus about 8 years ago. The vast majority of hemophiliacs who have the virus

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nationwide are believed to have contracted it through injecting Factor VIII to control their hemophilia, a genetic disorder that undermines the body's ability to stop bleeding.

Due to the rules of genetics, hemophilia very rarely strikes women, but mothers who carry the defective gene that causes the disease commonly pass it to their sons. It can also occur spontaneously through genetic defect.

A common belief is that a hemophiliac can bleed to death from a cut. In fact, such incidents are extremely rare. The disease most often causes death when internal hemorrhaging strikes the brain or other vital organs.

Living with hemophilia is often difficult and painful. At home recently, Terry felt pain and a warming sensation in his knees—the familiar signs that he had begun bleeding in his joints. He had been playing with his 5-year-old brother Brandon, throwing plastic “grenades” around the house, which caused the “bleed.”

As his brother looked on, Terry put four small glass medicine bottles on the kitchen table.

With skill that comes from long practice, he mixed it all together into a solution of concentrated Factor VIII, the blood protein he needs for his blood to clot.

But even after all these years, he struggles with the needle. So his mother, Paula Chisholm, came to his side and slipped the needle under the skin on the back of his hand and into a vein. But it was Terry who pressed down on the syringe to send the medicine into his body.

After its invention in the 1960s, Factor VIII enabled hemophiliacs to stop their bleeding at home and avoid lengthy infusions in hospitals. The concentrated medicine is easily injected, which made it possible for hemophiliacs to do things they couldn’t do before. Gradually, hemophiliacs entered the mainstream of American life.

In the mid-1980s, after the AIDS virus infected the Factor VIII, manufacturers began using new processes to kill the AIDS virus and other viruses in Factor VIII.

When Terry begins bleeding in a joint, it can cause such pain that he must go to the hospital, where he is given pain killers.

When he was younger, he had to use crutches when his knee joints became damaged by internal bleeding.

His mother said her son has experienced more pain than she ever will in her life.

“Sometimes it’s real hard when he’s lying in bed and we’re sitting there and there’s nothing I can do,” she said.

When Terry’s elbow joint begins bleeding, the joint sometimes locks in place and aches, making it impossible for him to feed himself.

His joints can also bleed if he does something as harmless as sleep on the floor.

This year he has missed about one-third of school. The illness has caused him to drop back two grades, and he is now in the 4th grade at Walker Upper Elementary School.

Terry’s condition has made life difficult for his sister Sherry, too. Some students at her school, Walker Junior High, have “turned their noses up” at her after learning that her brother has the AIDS virus.

It hasn’t always been easy, but the 13-year-old girl has come to a simple philosophy about the experience. “I don’t need friends like that,” she said.

“When I first found out he had HIV, it was hard,” she said, adding that with time she has come to terms with the illness.

Hemophilia has put a financial burden on the family. The Chisholms had to drop their private insurance in 1988, since they couldn’t afford the $700 per month policy.

Terry is now covered by the government’s Medicaid program, which pays for his Factor VIII through the state’s hemophilia program.

Terry is one of about 250 Louisiana hemophiliacs enrolled in the program. The program helps about 150 hemophiliacs each year buy Factor VIII, which costs an average of about $9,300 per patient each year, said Joann Patin, the program coordinator.
Terry Chisholm, left, a victim of hemophilia, is helped by his mother, Paula Chisholm, as he takes a blood-clotting protein called Factor VIII. The medicine helps Terry’s blood coagulate. His brother, Brandon, watches.