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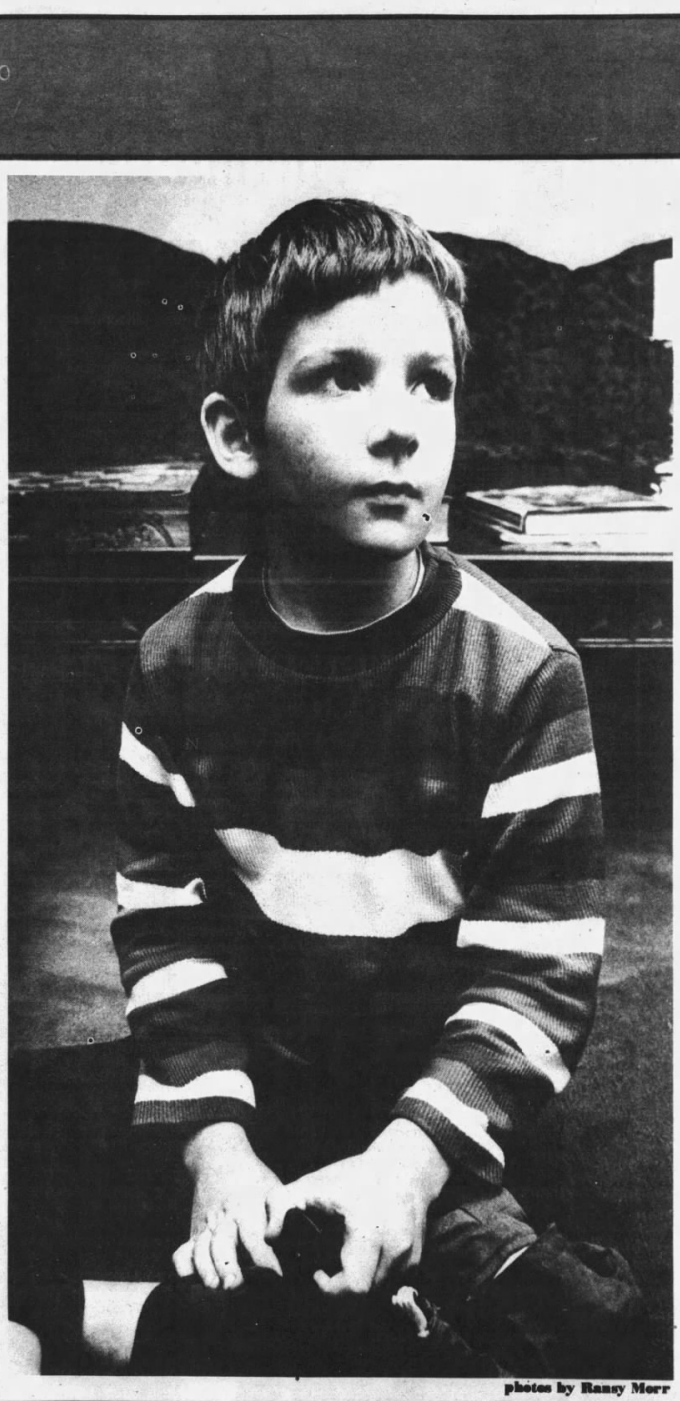

ERIC

He Lives With Hemophilia

by Tina Jeffrey

A seven-year-old dreams of neighborhood football games and rough-housing with his friends, but Eric Howell's dreams must be less rambunctious. One of 25,000 serious hemophiliacs in the United States, his smallest bump can cause a bleed. Still, despite his limitations, Eric is growing and progressing as a normal seven-year-old, just a little more quietly.

photos by Ranny Merr

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Mr. and Mrs. Arthur J. Howell of Newport News worried because their baby boy, Eric, seemed to bruise easily. The pediatrician tried to reassure the parents and said it might be because the child was very fair-skinned.

But Nancy Howell kept asking why, and the doctor tested the infant for anemia. The report was negative. Finally at nine months, Eric underwent comprehensive tests. The verdict stunned both parents: Eric has hemophilia, a deficiency of a blood-clotting agent.

Although the disease is transmitted from mother to child, as far as Mrs. Howell knows, there has never been a case of hemophilia in her family. Doctors say it's possible there could have been a mutation in her genes, producing the X chromosome which caused hemophilia in Eric.

The next few years were harrowing. Like more than 60 per cent of this country's hemophilia victims, Eric was treated by doctors who had no other hemophilia patients. Not until much later did his parents learn there is a National Hemophilia Foundation, and that there is a large hemophilia center little more than an hour's drive away, at Medical College of Virginia in Richmond, where specialists in the disease conduct monthly clinics.

Meanwhile they had raced to hospital emergency rooms time after time when Eric had a bleed, and "it was not unusual to run up a bill of $100 a visit," says Mrs. Howell. Once the child was put in a strait jacket while an inexperienced doctor jabbed him repeatedly, trying to find the baby's vein.

The Howells learned mostly by trial and error how to recognize when Eric is bleeding internally, and what to do for him to lessen the hurt. Blood seeping into a joint will cause pain, so at the first sign of Eric limping or favoring an elbow or ankle, they immobilize him to keep the joint straight. If it fills with blood and swells in a bent position, painful traction or plaster casts are necessary to straighten out the little limb.

The smallest thing can trigger a bleed. One Christmas the young man was gnawing on a candy cane when the sharp edge punctured a place in his gum. He was in the hospital for 11 days afterward, as medical personnel sought to stop the bleeding, and the bill ran to $2300.

Conversely, the seven-year-old is now in the process of losing baby teeth, and the other day pulled a tooth with no bleeding at all.

In 1972, the Howells began taking the child to Richmond to the hemophilia center. The revolutionary new treatment of injecting Factor VIII cryogenic compound into his veins to combat a bleed was begun. Somehow, it did not seem to help the little boy, and his mother began to suspect that something else was causing a problem. Two years ago, MCV doctors discovered that Eric's antibodies, the substances which normally fight dangerous infections, were working against the blood product, much as the body rejects a new heart in a transplant operation. When the cryogenic was placed in Eric's blood to promote clotting, the body defenses rejected it.

So the new weapon in the fight against hemophilia is powerless to help Eric, at least for the time being. The hope for the future is that the present antibody action against Factor VIII and Factor IX will weaken and permit his system to accept the much-needed treatment in dire emergency.

"I guess I'm overprotective with Eric," his

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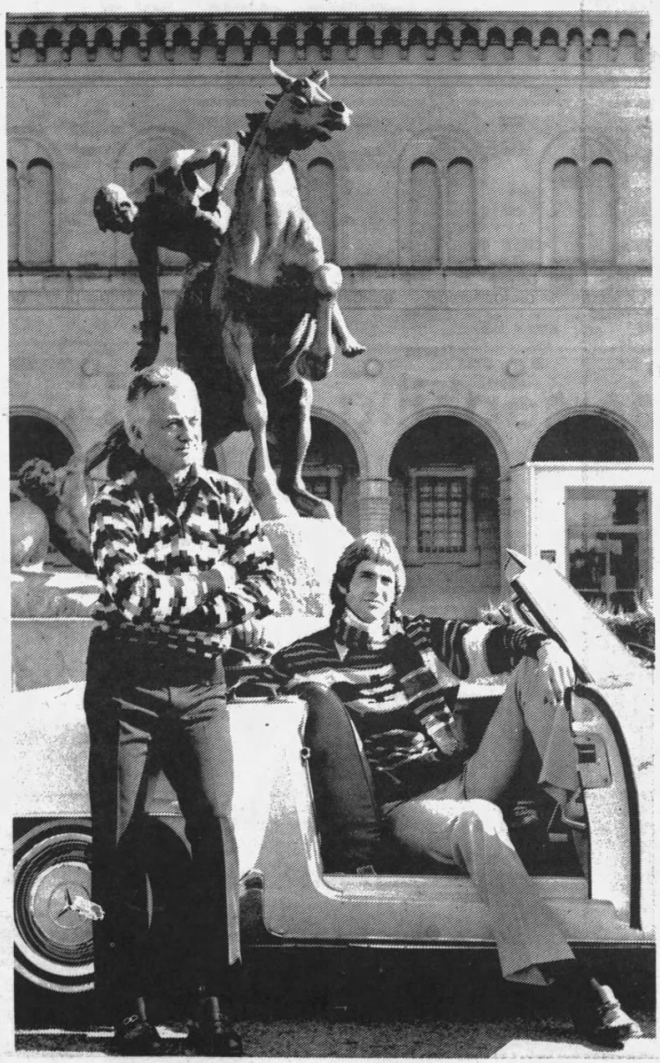

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Eric

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mother declares, "but I can't not be, because one more serious episode might mean the end. If he could take the cryogenic it would be different but he doesn't have that protection."

Jay Howell has major medical insurance at his job at Newport News Shipbuilding, and it has been a help with Eric's bills. Her Blue Cross helps some too. But still it's not enough.

Eric Howell gleefully shows his parents the hole where a tooth used to be. Fortunately, the tooth came out with no bleeding at all.

The emotional load on Eric's parents is something else. The only way they can endure the trauma of Eric's hemophilia is with strong faith in God's will, and by living one day at a time.

There are good days and bad days, sighs Nancy Howell. They can pretty well count on Eric suffering a bleed at least once a month — sometimes once a week, depending on how hard he plays. He doesn't have to be bumped to bleed; it can be spontaneous from over-excitement. That means they can generally expect trouble around holidays, like Halloween, Thanksgiving, Christmas, Easter, etc.

"We try to stay cheerful," says Jay Howell, "and not dwell on the bad times. It is a strain, though."

"It really gets to you when your child is crying with pain and there's nothing you can really do," adds Nancy Howell. "We know that the bleeds into his joints eventually will cripple him."

Meanwhile Eric is growing and progressing in mind and body at Palmer Elementary School, where he is a second grader. He has a wheelchair at school he can use if necessary.

Mrs. Howell works part-time for the law firm of Drucker and Diamonstein. She was instrumental in calling to Del. Alan Diamonstein's attention the financial plight of hemophilia parents and Diamonstein was successful in getting a state law passed giving some state aid to hemophiliacs. She used to work more hours than she does now, but her longtime baby-sitter moved away and she feels she cannot ask someone else to babysit a hemophiliac child. She serves on the board of trustees of the United Virginia chapter of the National Hemophilia Foundation, composed of parents and friends of hemophiliacs, who are observing this month as Hemophilia Month in Virginia.

Favoring a foot he hurt at school, Eric hitches a ride across the lawn in his dad's arms.

Hemophilia A Little Understood Disease

by Tina Jeffrey

A lot of people have mistaken ideas about hemophilia. They know it has something to do with bleeding but they're not aware that it is a disease which can usually be controlled.

So says Dr. Nancy B. McWilliams, head of the pediatric hemophilia department at Medical College of Virginia (MCV), Richmond, and she is enthusiastic about new treatment methods, and the new outlook for hemophiliacs' health and well-being.

Hemophilia is one of the world's least-understood diseases. People know that a patient with the ailment has a deficiency in blood-clotting ability. Mistakenly, they believe that a cut or scratch can cause the victim to bleed to death, but actually, visible wounds are not as serious as the hidden ones. Internal bleeding, set off by a fall or bump, can spill blood into muscles or joints, where it accumulates and destroys tissues. In the past, degeneration of joints caused by bleeding has disabled many hemophiliacs before they reached their teens, and a few have died of blood loss which could not be reached or stopped. Frequent hospital stays to replace blood or the deficient clotting factor and to heal joints have been the rule.

Today, however, there is fresh hope for youngsters who have this disease.

In the 1960s a way was discovered to separate the clotting substance, Factor VIII, from blood to freeze dry into a cryoprecipitate for treatment in concentrated form. Now this substance can be kept in home refrigerators so the patient, at the first sign of bleeding or discomfort in a joint, can get an injection, self-administered or by a parent.

"Some parents are scared and reluctant about giving a child an infusion; they don't want to put a needle in his arm. But it doesn't take an MD degree to start an intravenous infusion, it takes skill and practice," says Dr. McWilliams. "We let parents practice on us and on each other and they rapidly become very good at it. The parents are taught to treat at the first sign of a problem and not to wait until a joint swells."

With the home-infusion plan, real emergencies are headed off for hemophiliacs, and when managed properly, things seldom get to the point where a child has to take painkillers, she adds.

Hemophilia is not a common disease — it occurs in about one out of every 10,000 males and is one which is transmitted by the mother to half her sons through the laws of genetics, Dr. McWilliams points out.

"If her sons get her X chromosome which has the hemophilia gene on it, they will have the disease. But her other X chromosome is unaffected, so it's possible she could have a normal son."

Traditionally, hemophilia, if present, will show up in the male child during his first nine months of life. For some, it appears after circumcision, though not all. If there is a family history of hemophilia, doctors strongly advise

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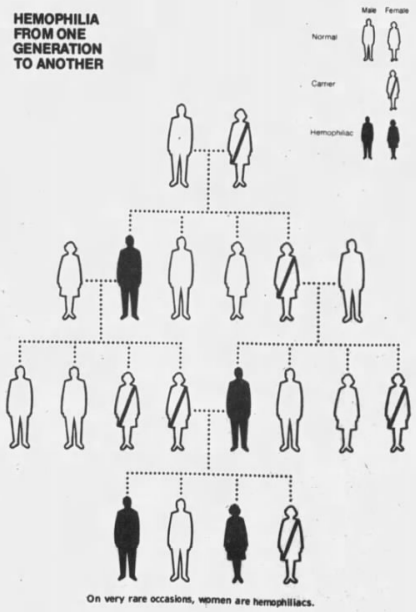

On very rare occasions, women are hemophiliacs.

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Hemophilia

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against circumcision. Parents usually notice that the hemophiliac baby bruises very easily and they seek medical attention.

Raising a hemophiliac child brings special problems. At the toddler stage, they fall and hurt themselves, and Dr. McWilliams recommends they wear a helmet until they're steady on their pins. The biggest danger for a hemophiliac is a bleed into the brain, but the major problem is bleeding into joints, mainly the knees, elbows and ankles. Once there is blood in the joint, there is some damage done.

Many older hemophiliacs grew up in an era before there was any satisfactory treatment, and are now in wheelchairs, on crutches or are very crippled, says Dr. McWilliams. The weaker a joint becomes, the more it bleeds, so it becomes a vicious cycle. The aim of today's treatment is to prevent the devastating complications to the joints, she adds.

Management of the hemophiliac child involves the care of a hemotologist, an orthopedist, a physical therapist, and a dentist, all trained to work with these patients.

"We encourage a healthy sports program for children with hemophilia," Dr. McWilliams notes, "with emphasis on swimming, fishing, golf, or track and tennis if the joints are up to it. Contact sports like football are out, but with judicious use of helmets, we allow them to play baseball. We encourage physical therapy to get muscles back in shape.

"Hemophiliacs are not sick people. They are not more susceptible to infections and their general health is good. Most children get to know their limitations .

"We tell teenagers with hemophilia they have to be rational about their decisions for a career — hard manual labor is not in the picture for them. If they're going to seek a trade, it must be something they do primarily with their hands...computer programming, watchmaking, etc. It's tough sometimes for these kids to get jobs, due to the ignorance of employers who're afraid they may bleed to death on the job. Hemophiliacs are people who really need a break in life, that's for sure."

It costs between $10,000 and $20,000 a year to treat a hemophiliac, according to Dr. McWilliams. It is a very, very costly disease and is no respector of race or socioeconomic group.

"One of the major deterrents in the past to adequate treatment has been that patients have rolled up such huge bills at hospitals that they're reluctant to go back."

Virginia has some funds through the Bureau of Crippled Children to help families of hemophiliacs. Some of these are matched by federal funds, but there's not enough for everybody, she says.

The hemophilia center at MCV would like to know about patients throughout the state, from their physicians or public health people, according to Dr. McWilliams. More than 60 per cent of all the country's 25,000 serious hemophiliacs are under the care of doctors who have only one patient with the disease, and she thinks the center at Richmond or the other at Charlottesville could offer additional evaluation and help.

Research is constantly going on to find new ways to help hemophiliacs. Right now there's a thrust to discover a foolproof test to detect carriers of the disease. In a family with a history of hemophilia, such a test could determine whether sisters of hemophiliac males would be able to pass the disease to their children. So far, this type of test has not been developed.

Dr. Nancy B. McWilliams, head of the pediatric hemophilia department at MCV, is enthusiastic about the outlook for hemophiliacs' health and well-being.

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