

Life & Times

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Hoping for a miracle

AIDS victim, 13, tries not to think about illness

By John Norberg

Journal and Courier

Jeanne White has loved and nursed her 13-year-old son Ryan through countless medical problems and fears.

Now she says the very substance that's kept her hemophiliac son alive is killing him.

White has filed a \$2 million lawsuit in Lafayette federal court charging that her son contracted Acquired Immune Deficiency Syndrome — AIDS — from the blood-clotting agent Hemofil, manufactured and distributed by Hyland Therapeutics Division of Travenol Laboratories.

The mother and son who live in

Kokomo were in Lafayette Thursday in the office of their attorney, Charles Vaughan.

Ryan, a slight young man brought down to 59 pounds by his sicknesses, sat quietly through the afternoon. He said he'd rather not think about it all.

He's smart and his favorite subjects are math and history. But he hasn't been able to go to school since Dec. 7. He stays at home instead, and watches cartoons and the soap operas, plays video games on his Commodore and makes believe with G.I. Joe toys.

Five months ago this was the last thing the Whites expected.

They can hardly believe it's happened.

"Did I believe it when they told me?" Mrs. White said. "No. I just thought, well the next test won't show that. It

will be different."

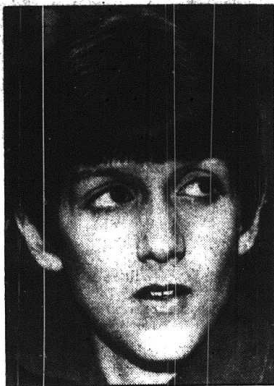
But it wasn't.

AIDS is a breakdown in the body's immune system. It is considered fatal, but Ryan, like many victims, believes he might be able to beat the odds.

It all started last December when Ryan became sick, to the point where he could hardly breathe. He was first checked in to Howard Community Hospital in Kokomo and then to intensive care at Riley Children's Hospital in Indianapolis.

"They told me they were afraid he might not live two or three days," Mrs. White said. "They thought it was AIDS. On Dec. 17 they told us they were sure it was AIDS."

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By Tom Campbell

RYAN WHITE: This Kokomo boy is fighting a new illness, AIDS, that seems to have been brought on by treatment for his hemophilia.

AIDS victim

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Hemophiliacs are considered a high risk group for contracting AIDS because of the transfusions they require to produce blood clotting. Twice a week, all Ryan's life, his mother has given him Hemofil intravenously.

Ryan first was given the then-experimental medication soon after he was born.

Mrs. White knew her son was in an AIDS high risk group. But she said the number of hemophiliacs contracting AIDS was still small.

"They said it was less than 1 percent," she said. "I thought, gosh, less than 1 percent, that's hardly anybody. And around here, no one's got it. I just figured the good Lord would take care of him. I didn't figure something that was helping him all these years could be killing him."

By Christmas, she knew differently. Doctors wanted her to tell Ryan on Christmas Eve, because they feared the diagnosis would leak to the news media. But she waited until Dec. 26.

"He was still in intensive care but the tubes were out of his nose and throat," Mrs. White said. "He took it real well. Me and the preacher went in and told him. The one thing he asked, he said, 'Does Laura know?' Laura is a nurse who volunteered to take care of him.

"That's all he wanted to know. Everybody thought he wasn't accepting it. I said, 'Ryan, you can't pretend that you don't have it.' He said, 'I want to pretend.'

"Then my little girl (Andrea, 11) said, 'Mom, you don't understand. He just doesn't want, everytime someone enters his room, to talk about dying.'"

Ryan was released from the hospital Jan. 17. He still doesn't like to talk about this. He mostly answers questions "yes," or "no."

"Yes," he knew about AIDS before he got it. He'd heard about it on the news. "Yes," he misses school. "Yes," his friends come and see him. "No," he tries not to think about it.

The family hopes for miracles.

"I hope they come up with something," Mrs. White said. "I know it's pretty far on down the road, but you've got to have something to hope for. You can't just think there's an end. You've got to have hope. I hope he'll be able to cope for as long as possible.

"You've got to be strong. You have to make the best of it. When he's feeling good he doesn't think about it."

But one recent night he had a problem. "In the middle of the night he was really worried," Mrs. White said. "He said, 'Mom, I'm scared.'"

That has been the only time.

Mrs. White isn't angry at the company that produces Hemofil from blood donations. Ryan still takes the treatments.

"You see it dripping into him and you want to rip it out," she said. "But it's what's saving him too. There's nothing we can do about it."

If she's mad at anyone, it's the homosexual community where AIDS first spread in the United States.

"I'm not mad at them," Mrs. White said. "But if it wasn't for them, Ryan wouldn't have AIDS, so it's kind of hard to meet one, you know. I wouldn't be nasty to them, but I would try to avoid them. I might be nasty to them and not realize it.

"The hemophiliacs who get it, and people like the Lafayette woman (Amy Sloan), they're just so innocent. I think, 'Why Ryan?' But you just have to lift up your head and go on.

"Cry? Oh yeah, I get sad days. When he was down there in intensive care I cried a lot. But every time I went through the door to see him, I would get my chin up. I would not ever let him see me down.

"All we can do is hope we can handle each problem that comes along. You just have to hope they can find something."