

Individuals with Tourette syndrome struggle daily with uncontrollable twitches, vocal outbursts and painful social embarrassment: Parade 8/19/82

'Why Is This Happening?'

IN APRIL 1982, JIM EISENREICH was a 23-year-old rookie center fielder with the Minnesota Twins. Savvy baseball people predicted he'd be a star. For the first month of the season, he more than lived up to expectations, batting over .300. But then his career came to an abrupt halt.

Ever since he was a child, Eisenreich had suffered from bodily and vocal tics. He'd come to accept them as a part of himself and didn't let them stand in his way. But this time was different.

"We were playing in Boston," he recalls, "and I had to leave the game in the sixth inning. That day, the tics were pretty bad. The next day, I left the game in the third inning, and the day after that, I left in the second inning. My tics were so bad, they caused me to hyperventilate.

"Playing in the majors was a dream come true, but I became self-conscious in front of 30,000 people. I was so embarrassed by what was happening that I thought, 'I don't want to be here.'"

Eisenreich spent most of 1982 on the disabled list, while numerous doctors attempted to determine what was wrong with him. By season's end, he had a diagnosis: Tourette syndrome.

"I'd never heard of it before, but I was relieved when they put a name to what I had," he says. "I thought, 'It's okay. I'm not the only one.' I'd always felt I was. I had dreamed I'd be cured. I just wanted to be able to live a halfway normal life. And I never gave up hope that I would."

More than 200,000 people in the U.S., or one in 1000, have Tourette syndrome, a neurological disorder—but most of them do not learn its name until mid-adulthood. The condition is characterized by multiple muscle tics (eye blinking, head jerking, facial grimaces) and at least one vocal tic (throat-clearing, barking noises, sniffing, cursing).

The men and women who suffer from Tourette are perfectly normal and, in fact, often highly intelligent and creative. Yet the symptoms of the disorder can make them appear inappropriate, weird or even mentally disturbed to those around them. "It's very unacceptable socially, because we do such strange things," says Eisenreich. "But people with Tourette can't help themselves."

There's no cure for the disorder, though now its symptoms often can be controlled by medication. Some people with Tourette prefer not to deal with the ridicule and disgust their behavior can provoke,



Jim Eisenreich with wife, Leann, and their 15-month-old daughter, Lauren.

and choose to be loners, even recluses. But for those who want to be engaged in the world, the social terrors that must be overcome may be the toughest challenge.

"Tourette is probably the most misdiagnosed childhood disorder," says Alan Levitt, president of the Tourette Syndrome Association (TSA) chapter in greater Washington, D.C. "It was long thought to be a psychiatric problem. It is not. It is a physical disorder, genetic in origin, and each case is different. Tourette affects three times as many boys as girls. The tics, which can be mild, come and go and change over time, and they can make life miserable."

Jim Eisenreich, a quiet and soft-spoken man, was born and raised in St. Cloud, Minn., one of five children and the only one in his family with Tourette. He developed the first signs at age 7. "I began blinking my eyes very hard, and

"I was relieved when they put a name to what I had," says Jim Eisenreich of the Kansas City Royals. "I thought, 'It's okay. I'm not the only one.'"

I couldn't stop," he remembers. "After a while that subsided, and I got vocal tics. Mostly, I would grunt and clear my throat. Next, my head and neck began to jerk. It seemed that as soon as one tic stopped, another one came right along."

"When I played Little League ball, the kids on the other teams would shake the fences in front of the dugouts and call me names," he adds. "I was lucky that I was a good athlete. Kids wanted me on their team. The tics weren't as bad when I played. I could concentrate on the field. I was at peace playing ball."

"When there's mental focus, the tics seem to go away," explains Sue Levi, who is a liaison for medical and scientific programs at TSA's national headquarters in Bayside, N.Y. "We don't know why. But there's a surgeon who has hand tics that disappear in the operating room."

If life was a bit easier for Eisenreich on the playing field, it was difficult in other areas. "I didn't date in high school or college," he says. "I wanted to, but I didn't feel anybody was interested in me."

It took 30 years for Susan Conners, 44, a French teacher, to receive a diagnosis of Tourette syndrome. Unlike Eisenreich, Conners' first motor tics—sniffing, blinking, whistling sounds—did not seem that peculiar: Her mother and all five brothers and sisters have the disorder. "We never knew what we had," she says, "though we knew we had the same thing. But my case is the most severe."

Conners, who grew up in Malone, N.Y., near the Canadian border, didn't get involved in many school activities because it was too difficult or embarrassing. "Fortunately," she says, "I had a good circle of friends who accepted me as I was."

"I was determined to become a teacher," she adds. "I had decided that I was not going to be known as the person who twitches all the time. But a lot of people thought I was crazy to teach because of my 'nerves.'" (The symptoms of Tourette have nothing to do with nerves, says Alan Levitt, although he points out that any of life's emotions can make them worse.)

Conners has been teaching at Mill Middle School, near Buffalo, for 23 years. "I was the most dynamite student teacher the school had ever seen," she says. "So, when one French teacher left, they hired me without an interview. It was a great relief, because interviews are a nightmare. The students are mostly very good about my Tourette. I find that dealing with it openly is the best way to handle it."

Still, she can recall many painful in-

B Y S H E R Y L F L A T O W

cidents. "When I had been teaching for only a couple of years, I caught a student standing in front of the class imitating me," she says. "It was devastating. This was before I knew what was wrong with me. Last year, I was asked to leave a performance of *Phantom of the Opera* in Toronto because I was annoying too many people. I'm stared at wherever I go, which is the most difficult thing to endure."

Over the years, both Conners and Eisenreich saw many doctors who were baffled by their symptoms. One doctor suggested that Conners had epilepsy. Eisenreich was told he was hyperactive and given Valium. Doctors ruled out Tourette, because he didn't have involuntary swearing, or coprolalia. "For many years, the medical profession mistakenly believed it could not give a diagnosis of Tourette to anyone who did not curse," Sue Levi explains.

Once diagnosed, Eisenreich was put on a drug called Haldol, one of several medications that can be prescribed for Tourette. It took him about four years to find the right dosage, but the medication has helped keep the tics under control. In Conners' case, however, Haldol led to depression and weight gain. "I've always been a very upbeat, happy-go-lucky person," she says, "and it was like a window shade had come down over my life. So I struggle along until I can find something that I can tolerate and is effective."

With or without medication, most people with Tourette find that their symptoms lessen to varying degrees with age. That, however, has not been true for Conners, whose tics have worsened. "I didn't have a problem with swearing until I was in my late 20s," she says. "I can control the swearing in my classroom. I swallow the words or turn to the blackboard and whisper them. I can suppress some of my tics for short periods of time during the day, but eventually I need to release them."

Conners' problem is compounded by obsessive/compulsive behavior, which is common to many people with Tourette syndrome. "I'd be in the middle of something, and I'd have to stop and count to 25 in my head," she explains. "These days, I have to touch the center of every doorknob before I leave my house. I have a lot of checking rituals. They interfere with whatever I'm trying to do."

It wasn't until she was 36 that Conners learned what was wrong with her—from a TV doctor and an article in *PARADE* (Oct. 15, 1978). "There was an episode of *Quincy* that dealt with Tourette," she recalls. "At about the same time, *PARADE* ran an article about it. I contacted the Tourette Syndrome Association, and they sent me information and a referral list of doctors. I knew immediately that's what I had."

Four years after Eisenreich got a name for what he had, he still was on the voluntary retired list. "In the fall of 1986, I asked the Twins for my release," he says. "I thought that some other team might be interested in me." The Kansas City

Royals purchased his contract for \$1.

He did not do well when he returned to the majors in 1987, and the following season was even worse. But Kansas City did not lose faith in him. Eisenreich rewarded that faith in 1989. He led the Royals in hitting with a .293 average and was voted the team's most valuable player. Last season, he hit .301—his highest average so far—and he's batting .271 at this writing. But he is far prouder of what has happened to his personal life. "I got married in 1990," he says, "and I became a father last year."

Lauren Nicole was born on May 26, 1991. "Leann and I discussed the possibility that our kids could get Tourette," Eisenreich says. "But that wasn't going to stop us from having children. You hope and pray that your daughter doesn't have it. But we know what to look for. If she does develop Tourette, we'll be able to help right away."

Eisenreich and his wife are actively involved in spreading awareness about Tourette syndrome. He often speaks to children with the disorder. "The question kids ask most is, 'How do you handle it when the other kids give you a hard time?'" he says. "I tell them, 'You have to explain why you do what you do. Hopefully, they'll understand and won't bug you anymore.' I also tell them to try not to let it bother them. But I know it's much easier said than done. Kids can be very cruel."

Conners runs support groups and frequently can be found in schools. "The minute someone's diagnosed and I find out, I offer my services," she says. "And when I speak to the teachers, they begin to believe that maybe the kid really can't help his or her tics. I've got letters from kids that can break your heart. They thank me for coming to their school and tell me how much better things are for them. Last year, one eighth-grader with Tourette received the Student of the Year award. He invited me to the ceremony, and I cried."

"I decided many years ago that whatever I had would not stop me from doing what I want to do," she adds. "I admit there are times when I think, 'I would like to not have Tourette for 10 minutes of my life—10 minutes where I could sit in my chair like a normal person.' I would be lying if I didn't say it was difficult. But I think it's made me a stronger person, a more tolerant person, a more empathetic person."

Says Eisenreich, "I believe that God never gives you anything you can't handle. There were some bad times in 1982 and '83, but I look at it in a positive way: I was finally getting help. A lot of people say, 'But your career was put on hold.' So what? A career can stop anytime. I'm not stuck on my career. If Tourette syndrome is the worst thing that I get in my life, I'd say I've been pretty lucky."

For more information, write: Tourette Syndrome Association, Dept. P, 42-40 Bell Blvd., Bayside, N.Y. 11361.