Cheese and Crackers

You can take the boy out of small-town Virginia...but when that boy is Shawn Decker, living with hemophilia and HIV, don't even try to take away anything else

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One night back in February, down at the local bowling alley, Shawn Decker was trying to nail his strikes and spares. Usually he plays well and gets a lot out of it. A 200-plus bowling score means more to him than a 200-plus T-cell count. "When the scores are high, I feel good," he says. But that evening, even they were slumping. That whole winter, in fact, he'd been bored and frustrated, spending more time holed up in his room, curled over a keyboard, than out and about with friends. "I had become something I didn't like, and I didn't even know the cause," he says.

He had turned reclusive once before. In 1987, toward the end of sixth grade, Shawn, who has hemophilia, also tested HIV positive. He acquired the virus from the clotting factor used to halt his frequent nosebleeds. Soon after, his school -- located in Waynesboro, Virginia, a town of 16,000 about 115 miles southwest of D.C. -- kicked him out. "I just ate pudding and watched TV for a month," he says.

For nine years after, Shawn rarely spoke to anyone about being positive. One year, he told his mother not to even bring it up around him. But after getting home from the bowling alley last February, Shawn had a revelation. He won't call it a decision. "A decision implies thought and reason," he says. "I just knew I had to do something besides bowl."

What he did was much more than edge his way out. In March, he put his story up on the Internet, where it became one of the few home pages on the Web devoted to HIV. Now a blossoming writer, Shawn created "My Pet Virus" -- address mypetvirus.com -- a compendium of his unique approach to life, his goofball jokes and his varied twentysomething interests. "My Pet Virus" opens with a main section centered on HIV issues, where Shawn holds forth on topics like safer-sex education: "I think instead of telling people, 'You'll die if you don't use a condom,' they should say, 'You might become HIV positive, thus subjecting yourself to endless amounts of ignorance and stupidity.'"

On the contrast between being HIV positive and having AIDS: "It's the difference between a mosquito bite and a shark bite."

And on his own experience with "Just Say No": "I've never smoked marijuana anyway, because I was always afraid it would lead to harsher drugs, like AZT."

The website's an appealing, fun introduction to his Waynesboro worldview. More important, it's drawn Shawn, now 21, out of his funk. About the same time he started "My Pet Virus," he joined an HIV support group and, for the first time, met other people with the virus. Then he e-mailed a letter to *POZ*, which invited him to visit New York City last summer. That's how I got to meet him.

At an upscale diner in the Flatiron district, Shawn's eating a grilled cheese -- an important element of what he calls his "12-year-old's diet" of pizza, milk, doughnut holes and peanut butter on Wonder Bread. One of his favorite foods, cheese is also one of his favorite words. It's a term he slaps on everything from the times he couldn't work up the courage to tell a girlfriend he was positive to the school superintendent responsible for expelling him.

"*Cheese* is lame, pointless, trite. I can just about describe anything with the word *cheese*," he says, giving his first-ever interview since deciding to open up about his life. He's not nervous, and he's not shy. Before I know it, Shawn strikes up a conversation with the woman at the next table and bonds with her over childhood memories of accidentally killing pet goldfish.

It's a typical scene. Shawn takes in Manhattan easily, with a warm, sure smile and a gentle, understated attitude. At the opening of the new Chanel store on East 57th Street, he doesn't bat an eye when Karl Lagerfeld and his latest six foot supermodel saunter by. And while I'm waiting in line at the bar, worrying if he's retreated to a corner, he's making more new friends. Nerves do hit him the next day when he heads out to tackle yet another first, speaking on a panel. It's called "HIV and Dating," one of many panels during the *POZ* Life Expo at Manhattan's Jacob Javits Center. Not surprisingly, he gamely holds his own against the other two speakers.

It's the same story later in the week at Squeezebox, the late-night rock 'n' roll drag club, where an over-the-top band -- complete with a clown on stilts, a headbanger with a blowtorch and naked dancers covered with various dripping condiments -- are performing. "Cool," he says, unfazed.

During the four days we hung out together, Shawn was all about positive enthusiasm. Admirably focused on the present, he tells me about his past with an outrageous matter-of-factness. While I'm shocked at how trying the first two decades of his life seem, he refuses to dramatize it. Even in "My Pet Virus," Shawn doesn't dwell on the details of his medical history, which is full of tenacious physical battles and countless hospital visits.

It was only after I called and spoke with his mother that I got a feel for the whole 411.

A tough, outspoken woman who works as a real estate appraiser, Pam Decker is the activist in the family. (Shawn's father is an alcoholic-beverage control [ABC] agent for the state of Virginia; his older brother, Kip, is a chemist at Merck & Co. who happens to be working on the protease inhibitor Crixivan.) Pam Decker's the one who captained the battle to get Shawn back in school after he was kicked out. She's geared up to help lobby for congressional passage of the Ricky Ray Hemophilia Relief Fund Act, which would provide monetary reparations from the blood industry for infected people with hemophilia -- what one might call "blood money."

And Pam's the one who tells me about Shawn's first hemorrhage, the result of his circumcision.

Eighteen months later, he hemorrhaged again, from a swollen knee. “They told us he would never walk. All kinds of good stuff,” Pam says, her voice both spirited and daunting. When Shawn was finally diagnosed with hemophilia at age two, Pam became all-out protective. “I tried to design a house with no edges, a hemorrhage-proof house,” she says. “You haven’t lived until you’ve seen foam-rubber trucks.”

The clotting factor gave him hepatitis B at age four. “He couldn’t eat anything. He went into a coma,” says Pam. For a while, doctors didn’t think he’d make it.

“Mom tells me my brother said, ’You know, Shawn would be better off dead. You guys don’t let him do anything. You don’t let him just be a boy,’” Shawn says. “And from that point on, I just got to do whatever.”

After he recovered, Shawn parlayed his newfound freedom from foam trucks into baseball. “He was also into punt-pass-and-kick. He ran and kicked the ball and hemorrhaged his ankle,” Pam says. “I made this vow that I’d let him live if God did, and that’s one vow I haven’t broken.” Not even after two neighborhood boys repeatedly banged Shawn’s head against the sidewalk to see how easy it would be for the hemophilic second-grader across the street to bleed to death.

His first HIV-related symptom -- shingles over almost every inch of his body -- hit in 1984, ending a five-year respite from serious illness. After he got well, his parents took Shawn to a clinic across the North Carolina border for what Pam calls “a poor man’s AIDS test.” Shawn wasn’t told that he had tested positive. So when a year later he had surgery that dramatically reduced the number of his nosebleeds, “that was kind of like a cure for hemophilia,” he says. “That was one of the coolest things.”

Pam, then the secretary of the local chapter of the National Hemophilia Foundation, says the elation didn’t last long. “In 1986, Shawn started to lose weight. He started to have memory loss. He had sore throats that we just couldn’t get rid of.” Soon after, she had him tested in Virginia, and when that test also came back positive, she informed the school. He was immediately expelled. Not only did he miss the last three weeks of classes, he was forced to sit alone in the cafeteria during his elementary-school graduation ceremony.

Through it all, Shawn didn’t even know why he had been expelled. “I guess I thought it was because of a fight I got in that year,” he says. Later that summer, his parents told him he had the virus, but mistakenly told him he had AIDS.

While Shawn’s parents managed to keep his plight out of the national media spotlight -- then blazing on the Ray brothers in Florida and Ryan White in Indiana -- his anonymity wasn’t protected locally. After fighting the school board and winning reinstatement, Shawn showed up for his first day of seventh grade to find a small convoy of cop cars sitting in the parking lot. “They passed out a red flyer in homeroom saying a student at the school was HIV positive,” he says. On the back was a reprinted editorial that discussed the link between AIDS and hemophilia. Shawn was the only known student with hemophilia at the school. Shawn says everybody made the connection. “I was kind of like, ’That’s cheesy.’”

Despite his mother's urging, Shawn decided not to formally go public. "If I had done that, I probably wouldn't be here right now because of the toll of the stress," he says. "It would have been too hard to be known as 'HIV Positive Boy battling his way through the school system.'"

As it turned out, he made his way through the system pretty normally. He got average grades, dated girls, tested his limits with alcohol and stayed closemouthed. "In eighth grade, a girlfriend I had came up to me crying. Somebody told her, 'Shawn has AIDS,' and I denied it. I wasn't really lying. I was HIV positive. Eventually she found out because I was at her grandmother's, and her dog bit me. I was kind of bleeding out the leg, and her mom called my dad and he told her. I was mad at him, but she didn't wig out about it. I eventually broke up with her because she treated my friends like crap."

The situation repeated itself with his tenth-grade girlfriend. "We'd been going out a couple of months and my mom was putting pressure on me to bring it up. I told her, 'Yeah, yeah, OK, Friday night I'll tell her.' Then we were out having a good time, and I just couldn't do it. It was pretty cheesy. But I wasn't putting her at risk. We never had unprotected sex or anything. My mom ended up talking to her mom about it, but we continued to go out. Then we kind of drifted apart that summer. She didn't call."

As if rejection wasn't enough, a small group of teenagers beat up Shawn and a friend, busting one of Shawn's eardrums. "We took them to court, and we won," Pam says. "I spread the word that next time there would be no police. There would be mountain justice. We'd hire some rednecks, and they would break their legs. That took care of the problem." Pam believes Shawn's HIV status was a factor in the attack. Shawn doesn't. "In a nutshell, we were on the wrong street," he says.

Another night, Shawn pushed his hepatitis-damaged liver too far. "A friend and I went to a dugout with a bottle of vodka and slammed it," he says. "I passed out at a church. I blacked out and spent the night at the hospital. Mom made it a little more dramatic. She said I was in a coma, but I think I was taking a nap. It was a big bummer, with my dad being an ABC agent. That was the final hurrah for my drinking days. It was just a classic bad summer," he says. "I got dumped, jumped and in a drunken slump."

By his senior year though, Shawn bounced back. He was unanimously chosen Homecoming King. He was voted Best Personality. He even started a short-lived band. And at his graduation, he wasn't alone. More than 500 people celebrated with him at the local Moose Lodge.

After the festivities ended, that's when Shawn retreated again. He didn't go to college or get a job. He had another medical scare -- this time hepatitis C. (Pam Decker claims he contracted it from the new, safe factor made from recombinant DNA.) And he gravitated back to his room and his music. Some weekends, he'd journey to nearby Norfolk to visit a few friends there, but he barely saw anyone in Waynesboro. All that was before his Web awakening took place. "We've been lucky," says Pam. "Graduation from high school was our long-term goal. He was never supposed to live that long."

Cruising around "My Pet Virus" is a bit like reading a map of Shawn's passions. He's devoted

untold bytes to the Cure, Nirvana, Seal and Nitzer Ebb. He's committed to his Roland keyboard. "I'm one of those synth dweebs," he writes, including a list of his favorite albums and throwing in the phone number for the Make-a-Wish Foundation, which helped him meet fellow synth dweebs Depeche Mode backstage. "I got something in the mail a couple of weeks ago about these inspirational heal-yourself HIV tapes," he says. "That's what music has done for me."

Elsewhere within "My Pet Virus" are random shots of him with his cats and with his chow dog, Golddust, named after a professional wrestler. There's a list of celebrity crushes that includes a Katarina Witt photo gallery and a paean to Janeane Garofalo.

As the website testifies, his other obsession is boxing. The site features critical comments on loved and unloved contenders. While he jokes that he'd like to become the world's first boxer with hemophilia, so far it's just a spectator sport for him -- although he did recently begin writing for a boxing 'zine called *Heavy Hitters*. The announcement earlier this year that boxer Tommy Morrison is HIV positive also prompted Shawn's decision to speak out. "What affected me was that yet another person was saying that he didn't think it could happen to him," Shawn says. "I was like, 'Man, it's '96.' How much longer can that be said?"

Shawn's wry optimism shows no signs of flagging. If it sometimes seems like a form of denial, undoubtedly it is. Telling me about the time he was attacked, for instance, Shawn didn't even mention that his eardrum had been busted. But a negative word like *denial* hardly describes an outlook that's so obviously working for him. His anger seems to float away. Asking about the class-action lawsuit underway against the companies that sold him infected blood products doesn't provoke a rise. "What am I supposed to do? Wait on the edge of my seat to be compensated for my pain?" he says with only a jab of sarcasm. "It's not that big a deal to me." Listening to him joke that death is only a dirt nap, I see a sense of acceptance. "I don't have a life without hemophilia and HIV. I can't compare it to anything."

Shawn's now been positive at least 14 years, an estimate based on a test of a frozen blood sample from 1982. "I might otherwise be in college. I would probably be engaged to some girl. I would probably be less of a human being," he says.

And like the writer he is, Shawn corked this story himself. He was at the Javits Center, having finished speaking on the *POZ* Life Expo dating panel. We were hugging goodbye when he whipped out a roll of Mentos, the candy that's advertised on TV with commercials offering ludicrously happy endings to silly little problems. He held up the roll like a cheesy spokesmodel and said with a big smile, "My whole life is great now."

It's ironic, and he means it.

Waynesboro World: Shawn in 1990; with brother Kip (clockwise from top left); mom Pam and dad Buddy in 1987; at graduation in 1993; in New York City in 1996; a farm leaguer in 1984; in New York; with prom date Sherrie in 1993.

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