Faith, Hope and Monica

A rural Louisiana woman turns God's country into AIDS country

April 1, 1998 By Benjamin Morrison

It's so good to be in the land of the living. It's so good to be alive."

Monica Johnson sings from memory in a high, strong soprano, a cappella. There will be a choir, piano, organ, saxophone, even congas at the main service later this morning, but this nine o'clock pre-service is for the early birds of Macedonia Baptist Church in Monroe, Louisiana. Johnson has driven the 35 miles from Columbia, where she lives, just as she does every week. She spends Saturday night with a rotating roster of friends, and worships all day Sunday, from early morning Sunday school to the regular service. "Thank you, Lord, for your goodness. It's so good to be alive," sings Johnson, cradling her three-year-old son, Avery, who will soon be too big for his mother's arms. Though Avery is animated outside of church, he knows better than to misbehave during services. Not that the congregation would object: There is a family feel to the 100 people gathered here, marked by the uninhibited calls of "Amen!" in response to Rev. Robby Williams' preaching. The 150,000 residents of Monroe may have awoken to a rare November frost on their car windshields this morning, but the inside of the Macedonia Baptist Church is ablaze with the glory of God.

"I don't believe in atheists," Johnson says when asked about her religious convictions. "Everybody believes in something." Not that her own faith hasn't been tested -- by her HIV infection and the death of her first son, Vaurice, from AIDS. "I admit I questioned the decisions God made," she says, "but my grandmother told me everything happens for a reason, and God's not going to put more on you than you can handle."

Indeed, the white streak that has run along the middle part of her dark hair since childhood can in retrospect be seen as God's hint that hardships were in store for her. "It used to be thinner," Johnson says about her streak, and though she laughs about it, the 33-year-old has earned her recent gray hairs the hard way.

It began with a 1985 letter informing Johnson, who was then attending Monroe's Northeast Louisiana University, that the person whose blood she had received during a hospital stay the previous year had died of AIDS. She shared the news with her mother, and both turned to God to see them through. "For us, it was not a time to cry," she says, "just a praying time." Johnson went in secret to a doctor's office to be tested for HIV. "The results were inconclusive," she says, which at the time she took to mean negative.

Johnson also told her boyfriend, a football player at her university, about the letter. “Neither one of us knew much about HIV then,” she says.

They were married in 1989, settling in Columbia, her husband’s hometown (pop. 900). Johnson was still in school, pursuing a degree in medical technology. To earn some money, she followed in her mother’s schoolteacher footsteps. “I knew the school principal there, and my mother-in-law worked as a teacher’s aide, so I got hired as a substitute teacher, two, three, sometimes five days a week,” she says.

Johnson had spent summers with her husband’s family before their marriage, so she was already connected to a local church -- two churches, actually. Columbia is so small that services were held only once a month at each of the town’s predominantly black Baptist churches. Interestingly, she declined to join either church, splitting her time between the two congregations. “They were my husband’s churches. One of them was his grandmother’s church and the other was his grandfather’s church,” she says. “It just didn’t feel right.”

Neither did her marriage, about which Johnson is stubbornly tight-lipped. “Can’t we leave him out of it?” she asks in response to this reporter’s prying. “We only stayed together for our son,” Johnson adds. “When I found out I was pregnant, I told my obstetrician about the transfusion. She retested me for HIV, and the test came back positive.”

It was a double whammy: Not only did she have to deal with the news of her own serostatus (“Not a big surprise”), but she wrestled with what to do about the baby she was carrying, knowing there was a 25 percent chance she would transmit the virus to her unborn child. “I got advice from a friend who couldn’t have a child,” Johnson says, “and she told me that if there was a chance that her child might be born with HIV, she would take it to have the child.”

So did Johnson. Vaurice was born on April 15, 1990. “We had a crawfish boil the day before, and crawfish was my food when I was pregnant,” Johnson says. “My water broke in the afternoon, but I didn’t tell anyone because I wanted to eat crawfish.” By the time Vaurice was delivered by C-section, it was a few minutes past midnight on Sunday morning -- Easter Sunday, the most important and joyous Christian holiday. To this day, Johnson honors Vaurice on his birthday -- by sending dead flowers to the White House. “I buy a bouquet in March and let them die,” she says. “Then I send them to President Clinton with a note reminding him of all the promises he made that he didn’t keep.”

Johnson’s doctors advised her to wait several months before testing Vaurice for HIV. (More recently, infants at risk of infection are routinely tested three times during their first six months.) Sadly, a test proved unnecessary in Vaurice’s case: He developed thrush at five months. When they were unable to treat it effectively, Vaurice was hospitalized in New Orleans, four hours south of Columbia. “They told me he wouldn’t live to be one year old,” Johnson says. “I cried for days.”

Columbia is the coral-snake capital of Louisiana, but Johnson learned that it breeds other kinds of snakes. Though it is only a 45-minute drive from Monroe down U.S. Highway 165, the distance seems longer, a dark stretch of asphalt interrupted by the garish glow of the cluster of service

stations that defines downtown Columbia. “Local life centers on those seven or eight gas stations,” says Johnson, pointing out that in addition to filling your tank, you can rent a video or get a good meal at most of them. “Our Exxon has very good hamburgers.”

Richard Womack, director of Monroe’s only AIDS service organization, the Greater Ouachita Coalition providing AIDS Resources and Education (GO CARE), describes it as a “one-horse, two-stoplight town,” though Vickie Williams, one of Johnson’s Columbia friends, corrects him: “We got three stoplights now.”

What they didn’t have was HIV -- or so they thought, until word of Monica’s and Vaurice’s diagnoses leaked out: The wrong pair of eyes spotted it on an insurance claim at the local oil company, where her husband was a meter reader. Coworkers refused to work with her husband, so he was laid off (with pay) for three months. Even when he tested HIV negative, he wasn’t allowed back. “The people he worked with said the results didn’t mean anything because we slept together every night,” Johnson says.

Johnson herself was quickly phased out as a substitute teacher. “Columbia Elementary School asked me not to come back. Then I got a lawyer, and I was rehired for a certain while to work at the school-board office -- I couldn’t go to the schools. At the end of that time, they said they never needed me again,” she says. Even her mother-in-law’s job was in jeopardy. “I had lived with her, and often ate at her house.”

Naturally, Johnson turned to her churches in Columbia for support. “They did as much as I expected,” she says, “but I didn’t expect much.”

It was 1991, and Johnson found herself an outcast in her own town, the mother of the first child known to have HIV in a 12-county region. Says Johnson’s friend Cathe Varner, “For it to happen in such a small community, some really bad crap got out.”

When Johnson walked through town with her baby, neighbors would cross the street to avoid them. “I remember going to the post office, and a friend of a friend was talking about me -- and she didn’t even know me,” Johnson says. “When I went to the drugstore to buy medicine, they disinfected the counters behind me.”

Johnson made the most of her time with Vaurice. “I decided to resign from God’s job of deciding when people go and when they stay. And I have this thing about doctors telling you how long someone will live. They’re not God, so they don’t know,” she says. “After that first bout with thrush, Vaurice got better. He was crawling, then starting to walk. Just a little terror.” Determined not to miss a moment with her son, Johnson spent every night of his three-and-a-half-year life with him. “We had birthday parties every month,” she says. But Vaurice only got sicker. “By the time he turned three, I knew he was getting worse. I just didn’t want to see how bad it was.”

“Vaurice was the first child we met with HIV,” says Richard Womack, Vaurice’s case manager at GO CARE. “At that time, he couldn’t walk or talk, but he had this way of doing ’sweet eyes’ -- smiling and sweeping his pupils from side to side -- that was absolutely amazing.”

Womack has become part of Johnson's small army of best buddies. "Her being HIV positive and having lost a son to AIDS is what brought us together, but that's not what keeps us together," he says. Indeed, the bond Johnson feels with her friends suggests that water can sometimes be as thick as blood. "I don't care who you are if I like you," she says, counting Womack and his male lover among her nearest and dearest. Another close friend is Michelle Lopez (*POZ* cover story, August/ September 1996). "Michelle is a black Latina lesbian mother. She and her daughter are HIV positive," says Johnson. "We're good friends."

Directions to Johnson's small, cozy house situated on a dirt road include crossing the Ouachita River, then passing the Exxon station on the right and Jitney Jingle on the left. Inside, a framed portrait of Vaurice dominates the living room, with smaller photos of him lining the hallway. A three-and-a-half-year-old boy is lugging his Barney pillow everywhere, like a security blanket, but it is not the boy whose picture hangs on the wall: Vaurice died in 1993.

Three months later, Avery was born -- to Johnson's younger sister. "I had talked with my sister about her being a surrogate mother for a child for me," Johnson says. When her sister became unexpectedly pregnant, the siblings recalled their earlier discussions, and Johnson decided to adopt her nephew. "We knew my sister was expecting a boy. I actually named him," she says. Johnson says that people often mistake Avery for Vaurice's twin when looking at their photos side by side. "Avery and Vaurice are very similar."

It is ironic that Johnson at last has a support system around her that could help her handle a child with AIDS, when Avery is HIV negative. Her marriage is over, and recently she's begun thinking that her time in Columbia may be over as well, prompting her to check the classifieds every Sunday for a house in Monroe, despite the limited disability income she qualifies for due to her recurring cervical dysplasia. Until recently, Johnson had no telephone. "It came down to having lights or phone," she says.

In addition to friends at GO CARE, Johnson finally found a church she felt comfortable joining -- Macedonia Baptist -- in part because its pastor, Robby Williams, is an old friend from Johnson's days at Louisiana College, a private Baptist school in Central Louisiana. "Everybody in the church knows about my HIV positive status. It's like a real close extended family," says Johnson.

Williams even gave her his blessing to organize HIV support at Macedonia Baptist. "GO CARE was trying to get the churches involved," Johnson says. "We act as buddies for PWAs -- give them a ride to the store, send a card, get them to GO CARE."

This is all a far cry from the standoffishness Johnson met at the Columbia churches. And those congregations were largely African American; the bigotry Johnson encountered from Columbia's white residents was worse. "Monica was the first person most Columbians knew with HIV, and she was black. It was more a racial thing than anything," says friend Vickie Williams. Another friend and neighbor, Susan Duplissey (who is white) agrees. "At the time I got a lot of flack for being friends with Monica and Vaurice," says Duplissey. "I used to bring my children over to their house, and my mother went berserk -- and she works at the hospital."

Johnson’s real-life wrangle with racism and AIDSphobia make her eminently qualified for her position on the National Minority AIDS Council (NMAC) advisory board. “While Vaurice was alive, I didn’t devote my time to organizational stuff. I had things to do for my baby,” Johnson says. But after her son’s death, Johnson became involved with NMAC, a lobbying group that provides technical support for AIDS service organizations nationwide.

According to Johnson, the latest NMAC program in Washington, DC, was a dinner to remember -- and she’s just talking about the menu. Several of her friends have echoed the same line: "Monica *loves* to eat.“ And at the Washington event, her priorities centered on food. Johnson was seated at a table of strangers, arranged by place card. The beautiful woman next to her seemed pleasant enough, but Johnson grew irritated because her companion kept being asked to pose for pictures and sign autographs. ”I was trying to eat, and the interruptions were disturbing me,“ she says. ”Finally I asked someone who she was, and they said, ’Miss America.’"

Besides gourmet meals, her NMAC involvement keeps Johnson up on the latest treatment developments. “I take AZT, 3TC and Crixivan,” says Johnson, whose most recent CD4 count was 800, and her viral load undetectable. She says that the treatment forums she’s attended as an NMAC rep stress early treatment, but this longtime survivor waited more than a dozen years before going the pharmaceutical route. “I was put off because of the tales I heard about horrendous side effects,” she says.

And what side effects has she suffered from her triple combination cocktail? “None,” she says with a smile. Then, without missing a beat, she adds, “I’ve just been blessed.” And when she says it, it sounds like something more than an everyday expression -- it’s a profound declaration of faith.

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