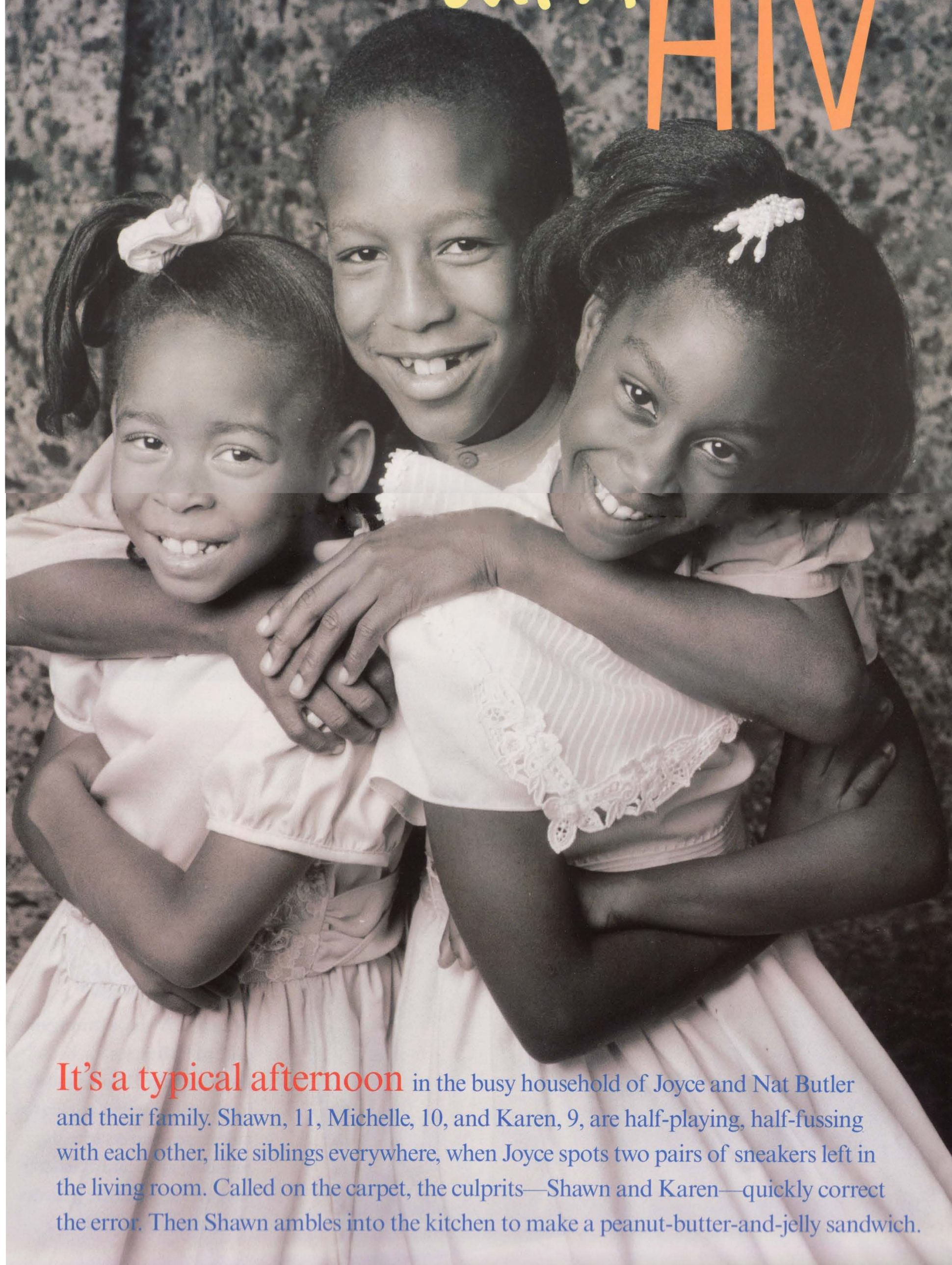


# Growing Up with HIV



**It's a typical afternoon** in the busy household of Joyce and Nat Butler and their family. Shawn, 11, Michelle, 10, and Karen, 9, are half-playing, half-fussing with each other, like siblings everywhere, when Joyce spots two pairs of sneakers left in the living room. Called on the carpet, the culprits—Shawn and Karen—quickly correct the error. Then Shawn ambles into the kitchen to make a peanut-butter-and-jelly sandwich.

A seemingly ordinary scene—but impressions can be deceiving. In reality, the Butlers are not so much an ordinary family as a living miracle, for which every new day is a triumph of love, faith, and dedicated medical care. Shawn, Karen, and Michelle were born of three different biological mothers, all of whom were infected with HIV (two have since died of AIDS). Tests show that Karen is free of HIV, but Shawn and Michelle are not so lucky; both have full-blown AIDS.

Joyce and Nat, already the parents of two grown children (a third died in young adulthood), began this extraordinary odyssey in the late '80s, when they began reading and hearing reports about babies being born with the AIDS virus. Yearning to help, the couple got licensed for foster care through Durham Social Services and requested children with special needs. Soon afterward, one-day-old Karen was brought to them. When they brought her to Duke two weeks later, they learned that she had been born to an HIV-positive mother who was also a habitual cocaine user.

Yet, Joyce says, the shock was quickly soothed by the Duke team's caring attitude. "Coming to Duke was the most enlightening and wonderful experience," Joyce recalls. "They were so attuned to Nat and me. 'You have nothing to fear,' they told us, and that was just what we needed to hear."

For the last few years, infants born to HIV-positive mothers have been given AZT, one of the main drugs used in the war against AIDS. Though Karen was born before this practice began, she, like some other lucky children, did not contract the virus. Explains Duke's Dr. Ross McKinney, head of pediatric infectious diseases at Duke Children's, "Karen had received some of her mother's HIV antibodies, but she never developed any of her own. We had to do a series of cultures on her to make sure she wasn't infected. But by age three, she had no more HIV antibodies, because she was virus-free."

Shawn and Michelle, by contrast, have waged a brave battle against rising tides of the deadly virus in their bodies with help from the Duke Children's team and an arsenal of medications. As if AIDS weren't difficult enough, both children also have other health problems. Michelle has a chronic heart condition that, before the Butlers began caring for her at age 4, was so serious her funeral had already been planned. Shawn, who joined the family at 2½, has severe learning disabilities. Both kids have clearly benefited enormously from

what Joyce sums up as "good nutrition, a good environment, positive people, and love."

The multidisciplinary care the children receive at Duke plays an important role as well. Both Shawn and Michelle visit the Duke Children's pediatric infectious disease clinic regularly. "Our patients are seen by neurologists, gastroenterologists, nutritionists, psychologists, and others," says Dr. McKinney. "It helps patients and families with adaptive strategies."

"The Duke Children's approach really works for us," Joyce agrees. "The team doesn't just treat the child, but the whole family."

While Karen has a reasonably bright outlook these days, the future is less certain for Shawn and Michelle. Neither has been given the latest AIDS therapy—protease inhibitors—because, explains Dr. McKinney, "these drugs must be used in combination with another drug that's new to the patient, and they've exhausted them all." Yet, says Dr. McKinney, kids with HIV are living longer than they used to. "We're taking care of quite a few teenagers," he says. "And the AZT regimen is really turning things around.

If an HIV-positive mother gets AZT during pregnancy and delivery, and the baby then gets it for a few months, there's a 95 percent chance that the child will not become HIV-infected."

For those who do develop AIDS, like Shawn and Michelle, there

is treatment and, if they're lucky, a supportive family environment like that provided by the Butlers, whom Dr. McKinney describes as "incredibly altruistic human beings who enjoy a challenge."

Back at the Butler household, the challenge of giving the children a normal life is one Joyce and Nat have embraced wholeheartedly. The couple has adopted both girls, and adoption proceedings for Shawn are in the works. The kids enjoy activities like drawing, reading, bike-riding, and tree-climbing, as well as a full calendar of family outings and vacations. And while there have been talks about death, "We don't dwell on it," says Joyce. "Life is precious, and we make the most of every day."

As this typical afternoon winds toward evening, Michelle, who has been playing a board game called "The Game of Life" with Shawn and Karen, comes in to give Joyce a hug and ask her what's for dinner. She gets a warm hug back and one of her favorite answers: ribs and mashed potatoes. "Mama, are you gonna put honey on the ribs?" she asks excitedly. Joyce, smiling, assures her that she will. For now, at least, life is sweet. ●



The Butler family, left to right: Michelle, Nat, Shawn, Joyce, and Karen