



# Living positively

When one couple started exploring adoption, they had no idea that an around-the-world journey would lead them to the love of their life: a tiny girl with HIV.

By Leslie Goldman

The Chicago home shared by Terri Smith and her husband, Brad Roback, boasts the sort of organized chaos so typical of families with a toddler. Terri sits at the kitchen table with their 18-month-old daughter, Sachi, sharing puréed-squash soup. Clad in a giraffe bib and multicolored knit booties, Sachi peers up at her mom with huge brown eyes, angling for a spoonful. "Hey, Toots!" Brad proclaims as he walks into the room, kissing his daughter on the forehead. Their home is an eclectic mix of modern orange and

aqua furniture, black-and-white family portraits, a rainbow of mismatched plates and goblets nearly tumbling out of a built-in hutch, and an armada of stuffed animals lining the floor.

Upon closer inspection though, a key detail emerges, suggesting this household is a bit different: In the kitchen, a cluster of syringes and bottles stand poised for Sachi's evening medication ritual. Soon, Brad will set about filling one needleless syringe with a bitter-

*Above left: Sachi at 2 months and only about five pounds. Above right: A healthy, happy 18-month-old.*

tasting but lifesaving HIV drug called Kaletra; a second syringe holds maple syrup, to sweeten Sachi's mouth immediately post-squirt. The entire process takes about a minute, and after a brief struggle, Sachi is happily sucking on a bottle of milk that contains AZT and Epivir, two more powerful antiretrovirals. Except for the raspy coughing of their dog Boutros, the room is peaceful. A statue of Ganesh—a jolly Indian deity with the head of an elephant, known as the Remover of Obstacles—looks over from the hallway, smiling.

There are 2 million children like

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Sachi worldwide—living with HIV, a retrovirus that had for years been considered a death sentence, and often still is in places like Haiti, Vietnam, Ethiopia, and India. But thanks to a small but growing group of would-be parents looking to bring a child into their homes and lives, and the increasing manageability of HIV in areas with access to medical care, they're finding homes...and thriving.

While no hard numbers exist for HIV adoption, the field is growing by "leaps and bounds," says Erin Henderson, the coordinator for HIV-positive kids at Adoption Advocates International (AAI) in Port Angeles, WA. In 2005 AAI helped two HIV-positive Ethiopian children come to the U.S.; in October 2009 the agency had 45 such adoptions in process or completed.

The fact is, science and medicine have come so far that "we would rather treat pediatric HIV than juvenile diabetes," says Kenneth Alexander, M.D., chief of pediatric infectious diseases at the University of Chicago. "If you look

ment and suspense, she went to pick up the baby, whom she and Brad would soon name Sachi Tulip (Sachi means "Grace" in Sanskrit).

The couple had seen just a few photos but had no reason to believe Sachi was anything other than a healthy baby girl. Yet the first thing Terri noticed in person was how small she was—only about four and a half pounds at 1 month. "She looked like one of those kids in the Sally Struthers commercials," she recalls of the malnourished newborn who was also struggling with listlessness, diarrhea, and dehydration. Nonetheless, Terri cried tears of joy. "I was so happy. I felt like, 'Oh, my God, she's so darling, and she's mine.'"

While Terri was in India that first month, trying to navigate the relatively nonexistent adoption process, a friend

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at how well our medications work, there's no reason not to expect that Sachi will one day see her grandchildren.”

## elation...then devastation

For a decade, Terri's job teaching Ashtanga yoga had taken her to India once a year to study with her guru. Friends there knew the couple wanted to adopt, so in August 2007 they called Terri and Brad with news of an eight-months-pregnant woman who would not be able to take care of the baby. Brad had to work, so Terri made the 24-hour journey to Mysore, India, alone that October. Her jet lag and exhaustion counterbalanced by excite-

suggested having the infant tested for HIV. Concerned that a Westerner bringing an Indian infant (with whom she had no legal ties yet) to get tested would raise eyebrows, Terri had her friend Deepak take her. The results were immediate, and he returned elated, announcing, "Good news! It's positive! She doesn't have it!"

But Terri knew what "positive" meant: Sachi *did* have it.

"I was wrecked. Devastated. Completely unable to deal," Terri recalls. "I didn't know what to do. We didn't know thing one about HIV, how long she would live, how much she would suffer."

Brad, who works for the city of Chi-



Above: Terri and Sachi at Comer Children's Hospital three days after they arrived in the United States.

cago in sustainable development, spent that first long night online, seeking out information. "I recall seeing some articles about living until age seven, that the quality of life for these kids wasn't very good," he says. "I didn't find anything too promising at first." Understandably, he grew frantic, wondering if Terri or he might be at risk. Some family members pleaded with Terri to drop the little one off at an orphanage; friends in India promised, "We'll find you a better baby." But Terri had been living with Sachi for a month and the bonding process had grabbed a firm hold: "She was my daughter. It was unfathomable that people's attitudes were 'find someone else to take her.'"

Fortunately, Brad's research led them to Chances by Choice, an agency that specializes in HIV adoption in nearby Oak Park, IL, which provided the couple the education and support they needed to go ahead. Still, the complex web of international adoption proved



daunting—Brad and Terri had to locate an Indian orphanage with a license to process international adoptions, as well as fill out reams of government paperwork to bring a baby with an infectious disease into the U.S. At last, a four-flight, 32-hour odyssey brought 11-month-old Sachi home to Chicago on August 25, 2008.

### managing HIV

“The first thing would-be parents ask me about is transmission,” notes Linda Walsh, a family nurse-practitioner and director of clinical operations and outreach for the University of Chicago’s Pediatric and Adolescent HIV team. “People come to me and say, ‘HIV adoption sounds like a wonderful idea and a beautiful thought, but tell me the reality for my family.’”

The reality is, there are only a few ways HIV can be transmitted: through unprotected sex, sharing needles or other blood-to-blood activities, breastfeeding, and from the mother to the child during pregnancy or childbirth. Sachi and her parents can—and do—share utensils, swap kisses, bathe together. Sachi can grow up and ride bicycles, play soccer with other kids, share a bathroom with girlfriends, all without fear of passing on the disease. (There is a tiny risk—1 in 4 million—of transmitting HIV through sports-related or other injuries, but there have been no known cases to date.)

The day after arriving home, an anemic Sachi was admitted to the University of Chicago Comer Children’s Hospital for ten days of blood tests and treatment for dehydration and a bad ear infection, which may have resulted in partial hearing loss.

Since then, Walsh and her team have had the privilege of watching Sachi transform from a slumping, malnourished infant to a bubbly, giggling little girl. When she arrived, her viral load—a measure of how many “pieces”

ing—unlike viral load, the higher one’s CD4 count, the better), and has her liver and kidney functioning checked to ensure the drugs are not damaging her organs. “With proper treatment, these children can live a pretty normal

“When you start this, right away you realize there are people who will be angry or who aren’t going to understand.”

or copies of the HIV virus are in the blood—was over 300,000 copies/mL. (Patients with a viral load of 100,000 are at risk of the disease progressing to AIDS and need treatment, according to U.S. Department of Health and Human Services guidelines.) Thanks to her medication regimen, after six months of treatment, that viral load was undetectable. (“Undetectable” doesn’t mean one’s HIV is cured, but that it’s below machine-measurable levels.) Sachi weighed in at 12 pounds on her first birthday, and nearly doubled that weight over the next year.

Today Sachi’s care involves hospital visits every eight weeks, which will eventually decrease to every three months. She undergoes a physical exam, has her viral load monitored along with her CD4 levels (a marker of how the immune system is function-

existence. It’s manageable,” emphasizes Walsh, who has watched kids in her program grow up and go off to college.

### unique challenges, happy surprises

Back at home, Terri and Brad say they don’t even think of Sachi’s HIV on a daily basis. Parenting her isn’t different than parenting any other child, aside from giving the medications, which has evolved from a challenging and disconcerting ritual to a seamless routine. What can be trying: explaining their daughter’s status to the rest of the world. “It’s really amazing because nobody knows about the advances in treatment,” Terri says. “Everyone is just as ignorant as we were.” Responses range from heartfelt concern about Terri and Brad’s bringing home a “terminally ill” child and the suffering that would

### what’s risky...and what’s not

#### HIV cannot be contracted from someone else by:

- ✓ swimming or bathing together
- ✓ changing a poopy diaper
- ✓ hugging and kissing
- ✓ playing with a drool-covered toy or other saliva exchange
- ✓ sharing a bed or toilet
- ✓ sharing food or utensils, or eating food prepared in the home of an HIV-positive child

#### There are only four ways someone can get HIV:

- ✓ through unprotected sex with an infected individual
- ✓ intravenous drug use or using contaminated needles
- ✓ through breast milk
- ✓ mother-to-child transmission (in utero or during delivery)

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surely ensue to a more selfish fear of contracting the disease themselves.

Sadly, a few people have dropped out of their lives; most, though, have welcomed Sachi into their hearts and homes with open arms. "When you start this," Terri says of HIV adoption, "right away you realize there are people who aren't going to understand or will be angry. It was really, really sad [that some friendships faded], but it didn't make me stop and think, 'Am I going to trade off my daughter for this person's peace of mind?' I knew we had to do what we had to do, everyone else be damned."

Disclosing a child's disease status is one of the most pressing issues HIV adoptive parents will face. In terms of

*Below: Brad and Terri get Sachi started on her HIV treatment and the journey to good health.*



disclosure laws, each state differs, but regardless of Illinois's requirements, Terri and Brad have decided they will alert Sachi's school of her HIV when the time comes for her to enroll. "My husband and I feel like if we decide to maintain secrecy about her condition,

then we'll be fueling the stigma, which causes a lot of emotional pain," Terri says. "We've decided to be really up front about it with anybody we have close contact with. I wouldn't broadcast her HIV status to people in a park where she's playing, but if I were to enroll her in preschool, I would talk to the director about whether they should let other parents know." (In a daycare facility or school that takes universal precautions—guidelines requiring the use of gloves or other protective barriers when touching someone's blood or other bodily fluids—the transmission risk is greatly reduced.)

On the horizon, the challenge of adolescence looms large. In addition to the potential social stigma of being a teen with HIV, the birds-and-bees discussions in these families will likely be more in-depth and serious than those occurring in the homes around them. Compliance with medication is another concern, as parents Lori and Greg Anderson of Newton, KS, found. The couple has adopted two daughters with HIV, Kalli, 8, and Nikki, 15. Their older daughter went through a

rebellious stage recently where she didn't want to take her medicine. But this insidious disease preys on missed doses, and if adherence is not as close to 100 percent as possible, the HIV virus can become resistant, rendering entire classes of medications ineffective.

*"We feel like if we decide to maintain secrecy about Sachi's condition, then we'll be fueling the stigma of HIV."*

Lori Anderson brushes aside the notion that parents who adopt a child with HIV are doing something extraordinary. "We're just everyday people," she promises. "I fully intend these girls will go to college, get married, live their own lives." By empowering her daughters to look after their health, Anderson is sure, "I'll be bouncing grandkids on my knee one day, and they'll be HIV negative because their moms are taking care of themselves." (In the U.S., mother-to-baby transmission of HIV can be prevented 99 percent of the time.)

Terri and Brad also encourage other families contemplating adoption to consider their less-traveled route. "Years ago, if an agency had called and said, 'We have an HIV-positive child,' I might have said no out of total ignorance," Terri admits. "But if somebody like me had told me their story, I probably would have considered this."

For this family, out of those tearful, soul-wrenching first nights following Sachi's diagnosis, a unique and beautiful sense of hope has blossomed. And when their little girl finally took her first steps and uttered her first word—"Mama"—Terri and Brad were over the moon, as any parents would be. "We know she's going to reach her potential," Terri joyfully proclaims, "and it will be as good as anybody else's." ✨

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