POZ

Sweet Home Alabama

When Silvia and Dick Glover adopted HIV-positive Caleb, now 3, they couldn’t understand why anyone would discriminate against someone living with the virus. Until they took him to an RV park swimming pool—and they became accidental activists.

April 1, 2008 By Regan Hofmann

Let me hand this baby to my husband,” says the sweet Alabama voice on the phone. “There, now,” she says to the fussing child. And then, sounding a bit like a schoolgirl asked to dance, she tells me, “Okay, I’m ready.”

The voice belongs to Silvia Glover, a 66-year-old grandmother who, with her husband, Dick, has three biological children, in addition to a foster child, Penny Decey (who came to stay for a short while when she was 5 and didn’t leave until she married), and one newly adopted 3-year-old boy, Caleb, who was born with HIV and cerebral palsy. At the moment, she’s also hosting a baby born to a woman who used drugs; if the woman can’t stop using, Silvia will keep the baby until a relative or adoptive parents take him. Penny, meanwhile, is now 27 and has a child of her own—they often visit. And the Glovers’ son Mark, who lives near Saraland, Alabama, the Glovers’ hometown, adopted a set of twins that had been foster children in his parents’ home. In four decades of adulthood, Silvia has cared for more than 60 kids whose parents were unable to care for them themselves. So, chances are, if you call the Glovers, you’ll hear a little one crying. But none of the children cry for long.

Few people quiet a child like Silvia. All she has to do is look at a baby and the tears stop. Her secret? “I don’t seem like I’ve got anything anybody else doesn’t have,” she says. “I just can’t see how anybody can’t love a child.” And it is that simple, motherly instinct that has propelled her, to her surprise, into the role of AIDS activist. “Every time I look into a child’s face, I see the good Lord,” she says. “The older I have gotten, the more I have learned to understand what a miracle life itself is. I can’t imagine anybody not putting out all their love and care for a child if they come in contact with the opportunity. The opportunity has been presented to me over and over and it’s made my life full. Very full.”

Silvia extends her nurturing to Dick, who is living with advanced non-Hodgkin’s lymphoma. She speaks about his cancer with the same tone she uses to discuss her drug-addicted babies and AIDS. It’s a reverential tone, overlaid with a matter-of-factness that comes from having lived daily with decisions that mean life—and death.

Most of the children Silvia and Dick have hosted have been infants. Over the years, they've never officially adopted any of them. Until now. On December 14, 2007, Silvia and Dick became Caleb's legal guardians.

The boy is perhaps the ideal icon for a new era of AIDS activism. Like Ryan White, an HIV-positive 13-year-old who became internationally known in the 1980s for fighting to stay in his school when its administration, teachers and parents wanted to banish him, Caleb, in another era, is emblematic of the same broken health care system. It is a system that once allowed White to get a transfusion of HIV-contaminated blood and that, three years ago, allowed Caleb to contract HIV at birth because his mother was not tested—and he and his mother were not treated—for the virus. Now, at 3, he has trouble eating, and at press time, he was back in the hospital with another bout of pneumonia. "Also," Silvia says, "he has bad dreams at night—from his medicine. Most nights he ends up part of the night in bed with us."

Silvia doesn't think her decades of mothering is heroic, nor does she understand the big deal about adopting and caring for an HIV-positive child. It never occurred to her that, in 2007, HIV could still be stigmatized—a belief that speaks to her conviction that people can be accepting of all manner of circumstances. She is now shocked to discover, however, that many of her neighbors have not journeyed, as she has, to that place of acceptance. But rather than becoming infuriated with America's home- and children-wrecking drug culture, she says, she is just glad that she's found a way to help do something about the wake of pain it causes.

Before the incident that thrust them into the national media spotlight, Silvia and Dick had mentioned Caleb's HIV status only at church and hadn't noticed any open discrimination against him—at first. In fact, when she discovered Caleb's HIV status, she asked the church to pray for Caleb.

But the couple's openess and benevolence was challenged last August, while they were vacationing at the Wales West Recreational Park in Silverhill, Alabama. In a casual conversation with the owner of the facility's wife, Silvia said that Caleb was HIV positive.

"I was talking to her in the office, since her husband has cancer and [my husband has cancer]," Silvia says. "And then I told her I was very proud of Caleb and that he was going to be our son and that he had HIV. After we got out [of the car] and set up [camp], her husband, Ken Zadnichek, came down and said that we could stay but Caleb couldn't use the grounds or go in the swimming pool or showers. We no longer felt welcome because Caleb was not welcome. Because our three sons had help set us up at the park [Dick was undergoing radiation and had only been out of the hospital two days], I asked if we could stay until the next morning because Dick wasn't able to move. They allowed us to stay, and we broke down camp ourselves the next morning without telling our kids."

When Silvia got home, she remembers, she said to herself, "This is wrong." Before long, Penny called the local TV news station; *Good Morning America* picked up the story, and more than 10,000 people posted comments on abc.com. On Labor Day, nearly 100 AIDS advocates from around the country, organized by the Campaign to End AIDS, arrived at Wales West. They led a peaceful demonstration and swam with Caleb in the pool from which he'd been banned.

In the months since the demonstration, Caleb has been the focus of many fund- and awareness-raising events. A World AIDS Day bike ride raised money in Caleb's name, and an HIV-negative cyclist, Brian Hodes, has arranged for a fund-raiser at a private home in the Hollywood Hills to secure funds for Caleb's medical care. Caleb will be the featured honoree at another AIDS Lifecycle fund-raising ride this June, and thanks to the organization, the Glovers are likely going to Disneyland and to a celebrity-studded event with the Elizabeth Glaser Pediatric AIDS Foundation this coming summer.

Will Caleb help change national and international perceptions about AIDS as Ryan White did? Perhaps. But right now, he's busy helping his new dad fight his cancer. "I cannot tell you how Caleb helps Dick," Silvia says. "When Caleb walks in the house, my husband just lights up. Because once you get to a certain age, it's so much easier to just sit down, especially if you're feeling a little poor. Well Caleb isn't going to let you do that—he's going to have you playing with him. Dick used to watch a lot of football, but now he's watching more cartoons."

Silvia adds, "Caleb has taught us: Just slow down a little, worry less about the things we tend to worry about. As you get older, your circles become smaller. Caleb makes us not let our circle get too small—does that sound funny? You have to take Caleb to get an ice cream, or roller-skating, [or] to an Easter egg hunt. These are all things that we would [otherwise] give up. With Caleb, [we] don't get to. Isn't that wonderful? People always think we're giving to Caleb, but he's giving to us more than we could ever give back to him."

Silvia says she's been surprised by the national reaction to Caleb's story. "Locally [in Alabama]," she says, "there's not that much being said or done for HIV. I did not know that this was something that most people sweep under the rug. After that experience, I'm not as open [about disclosing Caleb's HIV status], although I have told everybody who comes in contact with Caleb in a medical way or at school that he has HIV. But I'm more cautious now. I sat next to somebody [one recent] Sunday morning at church [and saw that] their children are not allowed to touch Caleb.

"You can shout something from a rooftop, but if somebody's made up their mind, it's awful hard in one conversation to change it," she says. "We come to realize things, but not just because someone tells us to. Over the years, I've changed my mind or mellowed in the way I felt about something. In the 1980s, I became a rape crisis volunteer with my sister, and one of the very first calls we had to make was to a man that was at the hospital. He'd been brought in by his boyfriend—he was a homosexual man. And he was wearing the pink tights and all of that. My job was to go in and comfort the victim, and my sister's job was to stay with the victim's family or friends. So when I first walked in, I remember thinking, 'Oh dear God, don't give me AIDS.' But because I knew I needed to comfort this young man, I told him that black or white, male or female, what happened to him was wrong. And I held him in my arms. But I remember the fear being there. I'm not sure exactly when I became more educated, but over the years, that fear totally left me. That happened just from the general education that exists out there with HIV. At the time we received Caleb, there was no fear whatsoever in my mind about HIV. It existed in the ’80s, but it shouldn’t exist now.”

Most of the foster children that come to the Glovers are born to parents who are using drugs. If parents test positive for drug use in a hospital in Alabama, the Department of Human Resources will investigate the living conditions at home and if they find them unsuitable, recommend that the child be given to a relative, if one is available. If not, the child will go into foster care. Parents must prove that they’re drug-free and capable of staying that way before they can have their child back.

Silvia says, “I don’t understand, if they’re drawing blood and testing for drugs, why aren’t these drug users tested for HIV at the same time so that the children can be protected at birth? Because Caleb wasn’t. I don’t understand why that isn’t mandatory. It’s my understanding that some states are starting to do it, but I don’t think you find it in the South that much.”

Indeed, states have different laws about testing pregnant women for HIV. Caleb’s birth mother was not tested for HIV. When the Glovers noticed a deep abscess in Caleb’s side when he was about 7 weeks old, they took him to the hospital; it wasn’t until a week later, when they were back at the hospital because Caleb had pneumonia, that a doctor suggested he be tested for HIV. Silvia says, “[The nurse] asked if she could check him. She wanted to know if I knew anything about the parents. I said that the only thing that I knew about his mother—I had met her—was that she had some bumps on her skin. The nurse asked, ‘Do you mind if I test him?’ I said, ‘You can test him.’ It didn’t enter my mind [that he’d be positive] because as far as I know, we hadn’t run across it before in our foster children.” At the time, the Glovers were caring for 5-week-old twins. “I would not have brought Caleb home if I was worried that they could get HIV,” she says.

Silvia is not in touch with Caleb’s birth mom. She says the last she heard, Caleb’s mom is still not receiving any HIV care. “It’s been offered to her,” Silvia says, “but she continues to not take it. And continues to have babies. I believe there’s one due March the 7th. The baby will be the third she’s delivered since Caleb. Supposedly, one has lived, one has died and we’ll see about the next one.” The four children she allegedly had before Caleb were all born dead. “I don’t know how much is the drug use and how much is the HIV,” says Silvia. “My guess is that it’s the drugs that keep her from getting tested for HIV—she’s probably scared that they would show up on her [blood work].” Asked whether she is angry at Caleb’s mom for not getting herself, her children in utero, or her newly born treated for HIV,

Silvia says, “It’s hard to have any malice toward her because I believe that it’s just plain ignorance on her part. She hasn’t sought help, thinking that she either can’t get it, or that she doesn’t deserve it. I don’t know.”

Silvia says it is her understanding that Caleb’s biological father is HIV positive. “I’ve talked to him personally about getting help,” she says. “He has two children by a different woman that are older than Caleb; I think they’re about 9 or 10. They live with his mother. I told him they can see Caleb. I only have Caleb because he came through them. How can I hate them? I think that he owes it to his children to get himself some help. He really does—to stay around and be healthy for them." Silvia's current foster child was also born to a drug-using mother. When I ask her if he'll go back to his parents, she says, "Well, maybe a relative. But [the parents are] still hanging in. And I'll pull for them because children should be with their parents, if it's at all possible. But sometimes we get into generations and generations of the same [cycle] of poverty and drugs [and there's nowhere for these kids to go]."

Hosting the kids is one way to deal with the crisis of AIDS orphans in America. But ever since that day at Wales West, Silvia is determined to do more than that. She believes that the answer lies in removing the stigma so that people aren't afraid to get tested and treated for HIV. She thinks we need to educate people not only about the simple facts of HIV transmission—like that it cannot be passed between people in a pool—but also about rethinking who is susceptible and reconsidering the notion that people who get HIV should be condemned.

"If you've got a teenager and if they're doing what most teenaged boys or girls are doing, you might be dealing with HIV next week," she says. "HIV doesn't care what color you are, or how old or how young you are. It's just a disease that's out there. And you know what? When we smoke, we do [something] to ourselves too. But we don't hate people [who get lung cancer]. Really think about it. We get diabetes, usually, because we love to eat, and we're a little overweight sometimes; but we don't hold that against our mothers and our fathers and our children and our friends. Most [diseases] come from lifestyles, if you think about it. So you caused HIV, if you did this or you did that—so what? I caused my heart disease because I made certain choices. Does that make me less of a person? It doesn't. I just think you don't know where you're going until you know where you've been. There needs to be more understanding. And if you break it down, there's no room to be accusing anybody of this and that. HIV is everybody's problem. HIV is no longer [just] a gay man's disease; it's everybody's disease." Her prescription for help? "We [should] include the HIV [test] in our physicals, I think that would help; I think that would take some of the stigma away. I believe if we just incorporated [HIV testing] into our everyday health care, it would make a difference in our attitude toward it."

It's one thing to have beliefs and opinions, another to put yourself and your family in the media's spotlight to speak about them. Why has she chosen this path? "I'll speak up, because there are a lot of Calebs out there. Somebody's got to do it," she says. "It wasn't a job that I ever set out to do, but I'll protect Caleb any way I can. And if education is one of them, then I'll try my best. The only way that I know that will change anybody's mind is to get it out there, and let them know that you can live healthily for years with HIV.

"I want Caleb to be able to go to school and be involved in community sports, like Dixie Youth and T-Ball, without being discriminated against or being set apart. He can be a child with a health problem, because a lot of children are children with health problems. But I don't want to feel that he feels that he's less of a human because he has HIV. I want him to be accepted for being Caleb, and not for being Caleb with HIV. I just want Caleb to be someone that people understand instead of fear."

And as if on a cue, a little one cries out in the background, and she says, “I have to go.”

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http://beta.docker.poz.com/article/HIV-discrimination-pool-14222-4949