

# no place to call H O M E

HOUSING INSECURITY PUTS CHILDREN'S CARE,  
TREATMENT AT RISK

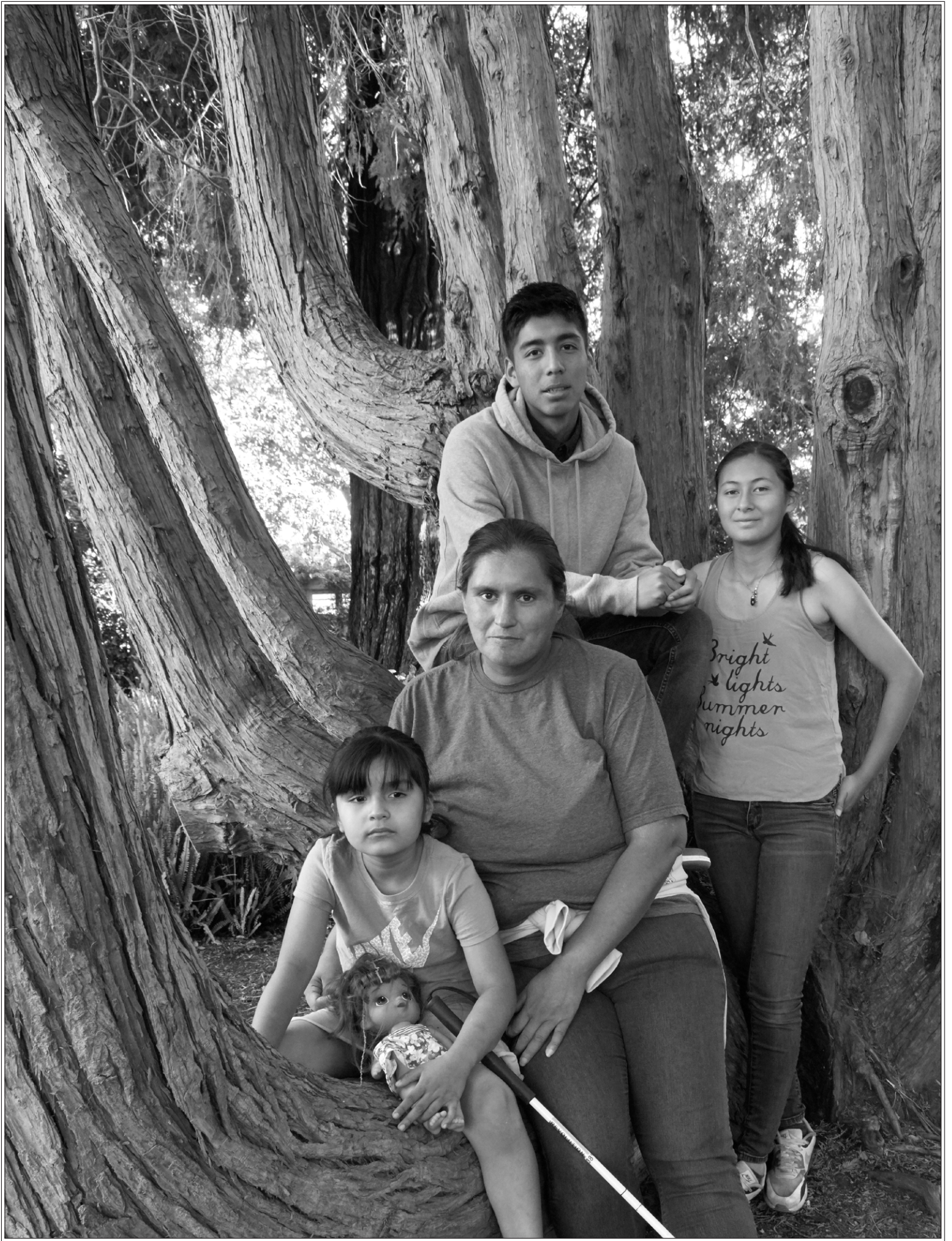
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ntil a few months ago, "home" meant one thing to 5-year-old Joy Gutierrez: A two-bedroom apartment in Daly City, California, shared with her mom, two siblings, her favorite aunt and four cousins. It wasn't fancy, but Joy — born with a genetic disease that causes blindness — loved it. She knew the voices of everyone in her family, how to move through the familiar space and how to turn on the TV for episodes of *Dora the Explorer*. Joy's mom, Patricia Gutierrez, walked her to preschool, the local playground and a nearby mall. "She likes to be independent," Gutierrez says of Joy, who was beginning to learn her Braille letters in preschool and was becoming adept at using a white cane to navigate the shadowy world apparent through her extremely limited vision. "If it's hard, she wants to try."

But in June, Gutierrez and her sister received an eviction notice on their shared apartment. By early August, unable to find housing she could afford, Gutierrez and her children were living in a shelter 12 miles from their old neighborhood. Joy misses their apartment, their neighborhood, and her aunt and cousins. She keeps asking why they can't move home. "She wants to go back," Gutierrez says. "It's been very hard."

BY ERIN DIGITALE

PHOTOGRAPHY BY LESLIE WILLIAMSON

Patricia Gutierrez and her children, Joy, 5, Carlos, 17, and Rosa, 14, are looking for housing after being evicted from their Daly City apartment.





Harder still is the fact that Gutierrez is unsure she'll be able to remain in the Bay Area. San Francisco is home: She grew up there before the current era of vertiginous housing costs. Since Joy was born in 2011, Bay Area rents have risen more than 25 percent, to median levels of nearly \$2,800 per month in Silicon Valley and \$3,900 per month in San Francisco. Home prices have jumped 75 percent, to a median sale price of more than \$1.2 million for San Francisco and San Mateo counties and \$755,000 across the Bay Area. Gutierrez is a single mom with three kids, two of whom are disabled. She sustains her family with child support, disability payments and various types of public assistance. For families like hers, the region is increasingly unaffordable.

To help families in similar situations, several Stanford pediatricians are working to strengthen the options for doctors and families tackling social problems that can have damaging downstream effects on children's health. Yet the collision be-

ment associated with many health problems. After genetic and neurological testing, Alcorn and her colleagues arrived at a devastating diagnosis: Leber Congenital Amaurosis, a genetic disease that interferes with the function of the retina.

"It's a very severe form of childhood blindness," Alcorn says. The disease affects about 1 in 50,000 to 80,000 children and can be caused by mutations in any of at least 17 genes. The disease is transmitted through a defective gene copy from each parent. Most parents don't know they carry a disease-causing gene until their child is diagnosed.

Alcorn discussed the disease with Gutierrez: Joy would probably have normal intelligence and learning capabilities, but would be severely visually impaired, likely legally blind. She might poke at her eyes to produce stimulus to the retina, and Gutierrez should try to discourage this. Gutierrez would need to help Joy navigate their home and neighborhood, and

## 'EVICTION IS STRESSFUL FOR families even WITH A CHILD WHO DOESN'T HAVE

tween housing and health creates problems that are extraordinarily hard to solve.

Case in point: If Gutierrez moves away, it means pulling her children from the support network she's fought to develop for them. Her son, 17-year-old Carlos, has no special medical needs, but it's his senior year in high school, a wrenching time to leave. For the girls, it's even harder: 14-year-old Rosa, who has significant developmental disabilities, uses a local nonprofit organization that helps developmentally disabled people become more independent, and Joy has been seen since infancy by Deborah Alcorn, MD, Service Chief, Pediatric Ophthalmology at Lucile Packard Children's Hospital Stanford.

"I don't want to move far because I love Dr. Alcorn," Gutierrez says. "She's been helping my daughter ever since she was a baby."

### A DEVASTATING DIAGNOSIS

JOY WAS A FEW WEEKS OLD WHEN GUTIERREZ NOTICED HER DAUGHTER'S erratic eye movements. Joy's pediatrician referred her to Packard Children's, where, at the age of 7 weeks, the little girl was seen by Alcorn, who is an associate professor of ophthalmology and of pediatrics at the Stanford School of Medicine.

Alcorn noted that Joy had nystagmus, a roving eye move-

advocate for what Joy needed at school. Given Joy's severe early visual loss, Gutierrez needed to know that other areas of Joy's development, especially social development, could also be delayed.

"Some parents get a dismal diagnosis, and they assume 'There's nothing I can do,'" Alcorn says. "Not this mother: She told me right away, 'I want to know what resources I have available, and I want to make sure I get all of them.'"

Alcorn referred Joy to the Blind Babies Foundation, which sent an expert to the family's Daly City apartment. At the age when most babies would start getting into everything, Joy lay still. "I guess she was scared," Gutierrez says. "They really helped support me, getting her active and making sure she'd be able to move around and do stuff like normal kids."

As Joy entered preschool, Alcorn contributed to Joy's Individualized Education Program, specifying that she needed comprehensive visual services, including Braille instruction and, eventually, help using a white cane.

Today, Joy has minimal vision; at best, she can tell if a hand held near her face is moving or stops. Highly sensitive to light, she often wears sunglasses. Some days her vision is a little better, sometimes worse. Alcorn continues to monitor her.

Alcorn also tries to instill the right amount of hope. Some LCA patients are receiving gene therapy, a treatment that

doesn't produce normal vision but makes daily life easier, she has told Gutierrez. Gene therapy is not yet available for the genetic defect Joy has, but that may change. Alcorn wants Joy to continue being seen at Packard Children's because an academic medical center is a superb place for a child with a rare genetic disease to access such cutting-edge treatments.

#### NEED FOR ADVOCACY

**A**LCORN WAS ASKING A ROUTINE QUESTION ABOUT THE FAMILY'S home life during Joy's most recent appointment in June when she learned the painful news that they were being evicted from their Daly City apartment.

"Joy was very upset," Alcorn says. "She was very attached to her aunt, and now her aunt was not going to be able to live with them."

## A medical issue.

Ideally, when the stability of a family's life is threatened, pediatricians can provide a bridge to resources that help.

"People may be worried about using services in the community, but they come to us," says Dana Weintraub, MD, clinical associate professor of pediatrics at the School of Medicine and an advocate for families in need. "We're a place of trust."

Many pediatric hospitals and health care systems employ social workers as front-line caregivers to address families' non-medical needs. Packard Children's has about 40 full-time social workers, several of whom specialize in children with specific medical problems, such as cancer or organ transplantation. Social workers often link families to other sources of help — including nonprofit or advocacy organizations.

By the time she saw Alcorn in June, Gutierrez had already been connected to the Legal Aid Society of San Mateo County via her social worker at California Children's Services, which provides case management to children with certain severe medical conditions, including blindness. Gutierrez had sought legal aid for assistance with Joy's Individualized Education Program, which she felt her daughter's preschool was not following. Soon her attorney was also asking about her eviction.

The household had kept up with its \$2,000 monthly rent payments, but the landlord was fed up with the family's requests that he repair the toilet, which kept flooding their unit, Gutierrez

says. In Daly City and many other Bay Area jurisdictions, landlords can evict tenants without cause. The landlord gave 60 days' notice, as required, leaving the family in a difficult situation. The family's requests for repairs weren't in writing, making it hard to prove the landlord was retaliating against them.

"We gave them lots of advice and support, but they decided they didn't feel like they could defend against an eviction," says Kate Stanford, JD, the Legal Aid Society of San Mateo County attorney who has been working with the family. Many families won't complain about habitability issues, she says, because they fear exactly what happened to Gutierrez: Ask for reasonable repairs, get served with an eviction notice. "And once a family is homeless, there's not a lot to be done legally," Stanford says. "We shift our focus to making sure the family has the income supports — food stamps and other public benefits — to become stable again."

When the eviction date arrived and Gutierrez had not secured housing, the county put her and her children up in a hotel for a few days, then offered the spot in the shelter.

"Eviction is stressful for families even with a child who doesn't have a medical issue," says Weintraub. "But when a child with complicated health care needs is evicted to the street or a shelter, they're not getting the care they need in a safe environment."



Dana Weintraub, MD, is a clinical assistant professor of pediatrics at the School of Medicine and an advocate for families in need.

For Joy, any change of environment increases her risk of injury as well as her sense of disorientation. Although she's an active kid — who, with help, adores using playground slides and swings — it's difficult for her to navigate the shelter, where the family has a small bedroom to themselves but must use a large, shared kitchen and living areas that are not laid out with a blind child in mind. "I'm with her most of the time, watching for her. She will bump into stuff and trip and fall," Gutierrez says. Joy and her siblings are entitled to remain in their schools in Daly City, and are now being bused 30 minutes each way.

Beyond helping individual families, physicians also have opportunities to shape policy at a larger scale in their communities, as politicians and other influencers see them as trustworthy sources of expertise on vulnerable kids, says Weintraub.

"So much of what impacts children's health is local," says Lisa Chamberlain, MD, associate professor of pediatrics. Over the past 15 years, Chamberlain, Weintraub and their colleagues have secured many local advances for children's health: Packard Children's provided financial support when Santa Clara County became the first in California to create a low-cost health insurance program that covered all children residing in the county, regardless of their legal immigration status, for instance. (The hospital also supported similar programs in nearby San Mateo and Santa Cruz counties, and supported the development of a state bill that in 2016 extended eligibility for this type of health coverage to all children residing in California.) Packard Children's played a large role in providing logistical support, funding and coordination with local and federal officials to establish and maintain the Ravenswood Family Health Center, an East Palo Alto clinic that provides free or low-cost medical care to needy patients near Stanford. And, in 2012, Chamberlain worked with a local school district to start a summer lunch program for children who receive free lunches during the school year.

Chamberlain, who has been medical director of Stanford's Pediatric Advocacy Program since 2000, was recently named associate chair of policy and community engagement for the School of Medicine's Department of Pediatrics. In that role, she is developing a strategic community engagement plan that recognizes and strengthens long-established partnerships between Stanford and other community caregivers looking out for at-risk families.

Yet, Chamberlain worries that the financial engine of Silicon Valley is leaving a lot of families behind. "Because of our economy, we're facing really significant risks right now," she says. There's more food insecurity as families shift their incomes to meet rising rents, many extended families are crowded into small apartments, and parents often face very

## 'BECAUSE OF OUR ECONOMY,

long commutes to reach their jobs. All of these elements of the housing crisis can hurt kids' health.

The broader outlook is important to doctors on the ground, Alcorn says. "You don't just take care of the child; you kind of inherit the whole family," she says. "I want to do more than just ophthalmology for kids. It's not like I'm just coming in, checking their eyes and they're out the door."

### PREVENTIVE LAWYERING

**W**HEN WEINTRAUB CAME TO STANFORD FOR FELLOWSHIP training in 2002, she joined an American Academy of Pediatrics physician advocacy group, which soon hosted a guest speaker from the country's first pediatric medical-legal partnership, located in Boston. Through these partnerships, pediatricians screen patients for legal problems and connect families to pro bono or low-cost attorneys who can head off health crises.

"It resonated with me because of my work with families dealing with poverty," Weintraub says. "They were struggling with issues that we as pediatricians aren't trained to address, but legal professionals are able to handle."

After receiving support from the hospital's leaders, Weintraub in 2004 founded the Peninsula Family Advocacy Program, a collaboration between Packard Children's and the Legal Aid Society of San Mateo County. (Kate Stanford, the attorney assisting with Joy's Individualized Education Program, is the partnership's legal director.) Housing challenges were among the first legal problems the team addressed.

"One of our very first cases was a child who was 10 months old, who had been in the ER twice in the past month, once resulting in hospitalization," Weintraub says. The family's apartment was beset with mold, cockroaches and grimy carpeting. A letter from the child's physician to the landlord explaining that these allergens appeared to be fueling the child's asthma — and mentioning the housing habitability codes that were possibly being violated — got a rapid response. The landlord let the family stay rent-free in another unit while the carpet was removed and the cockroaches exterminated.

"After that, the child's breathing improved," Weintraub says.

# we're facing REALLY SIGNIFICANT risks RIGHT NOW'

The landlord's quick action made an impression on Weintraub. Coming from a doctor, the message that a housing issue could be harming a tenant's health carried a lot of weight.

In addition to housing, the partnership addresses many other social and legal problems, including immigration issues, domestic violence, special education, or being unable to pay bills or buy food. But families still fall through the system's cracks. Once a family has been evicted, they are, to a large extent, at the mercy of the housing market, and there is little that pediatricians — or anyone else — can do.

## FEW TENANT PROTECTIONS

**A**S BAY AREA RENTS RISE, the reasons behind local evictions are evolving, says Shirley Gibson, JD, directing attorney of the HomeSavers Project, run by the Legal Aid Society of San Mateo County. The project, founded in 2007, provides free assistance to families struggling to keep their housing.

Ten years ago, nonpayment of rent far outstripped other reasons for local evictions; today, no-cause evictions are equally common, a sign of a housing market that heavily favors landlords.

"We don't get a lot of candid information from landlords, but we have enough anecdotes to suggest that, hey, they cleared out that whole building of families with kids to attract tech workers who work down the street," Gibson says. In most housing markets, getting rid of all your tenants would be "cuckoo," she adds. "Why would you do that, except if you can double the rent?"

Racial and ethnic minorities and children are being especially hard hit, according to HomeSavers Project data. Seventy percent of the project's clients who fought evictions between 2012 and 2015 were from households with children, and Hispanic and African-American households are being displaced at rates far above their representation in the county population.

Very few Bay Area communities have tenant protections such as just-cause eviction or rent control. Given the intensity of the region's housing crisis, "the notion that you can just kind of ride out whatever is happening with the housing market and let the market correct itself is not a workable approach," Gibson says.

Building more market-rate housing won't alleviate the

crisis for low-income families, either. "We need to build affordable housing and be precise about what we mean by 'affordable,'" she says.

In other words, will it be accessible to families like Joy's? Few local municipalities have laws to allocate any development funds toward affordable housing, but in those that do, Gibson and other Legal Aid attorneys have brought lawsuits to ensure the laws are followed. Other local agencies, such as the Housing Leadership Council of San Mateo County, advocate with public officials and other decision-makers for more affordable housing.

At press time, Gutierrez still did not know where the family would go when her time allowed in the shelter expires. In mid-October, she estimated that over the previous month, she had inquired about 40 apartments; four landlords replied. All rejected her applications: Her income was too low, they wanted tenants whose income came from jobs rather than public assistance, her credit wasn't good enough, or their units would not accommodate four people, they told her.

Gutierrez has worked in the past, but even with child care help from her sister, Joy and Rosa did not do well. Rosa would go all day without eating or showering. "She'd just lay in bed talking to herself," Gutierrez says. Joy would fall and get hurt. Others lack the patience Gutierrez has for her kids. "I don't get frustrated; I don't push my kids to the side," she says. "They need my attention. I'm fully right there. Joy, all she wants is for me to hug her."

For now, Gutierrez is trying to limit her housing search to Daly City, South San Francisco and San Francisco to enable Carlos to finish his senior year. "Once he's done, I could go anywhere I need to go," she says. Though she's reluctant to move Rosa away from her support system and her friends, and worries about disrupting Joy's medical care, she knows she might have to.

Most of all, Gutierrez longs for stability. She wants to live where "we won't have to move around so much or worry about where we end up afterwards; somewhere where my kids could say, 'This is our home. My mom could pay for it.'" **SM**

— Contact Erin Digitale at  
[digitale@stanford.edu](mailto:digitale@stanford.edu)

## WEB EXTRAS

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