More From Life on the Edge in America

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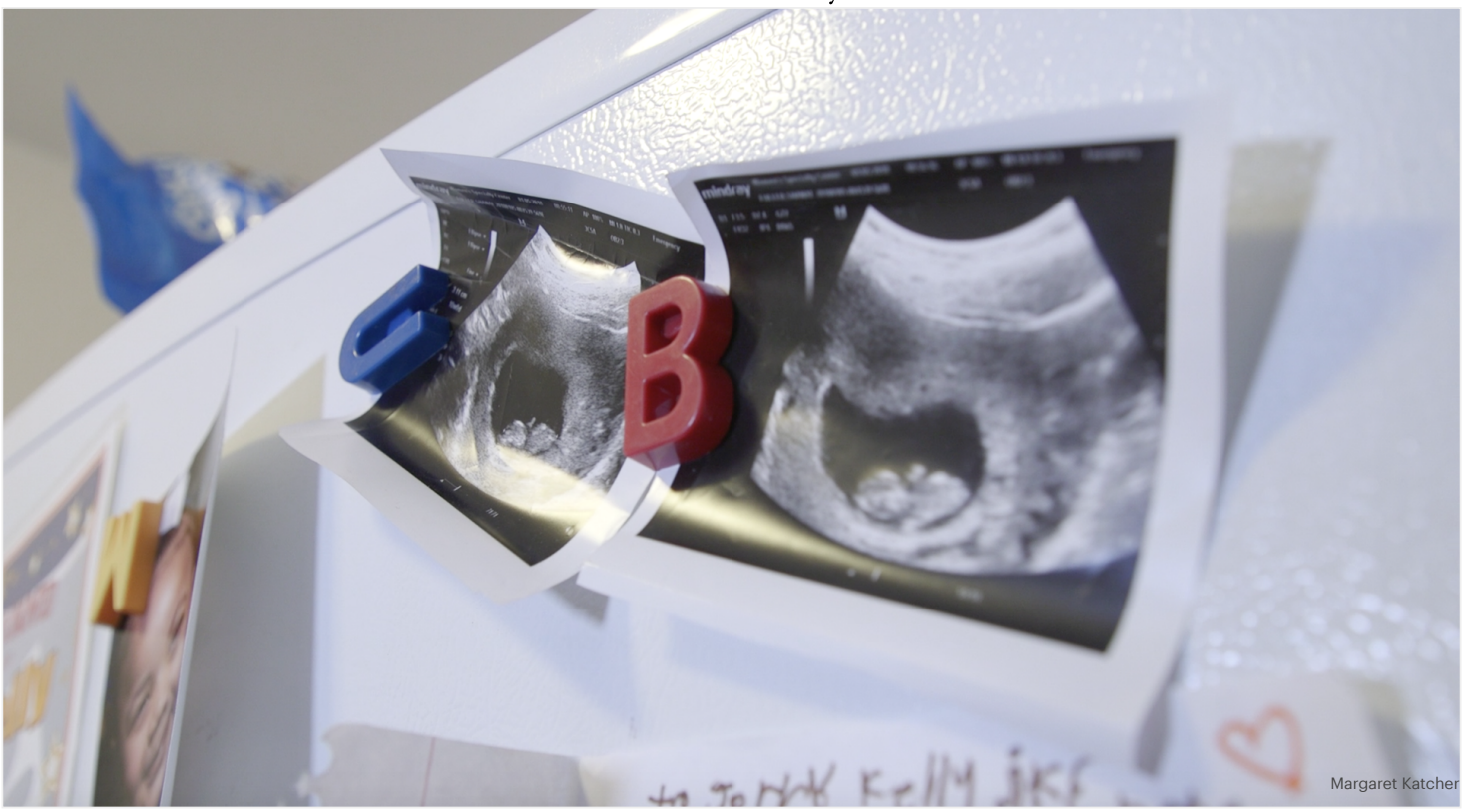
A Mother's Zip Code Could Signal Whether Her Baby Will Be Born Too Early

Every year, more than 400,000 women in America have babies who are preterm, low birthweight, or who die before their first birthday.



Margaret Katcher

Story by Margaret Katcher

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Editor's Note: *This article is part of a series exploring the vast racial and economic inequality in Fresno, the poorest major city in California. These stories were reported by students at the University of California*

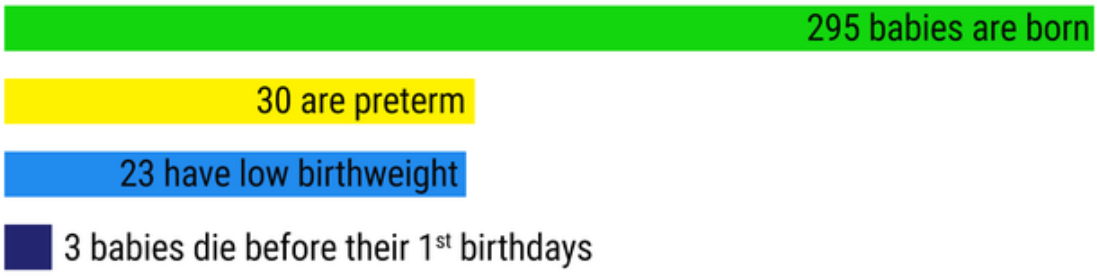
at Berkeley's Graduate School of Journalism.

When baby Rodrigo was born, he didn't make a sound. Lucy Gomez had been in a Fresno County hospital for a week since she first showed signs of labor. She'd reached only 23 weeks in her pregnancy before she gave birth—barely within the realm of viability for life outside the womb—and something was very wrong.

She remembers her doctor directing her not to push her placenta out, but to keep it intact until the neonatal intensive care unit (NICU) team arrived. "He's been born in his sac," the doctor said. Gomez lay on her side and cried. Stillness surrounded her. "It must have taken them like three to five minutes [to enter the room]. But, it was eternal," she told me.

When the team arrived, they whisked the baby away. Half an hour passed. Then, Gomez remembers a nurse practitioner came to her side and told her, "Your son is alive, but we can't guarantee anything. His chances of survival are about 20 percent." Lucy's heart clenched at the sound of the number. The nurse practitioner listed the many terrible things that could happen to baby Rodrigo: he might never walk, speak, or breathe on his own. Gomez felt each word pile onto her shoulders. She must have done something wrong. She was to blame.

Gomez didn't have the birth she wanted, and she's not alone in her experience. Each year, over 400,000 women in America have preterm births, low-birthweight babies, or have babies who die before their first birthdays. Doctors lump these cases together and label them as "adverse birth outcomes." Commonly cited risk factors contributing to adverse birth outcomes include drug use, poverty, and homelessness. But many cases aren't attributed to those circumstances. Pregnancy is inherently risky. Some babies just come too early, which is why the dogma of personal responsibility bears a lot of weight on many mothers who have adverse birth outcomes. None of the commonly cited risk factors pertained to Gomez, yet she kept wondering whether she'd caused her son's early birth, if she'd lifted too much or skipped a day of vitamins.

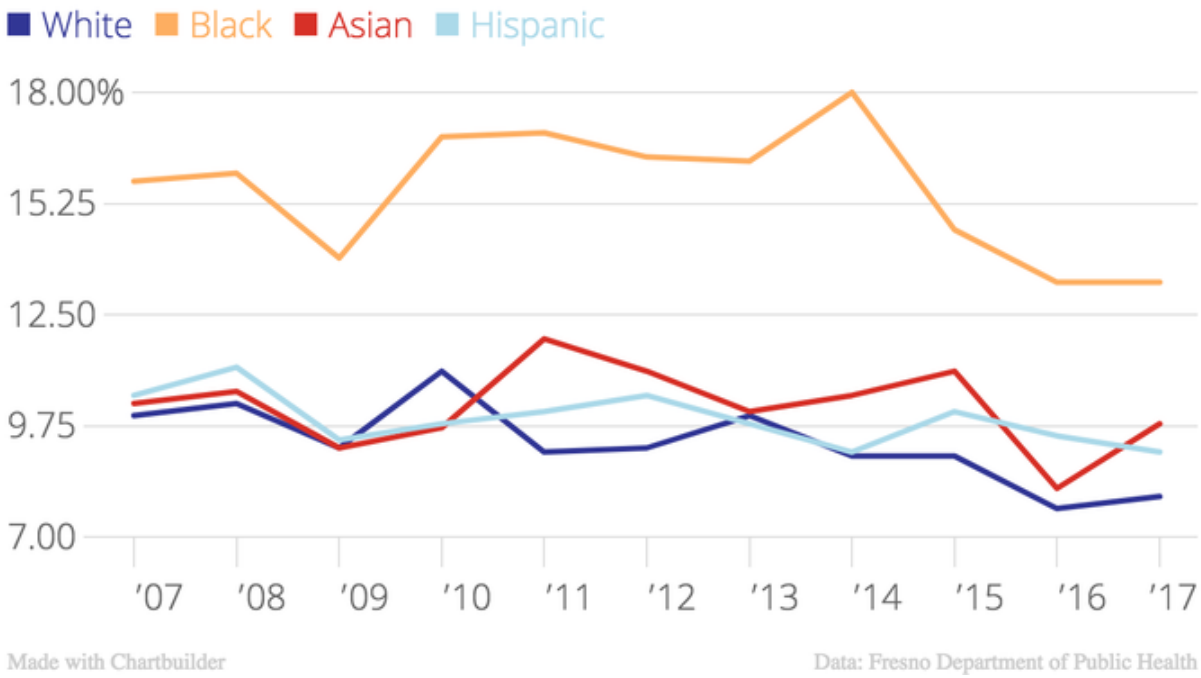


Average weekly birth outcomes in Fresno County. (March of Dimes)

How a pregnancy turns out though often has to do with much more than a woman's agency. For example, the risk of maternal death related to pregnancy is three times higher for black women than for white women. One team studied the racial disparities in five causes of pregnancy-related deaths, including preeclampsia, eclampsia, abruptio placentae, placenta previa, and postpartum hemorrhage. They found that black women don't suffer from these five pregnancy complications any more often

than white women, but that a black woman is two to three times more likely to die from one of the complications than a white woman with the same condition.

Researchers say that birth outcomes are not just a barometer of a mother's health, but the health of the community, and also a predictor of its next generations' health. In many places, adverse birth outcomes can be traced to a history of segregation and economic inequality. Fresno County's rates of preterm birth (identified as babies born before 37 weeks in gestation) have ranked among the highest in the state. However, these rates vary widely by location and race within the county. In one southwest zip code where black and Hispanic people make up 70 percent of the population, the preterm birth rate is 12 percent. Just 12 miles north of that zip code, the population is 66 percent white and just over 15 percent black and Hispanic. There, the rate is under seven percent.



Fresno County Preterm Birth Statistics, by race. (Fresno Department of Public Health)

Preterm babies are more likely to develop health problems in the future, and complications from preterm births are the leading cause of death for children under five. These births are pricey, too. The Center for Disease Control estimates that preterm births cost the United States $26 billion per year. Care for preterm babies in Fresno County cost the health system about $78 million per year. Gomez was on private insurance when she gave birth to Rodrigo. The price tag on her son's five-month NICU stay totalled nearly $2 million.

Fresno civic leaders consider the problems associated with adverse birth outcomes so severe that they've joined with a coalition of researchers to address it. Fresno County is one of six regions in the world to be included in the Preterm Birth Initiative, a 10-year, $100 million research effort backed by the University of California at San Francisco and supported by private funding from Marc and Lynne Benioff and the Bill and Melinda Gates Foundation.

John Capitman, director of the Central Valley Health Policy Institute, was one of the early developers and leaders of the initiative. He doesn't believe that commonly cited risk factors accurately represent the cause of birth-related health disparities. For example, the CDC lists "black race" as a factor

associated with preterm births. Capitman and his colleagues argue that it's not race, but racism that should be recognized. "We're talking about the impacts of racism and poverty and how our public systems do or do not mediate those impacts on people's health status," Captiman says.

Inequality's impact on health has been formally recognized in Fresno before. The county's history of housing segregation and concentrated poverty are inextricably linked to a gulf in quality of care and access to services. In 1974, the Fresno Department of Public Health laid out a vision for reorganizing the healthcare delivery system, wielding excerpts from a Society article called "Medical Ghettos:" "The reason the medical systems have not reached the poor is because they were never designed to do it," the paper reads.

While there have been periods of significant improvement, there has also been backsliding. Between 1992 and 2001, the county's black infant mortality rate decreased from 37 to 11 per 1,000 births. After creeping up in the early aughts, the black infant mortality rate then spiked 87 percent between 2007 and 2014, from 15 to 27 per 1,000 births. This significant regression led to a shift in the progressive public-health conversation from explicitly addressing poverty to systemic racism.

That shift is particularly relevant in Fresno county, where over half of the population is Hispanic and its residents speak as many as 62 languages. It's also where race and ethnicity are strong determinants of how a birth will play out.

Members of its public health department say that they recognize that the healthcare system is not a welcoming environment for all. Rose Mary Rahn, the division manager of Public Health Nursing in Fresno's Department of Public Health, asks, "How do we tackle that the health care providers are not being culturally competent?" Cultural competence or culturally responsive care are workplace euphemisms for non-racist services that meet patients' social, cultural, and linguistic needs. "There are not institutionalized practices that are changing it, like we don't have mandated cultural humility training," she says. "That's not consistent across the health care system."

In Fresno, and around the country, researchers have uncovered inequities in medical treatment. Evidence suggests that medical professionals ascribe different thresholds for pain when treating minorities and whites. The findings of one study published in the Journal of American Medical Association Pediatrics show that in appendicitis cases, black children are less likely than white children to receive pain medication. Pregnant women are also treated differently. A national survey found that black and Hispanic women were more likely to meet their delivery doctor for the very first time during labor compared to white women. This has implications on a woman's sense of choice and trust during her birthing experience. The survey also found that one in five black and Hispanic women reported poor treatment from hospital staff because of their race, ethnicity, cultural background or language.

These inequities were at play when Shanae Fuller spent months of 2014 with her preterm baby in the NICU in Fresno. Now 26-years-old, she found out she was pregnant with her second child at 22. She and her boyfriend went for an ultrasound to learn the sex of their baby. There, they found out that their baby boy had spina bifida. It's a rare birth defect where the neural tube, which houses the spinal

cord, doesn't close all the way. A bulge can form, made up of fluid, nerves, and the spinal cord. Physical and developmental disabilities can also follow. It's a defect that's rare for African Americans, who are less likely to have spina bifida than whites or Hispanics.

Throughout her pregnancy, Fuller asked lots of questions. She wrote down every word she didn't understand and looked it up for herself later. She says she felt judged and saw eyebrows raise whenever she asked for the spelling of a certain terminology. Doctors and nurses seemed to cut out all of the informative parts of the appointments. She says that medical staff acted surprised when she expressed interest in understanding her son's condition. They cut to the chase. "He may not make it. He may die."

Her son, Jerry, did make it. During his NICU stay, Fuller says, the resistance she felt from medical professionals continued. She says she had to interrogate them in order to be included in medical decisions, like whether her son should get a shunt to drain excess fluid in his brain, a condition called hydrocephalus. Fuller was hesitant to resort to surgical intervention. She found herself grasping at every scrap of terminology she could remember in order to push back against her doctor's recommendations.

Fuller asked to see proof that the fluid buildup in Jerry's brain was still severe, but she says the doctor looked at her like she was "stupid." The shunt might drain the fluid more quickly, and get Jerry out of the NICU sooner, but Fuller wondered if it was the only option. A new MRI eventually showed that the fluid was being reabsorbed, and a shunt wasn't necessary. Fuller felt like the doctor didn't anticipate or have respect for her advocacy for the life of her son. She wondered if the doctor's resistance to listen to her wishes and take her opinion seriously had to do with her race.

Shanae Fuller and her son (Julia Vassey)

In a survey conducted by First 5 Fresno, a public organization that invests in direct health, housing, and education services for young children and their families, researchers measured how moms felt during their perinatal period, the period of time just before, during, and after birth. The study asked

whether a patient's doctors or their child's pediatrician demonstrated "cultural sensitivity" during care. Forty-four percent of moms said no.

Despite those responses, only 10 complaints were filed against OB/GYNs in Fresno in the past five years. The low numbers are probably not a reflection of a system free of grievances, but instead one whose complaint system doesn't work well.

Black Infant Health is a California public-health program with regional offices that work directly with black women who are pregnant or new moms. Fanta Nelson, the coordinator of the Fresno program, said that many of her clients don't complain because they're scared of retaliation during their hospital stay. They worry doctors might pay less attention to them, rush through an exam or punish them with longer waiting times if they report them. Others see poor treatment as the status quo. When her clients have a bad experience with a hospital, Nelson says, they shrug their shoulders and say, "It happened to me. It's not the first time." Fuller said she never considered filing a complaint after her experience.

Joe Prado, the division manager of community health for the Department of Public Health in Fresno County, says that for all providers of care to become truly respectful and understanding of diversity, it would require a system-wide approach to train on competency. He likened such a change to the adoption of the Health Insurance Portability and Accountability Act (HIPAA). "Whenever you want to institute something of that magnitude it's going to have to be legislatively driven," he says.

The strain and harm of a negative experience in the hospital doesn't stem from practitioners alone. Simply having a baby in the NICU puts parents at risk for post-traumatic stress disorder (PTSD). For every three moms whose babies are warmed by an incubator, one mom meets the criteria for PTSD at their infant's NICU admission. That experience has lasting consequences. While 10 to 15 percent of mothers of healthy babies meet the criteria for postpartum depression, one study shows that postpartum depression symptoms can be found in at least half of mothers of babies in the NICU.

The stress can start immediately. Just after Fuller's baby was born, she watched a helicopter fly him for emergency surgery 15 miles away. Her mother and boyfriend immediately drove away to meet the helicopter for Jerry's surgery. She was abruptly alone, left to steep in her own fears of what would happen to her baby next. Stress from the NICU can be unrelenting, lingering between visits and after discharge.

Five months after her son's birth, Gomez's family prepared to take Rodrigo home from the NICU. Home was liberating yet terrifying, without the guarantee of a medical staff's watchful eye and without the beeping surveillance of Rodrigo's every bodily function. Then, Gomez got a piece of news that altered her plans even further.

Just a few weeks before Rodrigo was discharged, Gomez found out she was pregnant again. While Rodrigo's preterm birth hadn't been preceded by any known risk factors, short intervals between pregnancies is a risk factor for preterm birth. When Gomez went to her OB/GYN for her 16 week check-up, her nurse explained that her cervix was thinning, and that she should consider a surgical

intervention called a cerclage to sew the cervix closed. The procedure could poke and rupture the sack around the fetus. Gomez decided to wait a week to see how things progressed.

“By the time I went back, it was even more thin,” Gomez says. Nurses sent Gomez to the hospital, but it was too late to intervene. At 17 weeks, Gomez was dilated. “They did [an] ultrasound and they could see her. She was alive and I could see her moving. I could hear her heartbeat,” Gomez told me. “It was around 8:00 a.m. when we heard her heartbeat for the last time.” Gomez and her husband went home, where they knew they’d deliver a stillborn baby. They named her Sarita.

Gomez says that having her son, Rodrigo, who’d just come home from the NICU, kept her busy and from sinking into complete darkness. They buried Sarita on Jan. 4. On Jan. 6, Gomez went back to work. She masked her pain and costumed herself to match the expectations of strength affiliated with motherhood. “When you try to put grief aside, it will come back. With a vengeance,” Gomez says. “And that's exactly what happened to me.”

Around early May, Gomez told me she started feeling debilitating depression. She suddenly had to pull off the highway to weep uncontrollably. Gomez finally reached out to her doctor, who sent her to a therapist. “There is a stigma with mental health, seeking those services,” she says.

A mother’s mental health is connected to how her child develops, adapts, and learns, according to Dr. Cassandra Joubert, the director of the Central California Children's Institute. Joubert has has studied the mental health of mothers and infants in Fresno for 10 years, and she says that the quality of the mother-infant relationship in the earliest part of a child’s life is a strong predictor of childhood wellbeing. “If a mom is depressed, she's not able to give her child, through interaction and through a nurturing relationship, what that child needs for healthy brain development,” Joubert says.

A bill before California’s legislature would require providers to screen for anxiety and mood disorders during prenatal, postpartum, and well-child visits. The legislation actually makes it a crime for providers to not screen their patients. And yet, only half of the city’s OB/GYN providers said that they formally screen moms for depression, which is reflective of the national pattern. Slightly more than half of all perinatal medical providers said they don’t know enough about maternal depression. Three quarters of providers, including behavioral health providers, said they weren’t trained to deal with pregnancy-related mood disorders.

Experts like Joubert and Capitman believe it’s also important to focus on more culturally-specific approaches to providing mental health treatment services for underserved communities. Some alternative approaches exist in the system already through Black Infant Health.

La’Shawn Gaines is a 30-year-old mother who lives in Fresno. She relocated to California after living through Hurricane Katrina, the psychological effects of which were never discussed in her family. After visiting an OB/GYN during her first pregnancy, she learned that her years of suffering had a name: depression. Her doctor suggested that she find a therapist, but she says they didn’t formally screen or follow up with her. Gaines told me that after her daughter was born in 2010, she became an

alcoholic. “I didn’t know how to get help,” she says. It was years before she sought out professional assistance.

La'Shawn Gaines and her girls, in their Fresno home (Margaret Katcher)

In 2017, when Gaines was pregnant with her youngest child, symptoms of depression persisted. She withdrew physically, isolated in her bedroom with blankets hung heavily over the windows. She withdrew emotionally, incapable of doing more than the bare minimum, sitting in numbness as her two children tried to make her smile. One morning, her doorbell rang. Through her window, she saw a lone woman, Megan Black, and opened the door. Black explained that she was a part of Black Infant Health, and asked if she could offer Gaines any help. Black soon became Gaines’ case manager, and invited her to parenting meetings and prenatal groups.

Black Infant Health workers like Black pay home visits in areas with concentrated poverty. If they notice mothers or pregnant women, they reach out directly, and ask if they need support. After a few weeks of meetings, Gaines told Black that she was depressed, and didn’t know where to find help. “I have therapists here,” Black told her, referring to Black Infant Health. “I can give you a referral.” It was as simple as that.

These initiatives require investment, and the Fresno Department of Public Health says that targeted programs are often the first to lose funding when budgets are cut. In Fresno’s recent history, changes in spending for maternal and infant care seemed to have serious consequences. In the ten years following the establishment of Black Infant Health’s Fresno office in 1991, the county's black infant mortality rate decreased by two thirds, from 37 to 11 per 1,000 births. But then came funding cuts. In 2007, Fresno Black Infant Health had 11 employees and a $1.3 million budget. After the economic recession, in 2010, the organization had two employees and a $250,000 budget. In that span of time, the county’s black infant mortality rate more than doubled, to 27. That’s nearly three times the

statewide average that year. Rosemary Rahn of the Department of Public Health says she believes that the reduction in budget for maternal and child health led to an increase in adverse birth outcomes.

There are many factors that can cause fluctuations in preterm birth and infant mortality rates, but what happened in Fresno suggests a correlation between reduced funding for services like BIH and and infant mortality. Joubert says that tailored support shouldn't be seen as an addition to basic care; it should be considered a fundamental tenet of basic care. "We suffer at the local community level. We suffer at the state level. We suffer as a nation if we fail to acknowledge those disparities," Joubert says. "There's all of this push for 'we need evidence-based approaches.' Well, what good is evidence if you won't use it?"

After Gomez lost Sarita in 2017, she had good medical care to recover physically, and found a counselor to help her recover mentally. She and her husband tried to get pregnant again, and she did. She learned a lot over the years. She started interventions at eight weeks. On April 21, Gomez went into labor again. This time, the labor was early, but just by a few weeks. She delivered Francisco Xavier, a healthy five pound, five ounce boy by c-section. When she heard his cry, she says it was the most beautiful sound on earth.

Julia Vassey contributed reporting to this story.

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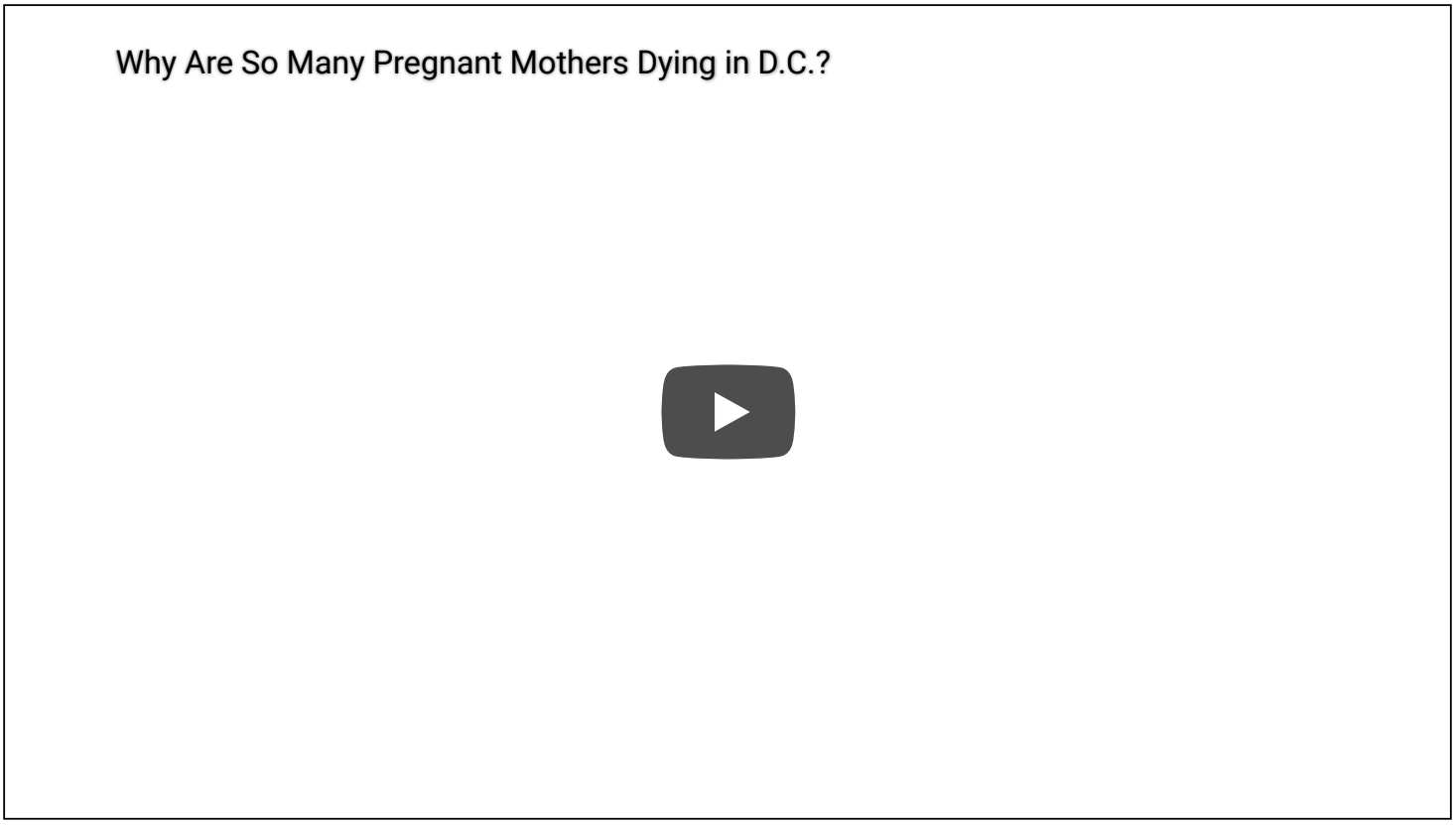

MARGARET KATCHER *is a freelance reporter and audio producer living in Oakland.*