

THE COVID CONUNDRUM

As health advocates seek equity in providing vaccines, many people refuse to get inoculated

SALLY J. ALTMAN, MPH

It had been a rough last few months of 2020 for Kim Daniel, a resident of Preservation Square, an impoverished neighborhood just a mile northwest of downtown St. Louis. She had lost seven family members ranging in age from 22 to 81, three of them to COVID-19.

Daniel, 54, has suffered all her life with a congenital heart disease that has taken her to death's door several times. And as 2021 rolled around, she had been feeling poorly. She had gotten tested for COVID in November, and thankfully the results were negative. But her doctor suggested that her feelings of fatigue and malaise might be related to her anxiety over the pandemic. As Daniel paraphrased him, maybe it's "the atmosphere of things."

As 2021 dawned, the Pfizer vaccine entered into Daniel's atmosphere of things. You might think it would give her some hope.

St. Louis City's public health officials made the vaccine available to eligible residents on a winter day at Union Station, a five-minute drive from Daniel's home. More than 1,800 residents got their first dose there on Jan. 30.

But Daniel, who likely would have qualified for a shot, said she wanted no part of the vaccine.

"This is too early, too soon, too new," Daniel said.

But would she at least talk to her cardiologist about the vaccine?

"No. I won't ask him because I'm not going to take it."

Don't you want his advice?

"I appreciate doctors and what they do, especially those who are willing to take the time to listen to me and will respond accordingly. But for me, in my life, the doctor's opinion is not the final opinion, so I don't."

Daniel may be wrong about the efficacy of the vaccine, but her point of view isn't based on ignorance. She reads widely and because of her lifelong health issues has a half-century of experience with some practitioners who have treated her and people she knows with indifference and sometimes cruelty.

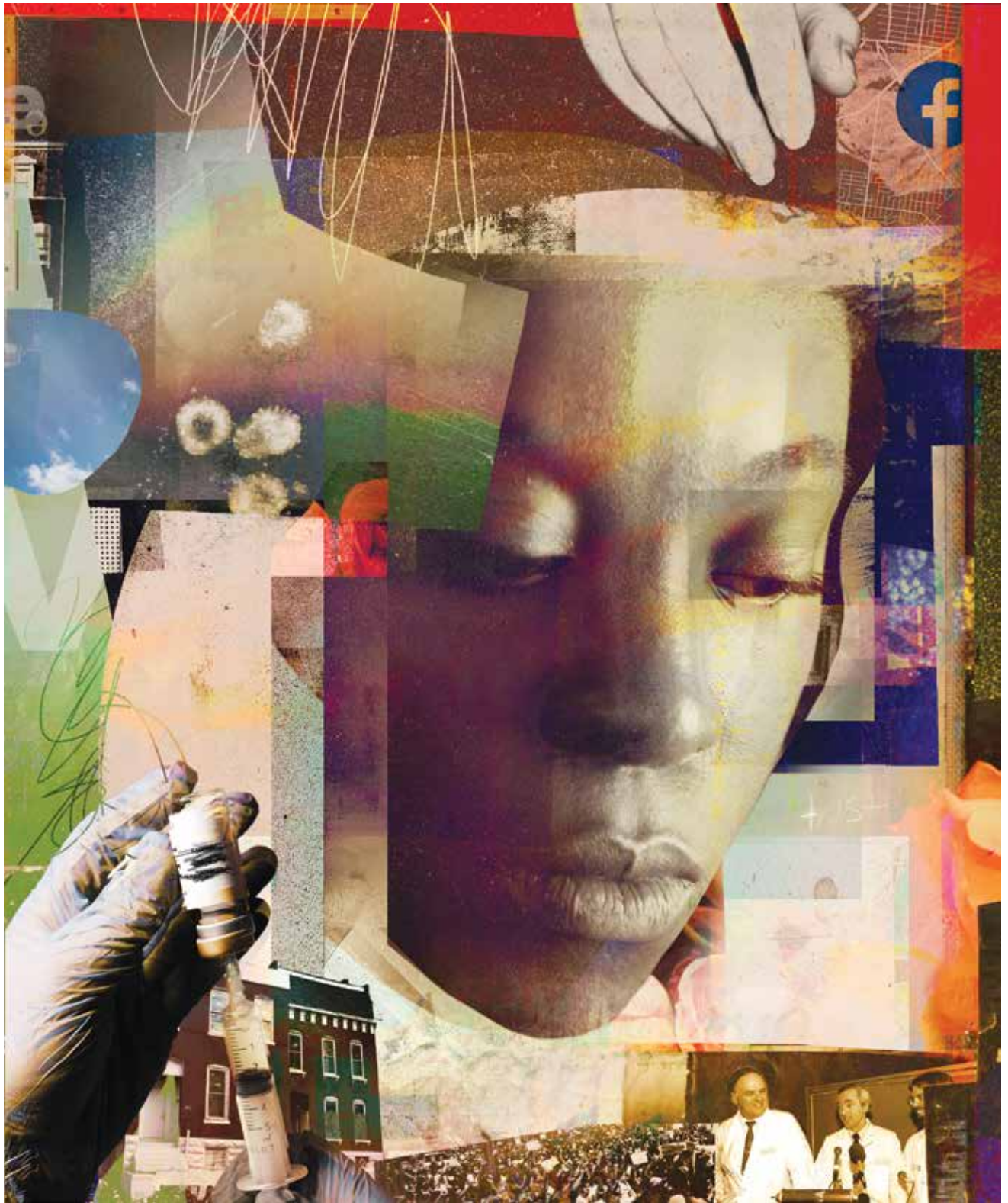


Illustration by Jon Lezinsky



Photo by Wiley Price

Kim Daniel distributes boxes during a food drive at the Flance Early Learning Center on Feb. 5, 2021.

The nonprofit racial equity storytelling project *Before Ferguson Beyond Ferguson* has written about Daniel and seven other nearby families in serial fashion since the start of the pandemic. As of this writing, not one of them has been vaccinated, nor do they want to be.

This amounts to no more than anecdotal evidence, but studies also show widespread resistance to the vaccine among people of color and those who may be most vulnerable to COVID-19.

This is particularly vexing for those who work in public health. Even before the pandemic — actually for decades — they had been clamoring for access to health care for people in marginalized communities. Without it, advocates say deaths from curable and treatable diseases fall far more heavily on people of color — a slow rolling genocide.

A case in point: Researchers at Washington University and Saint Louis University studied the social determinants of health in zip code 63106 where Kim Daniel lives, along with approximately 11,000 other people of color. They then applied the same lens to 63105, just 10 miles away, which is home to some of the region's wealthiest and mostly white residents. They found that the average lifespan of a baby born in 63106 in 2010 would

be 67 years old. Compare that to a life expectancy of 85 years for a newborn in 63105. And this, of course, was before COVID came along.

The pandemic made these disparities even more vivid. Analysts are finding that Black Americans have been dying from the virus at a rate 1.5 times as high as white Americans in cases in which race was known.

That should be a wake-up call to both white and Black Americans, public health advocates say. It should not only spur people to get the vaccine when they are eligible and when it can be supplied, but also to address the health care delivery system as a whole. With a new administration calling for racial equity and improved health care, perhaps this is more possible now.

But health workers on the front lines are facing a high degree of skepticism among those they want to help.

Along with Kim Daniel consider Beverly Jones, a community activist and social worker living in 63106. As a young adult recovering from a drug addiction, Jones pulled herself together, finished college and went on to an advanced degree.

"Are you going to get the vaccine?" a reporter asked.

"I am in no big hurry to get it."

“Why not?”

“It’s just too much. You all want us to just trust you all. You all rushed through this thing, put it together in six months, and now we are just supposed to fall in line and just go get it? No, no. I think you all need to do a little bit more, first, because my trust level ain’t all that great. It took me about 10 to 12 years to even get a flu shot.

“I’m just not willing to just keep opening myself up to new stuff. I’m just not.”

“So if they contact you, you’re not ready yet?”

“Yeah. I’m not ready yet.”

Tyra Johnson, who is also participating in the 63106 Project, is the single mother of three children, one an infant, and two who are preschool age. She is so fearful of COVID that she only rarely lets her children play outdoors and has decided to homeschool rather than sending her eldest two children back to classrooms.

Johnson has mostly relied on information she gets from her friends and what she finds on Facebook.

“Some people, they’ve been getting it, and they don’t know what’s all in it,” Johnson said.

“I saw a live video on Facebook. A lady took it and she dropped dead. It’s not safe.” Misinformation about the vaccine is spreading rapidly, and can make messaging a challenge for those trying to encourage vaccination.

Johnson is willing to quarantine and stay at home, but she is absolutely against getting the

vaccine. “I’m not taking it. Everybody in my family agrees and feels the same way.”

Steven Jones is 32 years old and the father of four daughters. He suffers from epilepsy, which has put a crimp in his ability to find work. Many of his neighbors have had to keep working with the general public, their faces just inches from potential contagion every day.

When asked if he registered for the vaccine, Jones hesitated, then said: “Overall, vaccines are great. (But) I have a problem with how fast they pushed it, the red tape that they cut through to get it done. They usually say it takes two to five years of getting it out to people, getting the data back, and seeing if any short or long-term effects are happening ... We don’t even know if those weapons even fire correctly or they’re gonna backfire.”

So no, neither Jones, nor his mother, nor the mother of his children, nor his children want to get inoculated.

And then there is Misha Marshall, a health care worker. Marshall works daily in pediatric clinics across the region as a medical technician.

“Do I think a vaccine is a great thing?” Marshall said. “Sure. Yes. Am I ready to get it? No. It’s too new. It’s way too new. Will I ever get it? I can’t say.”

Few public health experts find this skepticism surprising. Local experts Angela Brown, Bethany Johnson-Javois, Herb B. Kuhn and Dr. Will Ross, writing in *The St. Louis American* on Jan. 30, cited a study saying that Blacks were “the most reluctant group by far” to want to get inoculated when vaccines became available.

While this COVID conundrum is a nationwide problem, St. Louis gets a lot of attention as it has long been considered a locus for racial disparities since the police shooting of Michael Brown in 2014 and subsequent civil unrest.

The PBS News Hour interviewed Jason Purnell, vice president of community health improvement with St. Louis-based BJC HealthCare. He noted that the region is to some degree flying blind in its response because “we’re not tracking in a rigorous or reliable way where the greatest need is.”

Indeed, in a briefing in early February, the White House noted that nearly half the data collected on people infected by the virus and those receiving vaccinations did not contain information on their race or ethnicity.

Purnell, Brown, Johnson-Javois, Kuhn and Ross all say African-Americans have ample reason to be skeptical of their doctors and the health system in general.

“There are certainly legitimate reasons for dis-



BEFORE FERGUSON BEYOND FERGUSON
THE 63106 PROJECT

Before Ferguson Beyond Ferguson, a non-profit racial equity storytelling project, has been shining a light on the lives of people in the 63106 zip code as they deal with the daily impact of the pandemic.

St. Louis media outlets agreed to collaborate with Before Ferguson Beyond Ferguson and carry stories in serial fashion — a new “episode” approximately every six to eight weeks. So far eight families have been covered with one or more installments; reporting and research is underway for one more family. The project thanks its funders listed on its web page, including significant support from The Pulitzer Center.

The stories can be found at <https://beforefergusonbeyondferguson.org/63106-project/>.

trust based upon both history and contemporary experiences with public health and health care,” Purnell said. “Among the best ways to address distrust are to lead with empathy, listen intently, share information transparently and respond with accountability. We do have information to address concerns, but it has to be shared by trusted messengers in the spirit of supporting informed choices.”

Purnell noted that health care advocates should avoid regarding all African-Americans as skeptics. He cited a survey of 1,340 respondents from the National Foundation for Infectious Diseases, which showed far greater acceptance among older African-Americans, with 68% of those 60 and older saying they plan to get vaccinated. Just 38% of those aged 18 to 44 said they had similar plans.

Purnell noted health care workers can provide solid answers to skeptical queries about the vaccine.

Among them:

- Clinical trials were designed to include diverse populations, and COVID vaccines are highly effective whether people are getting the Pfizer, Moderna or the Johnson & Johnson versions. They are far more effective than the vaccines for influenza.

- When choosing between the vaccine or simply accepting the risk of contracting the virus, COVID-19 is by far the more dangerous option, according to information provided by *The New York Times*. “COVID vaccines carry little known risk. But the perils of COVID-19 have been well documented,” the *Times* noted. “About 20 percent of people who come down with COVID-19 symptoms develop serious, potentially life-threatening illness.”

- Known side effects of the vaccine are similar to those for flu and other common vaccines. Allergic reactions occurred in just one-half of 1% of participants.

- Most people will be able to receive the vaccination at no cost, and almost everyone for less than \$25. No one in the United States can be turned away if they are unable to pay.

Tami Timmer, executive director of the F lance

Early Learning Center, where Kim Daniel works and where Tyra Johnson once sent her children, finds herself in a delicate position when it comes to vaccine hesitancy.

Timmer, who is white, works with a diverse staff of 32 whom she wants to protect from COVID. So it makes sense to encourage them to get the vaccine when it becomes available.

Even so, Timmer says she is unlikely to make it a requirement, although F lance does require other vaccinations.

Timmer has polled F lance staff concerning the COVID vaccines and has found that no one has received an injection, and “a significant number” have said they will not get

it. She finds this dismaying, but unsurprising. “We prefer that people get the vaccine for their health, not because it’s beneficial to F lance. But we fully respect our staff and the journey their lives have taken them in making their own medical decisions,” she said.

Timmer says she understands that “the medical industry has not been fair or equitable to minority communities. They have no reason to trust the medical community right now. They just don’t.”

Many African-Americans are familiar with the Tuskegee trials in which African-Americans were told they were getting treated for syphilis when they were not.

Stories such as these are not only in history books but again “in the atmosphere of things.” Timmer recounted a story she heard from a nearby resident who frequently comes to the weekly food giveaways that the center started during the pandemic. Striking up a conversation, Timmer asked the resident about his family. The elderly gentleman noted that he was one of 22 children. Remembering that he was married, Timmer asked if he had any children. “No,” Timmer recalled him responding. “I was part of a forced sterilization.”

“This was a human being that lived across the street,” Timmer said. “Our medical community sterilized him.”

More evidence of indifference and cruelty: Numerous studies show that physicians failed to



Beverly Jones

Denise Hollinshead

respond appropriately when African-American patients said they were in pain. A meta-analysis of 20 years of studies covering many sources of pain found that African-American patients were 22% less likely than white patients to receive any pain medication, according to a report published by the American Association of Medical Colleges.

Testimony before a U.S. Senate committee revealed that in 1972 as many as 2,000 impoverished Black women with multiple children were forced into sterilizations without their consent or knowledge. Many others provided their consent but only after being told that they could not receive their welfare benefits until they did. The surgeries were performed with funds from the U.S. Office of Economic Opportunity.

In light of all of that, Timmer says she has learned to tread softly when it comes to vaccines — any vaccine. “We only had about 60 percent of our staff get free on-site flu vaccines,” Timmer recalled.

Even so Timmer said Flance has asked to become a distribution site for the vaccine when more supplies become available. “Foremost right now we are educating our staff,” Timmer said. “I send out at least twice a week videos, links and information regarding registrations.” The center has been working closely with the City Health Department, she said.

Meanwhile African-Americans in the forefront of medical science are mounting a much more aggressive campaign. Sixty Black members of the National Academy of Medicine signed on to an op-ed in *The New York Times* calling on African-Americans to get vaccinated. “Disinformation about the coronavirus and vaccines has pervaded social media, feeding on long-held ... distrust of health institutions in Black communities,” wrote the lead authors, Dr. Thomas A. LaVeist and Georges C. Benjamin. “The lies are an assault on our people, and it threatens to destroy us.”

Also joining in: the Association of Black Cardiologists, an 1,800-member nonprofit organization with a mission to bring attention to the adverse impact of cardiovascular disease on African-Americans. Adding to its news release advocating for vaccinations, the Association of Black Cardiologists published a series of photos showing their members getting injections. The captions included their comments. “Taking the vaccine is a no-brainer for me,” said Dr. Michelle Albert, a San

Francisco cardiologist and the association’s president, who stepped up for the Moderna vaccine.

Public health experts both on the national and local levels are also expressing concern about resource allocation. Missouri Gov. Mike Parson took criticism for funneling disproportionate amounts of vaccine to outstate regions. On March 10, he said he would send more vaccine to St. Louis and expand eligibility.

Health care advocates have called on states to use the Social Vulnerability Index, a measurement devised by the federal Centers of Disease Control. The index applies to every zip code nationwide and includes measurements on factors such as poverty, housing and access to transportation. On that scale 63106 rates as highly vulnerable. With 1.0 standing as the highest for vulnerability and 0.0 the lowest, zip code 63106 scored .0862. By comparison 63105 came in at .0176. The measurements are from 2016, the latest available. https://www.atsdr.cdc.gov/placeandhealth/svi/fact_sheet/fact_sheet.html

With a tool like that, policymakers would know better where to allocate their resources, and non-governmental organizations, such as faith groups, would know better where to focus their attention.

Testimony before a U.S. Senate committee revealed that in 1972 as many as 2,000 impoverished Black women with multiple children were forced into sterilizations without their consent or knowledge.

One such group in St. Louis is already at work. Faith and For the Sake of All coordinates activities among dozens of church groups aimed at improving the health and well-being of people in Black communities. The Rev. Gabrielle Kennedy serves as director for the organization. She has refused to wait around for governmental bodies and health care systems to create a fair and equitable rollout.

“There are systems that have to work and we understand all of that, but we couldn’t wait for that system to do what it was supposed to do,” Kennedy told St. Louis Public Radio in November. “We had to try and find a way to do it ourselves.”

Kennedy said the organization started by providing sites for COVID testing and flu shots. Now

it is mobilizing to educate people about the vaccine and, just as importantly, undertaking outreach efforts to ensure skeptical residents have all the information they need to make an informed decision about receiving an inoculation. Faith and For the Sake of All hosts panel events and small group discussions with area congregations to create relationships between Black communities and area health professionals.

Kennedy notes that some families are eager, in some cases desperate, to get vaccinated, including those who are caring for elderly relatives.

In all cases, Kennedy said, health workers and policymakers need to re-build relationships with African-Americans. “Without acknowledgement of past wrongs, and regular intentional interactions, it will be difficult to build trust.”

This article includes additional reporting from **JEANNETTE COOPERMAN**, **DENISE HOLLINSHED**, **AISHA SULTAN** and **RICHARD H. WEISS**.

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A previous article about the 63106 Project also appeared in the Fall 2020 issue of *Health Progress*.

RELATED RESOURCES

The St. Louis American article about the COVID paradox — overcoming disparities and vaccine mistrust: http://www.stlamerican.com/news/local_news/a-covid-19-paradox-overcoming-disparities-and-vaccine-mistrust/article_77bd30b0-636c-11eb-ad2e-efd02717be82.html.

National Foundation for Infectious Diseases: <https://www.nfid.org/>.

“Answers to All Your Questions to Getting Vaccinated for COVID-19,” *The New York Times*, Feb. 19, 2021, <https://www.nytimes.com/interactive/2021/well/covid-vaccine-questions.html>.

Association of Black Cardiologists vaccine news release: <https://abccardio.org/recent-news/abc-advocates-for-vaccinations-in-communities-of-color/>.

Social Vulnerability Index fact sheet: https://www.atsdr.cdc.gov/placeandhealth/svi/fact_sheet/fact_sheet.html.

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— REV. GABRIELLE KENNEDY

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