



Fighting From the Grave for the New York Health Act

MARIANA ARCHIVAL TAPE:

Attribution: Mariana Pineda speaking at rally/event in Albany, New York in 2022.

Audio: “My name is Mariana Pineda. I am an immigrant and a former public school teacher. I was discharged from the ICU in Sept, and in October, I was sent my first bill. I have not been paid since Oct. 2020. I used to live in a three bedroom home, I now live in a homeless shelter with my autistic six years old.”

That’s healthcare justice activist Mariana Pineda speaking at a rally in April, 2022 in Albany New York. She’s wearing a face mask and is using a rollator for stability.

Audio: “Lack of health care leads to bad outcomes leads to financial loss leads to homelessness. I am currently unhoused, I currently do not have a home health aide. Thankfully, I have Medicaid, and hopefully, I will cover this \$1,540 bill, which is the only bill I’ve received this week.” [Courtesy of Poor People’s Campaign: A National Call for Moral Revival, New York State Media Team](#)

After developing Long COVID, Mariana spent years navigating the same fragmented healthcare system she was fighting to change. She lost her job. She lost her health insurance. She lost her home. And in March, she lost her life. Mariana was just 46 years old.

How did a beloved teacher, organizer and healthcare justice advocate end up trapped in the very system she spent years trying to reform? And what can Mariana's story teach us about the lives that may still be at risk today?

Welcome to Code WACK!, where we break down how our healthcare system really works, what it means for you, and how we can make it better for everyone. I'm your host, Brenda Gazzar.

Mariana, who used the pronouns she, they and el, spent years fighting for the passage of the New York Health Act, a state-based single-payer bill that would guarantee health coverage for every New Yorker. Care would be publicly funded but still delivered by private doctors and hospitals.

Susan:

“She'd go to Albany every year to promote the New York Health Act, and she said once she was so disgusted with the legislators who didn't pass the New York Health Act. She said, “I hope when I die that I die on their doorstep, it will be a good message for them.”

That's Susan Karbiner, a tri-chair of the New York State Poor People's Campaign: A National Call for Moral Revival and a coordinator for the movement's Long Island region. Mariana met Susan and started working with the Poor People's campaign in 2018.

Susan:

“When she was a teacher, before she got COVID, she had what is considered pretty good health care insurance through her employer.”

For Mariana, losing her health wasn't the only crisis. Losing her ability to work also meant losing the insurance she depended on. Supporters of the New York Health Act say that should never happen.

Susan:

“Now, why should healthcare have anything to do with employment? This is really dumb. What about people who aren't employed or whose employers don't give them good health insurance? What about people who stay with an abusive husband because they're on his insurance and they don't want to lose it?”

She lost her insurance, and she had so many medical problems she couldn't afford to pay for insurance after she used up her savings, and as a result she had to go on Medicaid.

As Mariana's health deteriorated, access to specialized care became increasingly difficult. Friends say that once she lost her employer-sponsored insurance, the doctors she desperately needed became harder—and sometimes impossible—to reach. Here's what Carly Paris, one of her closest friends and a fellow activist, says about that.

Carly:

“She didn't have the insurance to be able to go to specialists, so she was kind of left just floundering, because there was nothing she could do. She'd go to the hospital, which would help her in the like acute stages, and they would eventually rather help her deal with that, but then when she'd leave there, there was really nothing for her to do, because the doctors were unobtainable for her.”

The challenges extended beyond doctor's appointments and hospital visits. As Mariana became sicker, everyday life itself became harder to manage. She struggled to obtain a home health aide through social services—support that could have helped her wash dishes, care for herself and her young son.

Supporters of the New York Health Act say it would cover long-term care services, including home health aides, potentially making it easier for people like Mariana to receive assistance at home.

Susan:

“One of the problems with home health aides is that there's a severe shortage because they don't get paid enough money. It's not that it's an undesirable job, it's that they can't afford to support their family on the minimum wage that they get as home health aides, so she would be told that she was going to get an aide, and then she wouldn't get one, and the person who was listed in her medical records as her backup got a call because they couldn't get in touch with her to say they had a home health aide for her, and that was two days after she died.”

Carly believes that had single payer healthcare been in place in New York, Mariana could have been alive today.

Carly:

“Well, It would have meant that she would have been able to see specialists easier. It would have meant that in the first place she wouldn't have lost her health care when she became unemployed due to illness. It would have meant that her friends who passed away before her for very similar reasons wouldn't have, and I think it could have meant that Mariana wouldn't have passed away at such a young age of 46 because she would have had [better] access to health care.”

Of course, no one can know with certainty whether a different healthcare system would have saved Mariana's life. But her supporters say that the obstacles she faced – financial, bureaucratic and logistical – are exactly the kinds of barriers the New York Health Act was designed to remove.

Carly:

“Even though Mariana did everything right. She got an education, she had so many certificates, she was a teacher. She still was at the whims of the healthcare system, and just getting COVID kind of derailed her life. And that can happen to anybody.”

Susan agrees and believes it could have dramatically improved the quality of the years Mariana had left.

Susan:

“There's no way I can know how long she would have lived but she could have lived longer. She could have lived a better life in her later years. She wouldn't have been in a shelter.”

For Carly, who suffers from chronic health conditions, having Medicare for All would be a game changer for her and her family.

As a child in elementary school, she was covered under her biological father's health insurance. After she became ill, she and her mother went to the pharmacy to pick up her medication – only to find out that he had dropped her from his plan without telling them.

Carly was also diagnosed with stage four deep infiltrating endometriosis and adenomyosis, which she's had five surgeries for after she was diagnosed around the age of 19. She says the surgeries and doctors visits were all paid for out of pocket.

Carly:

“My mom took out over \$60,000 and now she has no retirement fund. I mean, I'm in therapy for other things, but that is one of the things that comes up for me regularly, is how much I feel like a burden because of that.”

Carly's mother, who considered Mariana another daughter, had open heart surgery last year

Carly:

"She just had a mini heart attack and mini stroke and so I'm looking at her like, "Oh my gosh, she's working herself to death because she doesn't have a backup plan."

Susan's story illustrates another reality of America's healthcare system: the profound ways insurance shapes life decisions, careers and even marriages.

"Susan's husband gave up a job he loved so that they would have lifetime health insurance after Susan was diagnosed with an incurable disease."

Susan:

"He realized that he was probably going to die before I did, and that I wasn't going to have adequate medical insurance to cover my expensive payments, so he left the job, which he liked, and he took a job, which he did not like, but which guaranteed health coverage insurance for him and his spouse for life, so he died in 2017 and I am on Medicare, and the health insurance, which he made possible, that still covers me."

"I feel so happy to have been so loved, but it shouldn't be that way. Insurance shouldn't be tied to a job or a spouse, it shouldn't be tied to anything, it should be a human right for everyone."

Today, Susan continues the work that Mariana cared so deeply about. Much of that effort begins with a simple challenge: helping people understand what the New York Health Act would actually do.

Susan:

"It provides every kind of coverage that private insurance covers plus hearing, vision, dental, mental health, reproductive care and long term care all at a savings compared with what we're paying now for health care. We're paying more for health care than any other country in the world and getting worse care than all the other developed countries."

Susan and Carly continue the fight. But they say the movement lost something irreplaceable when Mariana died—a leader, an organizer, and a voice that inspired others to believe change was possible.

Carly:

"Oh my gosh, they lost one of their fiercest advocates, they lost one of their biggest, like, champions for it, they lost someone who was able to just bring people into the movement, bring so many people into the movement. They lost a great orator. They lost a huge force for the movement."

Mariana Pineda spent her final years fighting for a healthcare system she knew would save lives. Today, others are carrying that fight forward partly in her name.

Archival audio: **"And when I am too sick to fight, I know that all of you are going to keep fighting for us. ¡El pueblo unido jamás será vencido!**

(Crowd: "Fight, Fight, Fight, Healthcare is a human right.")

Rest in power, Mariana Pineda.

If you enjoyed this episode and would like to support Code WACK, subscribe, leave a review and share this episode with a friend.

This episode was powered by HEAL California, uplifting the voices of those fighting for healthcare reform around the country.

Thanks for listening. I'm Brenda Gazzar and until next time, stay healthy.