



Rise Up: 'They get rich while we fade away'

*Featuring Daniel Ray Hilsinger
Singer/songwriter and health justice activist*

Dispatcher: 911, what's your emergency?

*Caller: America's healthcare system is broken and people are dying!
(ambulance siren)*

Welcome to **Code WACK!**, where we shine a light on our callous healthcare system, how it hurts us and what we can do about it. I'm your host, **Brenda Gazzar**. This time on **Code WACK!** Imagine being diagnosed with bone cancer while in your twenties. How might that affect you and your life decisions? We recently spoke to **Daniel Ray Hilsinger**, a Northern California-based filmmaker and singer/songwriter who received that diagnosis 5 years ago. The healthcare justice activist writes songs to inspire change.

(partial lyrics of song "Rise Up")

Welcome to Code WACK! Daniel.

[\(01:04\)](#):

Hilsinger: Thank you so much. I'm so happy to be here.

[\(01:06\)](#):

Q: *Thanks for being here. So tell us a little bit about yourself. Who are you and where are you from originally?*

[\(01:12\)](#):

Hilsinger: I am originally from California – (the) Bay Area, that's where I was born and I grew up and I lived in a couple different places. I lived in New Hampshire and New York and then my dad actually got diagnosed and was sick. My dad fell and broke his jaw and then he ended up being diagnosed with a rare illness and so I moved home to California semi-temporarily. Six months after that, I got diagnosed with bone cancer and got really sick. So that year was just really tough and transformative and pulled me back home and my whole life has shifted, you know, dramatically since that point and I'm just really grateful to be here still and to get to be alive and to have my leg and to be able to walk and so many things.

[\(01:57\)](#):

Q: *Yeah. Wow. So you were 29 when you were diagnosed with bone cancer. Tell me more about the impact that had on you and your life.*

[\(02:06\)](#):

Hilsinger: Ooh. It was just so massive. It's like, you know, getting the rug pulled out from underneath you, I think was kind of an analogy of a feeling. It's so hard to describe and to remember and to think about even though it was five years ago. It all happened so fast too I think is a big thing. But I was at this point in my life where I actually kind of felt a little stuck. I wasn't doing quite well. My dad had gotten sick too, but I had just gotten into activism actually. That was the year that Bernie Sanders ran a presidential campaign. And I got kind of pulled into some of those ideals that he talked about and actually got elected as a delegate for the (Democratic) National Convention and two weeks later I was diagnosed with bone cancer.

[\(02:46\)](#):

So I kind of was in this really weird space where I, you know, was in a wheelchair because I just had a surgery to figure out if you know what was happening in my leg was cancer or not. And you know, it was just so scary. It's hard to even talk about I think and to remember, but it really just changed everything. You know, I think at that point in my life, I still had a goal or a dream to go back to New York and to make films. And, you know, that changed everything to just very simply I want to survive.

[\(03:19\)](#):

(Lyrics)

[\(03:21\)](#):

Hilsinger: For that first year or two, then it was, you know, once I was diagnosed, I was diagnosed with a really rare, aggressive form of bone cancer. And so it's like once I was diagnosed, it was like two weeks later, I'm in the hospital getting a surgery to put a port in my chest and a port is one way to administer really intensive chemo if you're going to get a lot of chemotherapy and then the week after that, I was starting inpatient chemo for like five days straight. And so I get that and then I go home for three weeks and then I do that again when I kind of would recover. And I kind of was just so into that program and that's when I think I first started learning more about healthcare justice specifically. And it's also when I just started learning more about health and wellness and what does that mean? And you know, what impacts our health and, you know, from the food we eat to the air we breathe to water we drink to, you know, our emotional and psychological health. It's just been really transformative. You know, I'd been learning so much since then, I think just because I, but like I needed to, to survive and yeah, it's been a big change.

[\(04:24\)](#):

Q: *Wow. What struck you the most about our healthcare system as you were getting treated and what struck you about the other cancer patients you met during this time?*

[\(04:33\)](#):

Hilsinger: One thing is I come from a place of privilege. I'm, you know, in a white body in this world and also a male body and I was born into a family where my dad was a doctor. And so I actually grew up with just excellent health care – one because my dad was a doctor and I had full coverage up until, I don't know, is it originally 18? And then it got, I think Obama extended it to mid-twenties. I kind of like am forgetting, but at that time, I wasn't covered, you know, in that way but I grew up with that privilege, but also a part of that privilege is, you know, the insiders of like a lot of my dad's friends are doctors. And so like on top of the insane privilege of being white in this world and being in a male body and having full healthcare coverage and not ever having to worry about it as I grew up, I'm also, you know, had just like anything with it's like personal connections.

[\(05:22\)](#):

So, you know, it's like my dad could answer these questions and I was pretty well versed in, I guess, like medical communication in the Western allopathic system. And so it was much easier for me to navigate situations and questions and answers with doctors and with nurses during the whole process than I think many people in this world, right? Because we don't all happen to have that experience. So I grew up with that privilege. At the time of my diagnosis because of the circumstances of moving back home to help my dad, when my dad was ill that same year, I didn't have health care. I was in this weird limbo where I ended up getting on Medi-Cal because I wasn't working. I was just helping my, you know, (being a) caregiver for my dad. And so I was

on Medi-Cal, but I think, you know, something that I was lucky and privileged to have was that knowing how to navigate the process to some degree and having a lot of support, you know, through personal networks of how to navigate the whole situation.

[\(06:19\)](#):

And so I want to speak to that. Not everyone has that. And so what I ended up seeing is I'm in the chemo ward at UCSF and I just had tremendous care, but I'm, you know, I'm seeing a wide range of diversity of people in that chemo ward. You know, one, most people are much older – just the chance of being diagnosed with something like this at that age is rare. But, you know, these people came from all walks of life and not everyone was able to navigate those circumstances in the same way that I was just because of my knowledge of how to talk and things like that and I met people really struggling and being at a time in your life when you are the, literally on the edge of life or death and it's just like an overwhelming pressure and fear also having to navigate this system that is so broken and is so confusing I think in many ways.

[\(07:18\)](#):

(lyrics)

[\(07:25\)](#):

Hilsinger: Like, even for me, even for me who had grown up in this privileged way, with all this knowledge, it was very challenging to be able to just like get through a day, you know, and it's like ...calling all the people and navigating the insurance and navigating providers and navigating the drugs and navigating all of these things is just so much. And I, you know, I met people who really were struggling with that. People, other people who are on private insurance, who, you know, literally are like spending hours of their day on the phone with their private health insurer, you know, fighting for which is how it actually feels. Even for me navigating, it felt, it almost feels like that. It's like I'm fighting for my life and I'm fighting to, you know, get the coverage that I need at the same time and that just seems like such an overwhelming and tragic and horrible burden. Like I can't even conceive of a world where that is, you know, where that is the norm, but it is the norm in the United States.

Speaker 6 [\(08:25\)](#):

Q: *Mmmm. Right. Wow. Thank you for sharing that. So how did you become inspired to become a musician?*

[\(08:35\)](#):

Hilsinger: You know, I've always loved music. I feel like so many people I know love music, and I've always enjoyed music. You know, when I was, I don't know, in third grade, I think I played clarinet for a year or two, something like that, you know, but that was like my only history and I think it was like something to do and something my mom wanted me to do, but it wasn't a thing really. And I think my whole life, I always wanted to learn guitar. You know, I grew up I think listening to the music that my mom liked most. And a lot of that music is like guitar-based

Western, you know, like classic rock or rock or folk music. And, you know, there were a couple times in my life where I was like, you know, picked up a guitar and like learned a chord or two, but I just never made time for it.

[\(09:18\)](#):

And then when I was diagnosed, I, you know, I made a couple decisions, but one of them was to pick up the guitar and really learn and, you know, spend time doing that because it's something I always wanted to do, but I never made time for, and you know, I was going to be in a position where I wasn't gonna be able to walk that much for at least a year. And so I was going to be bedridden a lot and not have a lot of energy, but also just not physically be able to move around that well but you know, you can still hold, I could still hold a guitar on my lap if I was in the hospital or at home and so I started learning and I don't know, somehow I'm still here and since then, I've just continued to learn. I'm still learning.

[\(10:01\)](#):

I'm like a baby on the mountain of learning, you know, music and guitar. But that's also when I started to write songs and I just have continued to do that. One other memory I have actually that's coming to mind is at the chemo ward where I was, there's this stairwell, you know, I would be in a wheelchair sometimes or I'd be on crutches or sometimes I could kind of walk and I'd have literally like a gurney attached to me because of the drugs and different things that are like essentially connected to my body. So I'd like wheel this gurney out to the stairwell that opened up into like an exterior stairwell with fresh air to breathe fresh air. And I'd just spend some time there. That's when I started singing, I used to sing in the shower sometimes, but it was just not a part of my life until then and you know, I'd sing covers, like I don't know, "Sitting on the Dock of the Bay" or like "House of the Rising Sun" or something like that. And yeah, I just have kept going since then. I just love it so much, just like I feel it's a big part of why I'm still here.

[\(10:59\)](#):

Q: Beautiful. So tell us about your latest music project and how it's connected to your advocacy for healthcare justice.

[\(11:06\)](#):

Hilsinger: A hundred percent. I guess this past summer is the first time I started sharing what I've been doing with people other than like my mom and my sister and like a handful of friends with the world, like, you know, breaching that kind of fear, social anxiety gap that is still a part of my life, I think. But I submitted the song that I wrote called "Shake" to this contest called The NPR Tiny Desk Contest and when I shared that video, a couple people who I had been involved with in my healthcare activism the past few years commented on the video saying, 'when are you going to write a healthcare justice song?' And I was like, man, yeah, why haven't I written a healthcare justice song yet? I can't believe it because a big part of my life the past five years has been, you know, being an activist for healthcare justice off and on for the past several years and I couldn't believe it and so that kind of prompted me to start writing. And so I wrote "Rise

Up” over that next month or so, and actually played it at a rally at the end of July and then over the past, I don't know, maybe six months I've slowly worked on a music video with friends and family for that song and just recently shared that, put it on YouTube and yeah, so far I've gotten really good I feel like feedback that also has just felt very powerful to hear other people's perspectives.

[\(12:29\)](#):

Q: *Tell us a little bit about the song. What is it about?*

[\(12:31\)](#):

Hilsinger: For me it's about, I'd say it's hard to talk about other than just it's like I want to sing the song right now is like my answer, but it's coming from my heart, it's coming from like this tragic experience of being sick and feeling alone and being afraid and not knowing what to do. And I guess that's in musical terms, like that's kind of what the chorus is and then the verses, the other parts of the song are kind of talking about my and also different people's experiences navigating the healthcare system and getting sick and working and then it eventually, you know, also kind of calls out different people, you know, and systems like pharmaceutical companies and private health insurance, and then it finishes with a just a cry and a plea, I guess, for people to come together and, and rise up and make a change.

[\(13:25\)](#):

(lyrics)

Q: *Thank you, Daniel. It's a beautiful song by the way.*

[\(13:54\)](#):

Hilsinger: Thank you so much.

[\(13:56\)](#):

Q: *So tell us why you support Medicare for All.*

[\(13:59\)](#):

Hilsinger: I just believe that health care should be a right and not a privilege – right now it is. I just fundamentally believe that like we all have inherent value and that we deserve to live like a healthy, amazing life following our dreams and people shouldn't have to fight for like, it just, it really blows my mind. To me. It's so sickening like how the system is because it's like you see these essentially, like all of the different layers are just trying to extract profit from people when they get sick, you know, whether it be like a pharmaceutical drug or the health insurer or whatever. And in my view, it's like, couldn't we treat each other like we want to treat someone we love? And so like for me, it's like, well, I want to be alive and I want the people I love to be alive and I want them to be supported when they get sick. So why not, you know, just do that.

Why not organize the system around care as opposed to temporary immediate profit and yeah. I just think it should change.

Speaker 6 ([15:04](#)):

Q: Yeah. How do you think your life would've been different if you had had Medicare for all when you were diagnosed?

([15:10](#)):

Hilsinger: That's a great question. I think it would be a lot easier. Definitely navigating the whole process. I also think all the people that I met on the chemo ward and the cancer support groups – lives, would've been so much better. And in the cases of people who aren't here anymore, who died, you know, there's like a tangible argument that could be made over that first, at least some of them that they'd still be here. You know, cuz I think like stress is such a big player in our health and wellbeing and you know, our body needs. We need time to rest. You know, rest is such a big part of healing and sleep. And so like just if someone really needs to sleep for 14 hours a day for a couple months or something and really rest during the day too, they should be able to do that. And if someone's being forced to like work a job while they have cancer or some other really, you know, intense illness and you know, spend an hour every day navigating the healthcare system, I think that affects, you know, our chances of survival and healing.

([16:16](#)):

(lyrics)

([16:25](#)):

Thank you, Daniel Ray Hilsinger. You can listen to the whole single Rise Up and support his music at DanielRayHilsinger.com.

Do you have a personal story you'd like to share about our 'wack' healthcare system? Contact us through our website at heal-ca.org.

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