

*Eileen Campbell:*

Would start by telling us a little bit about your father, Dr. Zuretti Goosby?

*Dr. Eric Goosby:*

My father was born and raised in Oakland. He went to school there, at UC Berkeley undergrad and then went to the dental school at the University of California San Francisco (UCSF) Dental School—he was the first African American to graduate from UCSF in 1948. My father was drafted during WWII but because of testing they did he was pulled out of the draft and offered to go through dental school. He set up practice in San Francisco and practiced there his whole life. He was very active in local politics, community organizing, the civil rights movement, the Anti-Vietnam War Movement, and labor issues that fell down racial lines.

My father was one of these people who always worked for consensus, who was always concerned about the minority position—not in a racial sense so much as in the non-majority position—and always went out of his way to make sure the minority issues were brought forward and not ignored by the majority. And over the years he established himself as an honest broker. My father was president of the school board when the busing issue hit the United States, and San Francisco was a prominent city in that. I can remember in middle school and high school for me it just dominated the house—meetings and people and controversy—because it was highly contested here in San Francisco. But my father and mother were both always conveners, so the meetings were always at our house. And we had a kind of a parade of central players at the local level but also at the national level. Robert Kennedy solicited my father for support in '68 when he wanted to run. Whenever Martin Luther King came through town, he stayed with us. Paul Robeson, too, who was a prominent actor/singer in that era, but played a huge role in San Francisco in convening African Americans around civil rights issues. Because African Americans were only around ten percent of the population in San Francisco, it was always about building a coalition and they were kind of the hub for mobilizing the community.

*Eileen Campbell:*

You said Martin Luther King used to stay at your house when he would come to San Francisco?

*Dr. Eric Goosby:*

Yeah, because in those days black folks didn't get access to hotels and that wasn't just in the south, it was in San Francisco, too. When I grew up, the Fairmont and the Hilton hotels did not serve African American people and that was in the 50's. By the early 60's it had pretty much been eliminated in practice, but the attitude remained. So that was the reason. It was common in those years.

*Eileen Campbell:*

How did it impact you watching your father so deeply engaged in these battles around desegregation, with all of these local and national luminaries visiting and staying with your family? How did it impact you as a kid growing up in that house?

*Dr. Eric Goosby:*

It was a positive impact. It was both my mother and father--they were both just as actively engaged. What I remember more is the convening of what in those years were called beatniks. People would come over and talk about social issues—for example, James Baldwin might write something about individual human rights, how an individual's rights butts up against the state, how there are common goals and then there are some goals in opposition to one another, and the government often needs to play a role in balancing that, making sure minority issues and concerns and issues are not lost to the majority will. So those discussions were very much in the context of coffee and poetry. My dad smoked cigars, and I remember all of those smells and the dark rooms and the berets, you know. All of them were serious as a heart attack though! These weren't social visits so much as earnest discussions around how we come together around problems. I feel very grateful to my parents for infusing me with that self-expectation. It very much defined, without speaking directly to it, what I thought I should do, and what I thought commitment was. The idea that talk was cheap, and actions speak louder than words just resonated throughout our house. And that was the way it was my whole life.

*Eileen Campbell:*

Did all of this influence your decision to become a doctor?

*Dr. Eric Goosby:*

I suppose it did in a kind of macro sense. The idea of service was very much part of the expectation of the house. That phrase, "Talk is cheap, actions speak louder than words" came from my grandmother--she said that all the time and lived it. And that went to my father and his siblings and then he transmitted that to us. It was not an intellectual exercise but really the way I was raised to think about myself-- the quality of my contribution, and the measure of the life you lead. So I do feel I was lucky to have them.

*Eileen Campbell:*

You saw your first patient with AIDS in 1979 when you were working at San Francisco General Hospital. This was before we even had a word for that disease. Can you take us back to that moment in time?

*Dr. Eric Goosby:*

Yeah, it was a patient in the Intensive Care Unit. He was a patient from Haiti and had what we had diagnosed as a Burkett's Lymphoma. We could not clear the sepsis that he had, so he was in

the Intensive Care Unit for about two months and then died from it. We never really knew what it was, although we knew he had an immune deficiency of some kind. We did not figure out that it was infectious even though we talked about it. But in that year, there was no awareness of it. Even though retrospectively you can actually go back to the late 60's and see cases that by their clinical course were clearly HIV.

*Eileen Campbell:*

So within a few years, 80% of the hospital's patents were AIDS patients. What percentage of your patients were surviving in those early years?

*Dr. Eric Goosby:*

None of them, ultimately. But with any given patient on any given admission the person would have two to three opportunistic infections that we often would get them through. Even though the infections were life threatening and we would convene their family thinking they may expire during that admission, we often got them through that acute infection. Not having any antiretroviral drugs at that time, they would be sent out and we basically would wait for them to get another opportunistic infection and come back in. But one hundred percent of my patients died, and that was a big part of the problem.

*Eileen Campbell:*

One hundred percent of your patients died. I mean, I almost get the sense of living in a war zone. You would have been exposed to so much death. What does that do to a person?

*Dr. Eric Goosby:*

It changes you, there is no question about it. You know, the type of personality that goes into infectious diseases likes to give magic bullets. People come in deathly ill and we give them a magic bullet and they turn around and walk out. It's about the cure. It's about saving people, not about managing their death. We began the AIDS ward and the AIDS clinic in the mid 80's, and we had the first AIDS-dedicated in-patient unit here in San Francisco, and the first AIDS-dedicated outpatient unit--Ward 86--all of which are still running to this day. They were there before antiretroviral treatment became highly active in the mid 90's. If you worked in those settings, you were taking care of someone and you knew the moment you met them that you'd be dealing with their death. After about 5 or 6 years all of us who were in those settings saw in ourselves an emotional liability that we had very little insight into.

For me it manifested when I'd see a pet or dog on the street. Dogs were big in our family so dogs really just pulled all the heartstrings. A dog without a human would upset me on a street corner. There were commercials on the radio for AT&T, the phone company, and they would say, "Just ring home. Just call your mother." They'd have the mother answering the phone and saying, "Hello, honey!" to her son or daughter and that would just well me up! And I'm not an emotional kind of

guy. And this was happening to everybody on the AIDS ward, both inpatient and outpatient, and we realized that we were damaged. You know, now you call it post-traumatic stress. In those years, we just endured. The personality type that gravitates to infectious disease as a profession, it's not the touchy-feely group of doctors, and I think we found ourselves needing to find a release for this emotional welling that occurred by not processing any of the loss. You don't get connected to every patient you have, but these were young people, usually well educated. A lot of them were coming out of Berkley's graduate school and law school. So they were people we could relate to maybe more than some of our other patients. And I would say after somewhere around my 400<sup>th</sup> death, I was pretty fried and, again, had little insight into what causing all of this. During this period, I had gotten married and my first kid was born in 1990. And when Eric Nicholas was born, it got more acute. On a subconscious and then later conscious level, I put the dots together on every one of these losses. These patients that we had were all somebody's son or daughter. And it just reverberated in a way that I found much more personally confronting and kind of unable to tuck away and move on.

And all of my colleagues who were in it, you know, full-time in front of this disease were having the same types of things happen to them. We all kind of reacted to it. We all did kind of turn towards more research thinking that that would buffer it but it didn't. You get connected to the research patients as well as your regular patients. I took an offer from the federal government, thinking I would do it for a year or two, to come and set up the Ryan White Care Act, which passed in 1989-1990. Senators Kennedy and Hatch passed this legislation and it was the first time in the US where US tax dollars went to responding to HIV. Research dollars started in the 80's, but US for treatment services didn't start until 1991. The Ryan White Care Act was named after an Indiana hemophiliac who contracted HIV through a blood transfusion. And so the legislation was passed, and money was appropriated. I moved back to DC thinking I would take a year to set this up, maybe two at the most, and ended up staying there for what turned out to be a decade.

*Eileen Campbell:*

With the birth of your son, you're saying the sense of loss became more acute, more real, and more personal on some level. It sounds like a part of what you did was shift to this big systems thinking about, how am I going to keep *thousands* of people alive. But what were the other ways that you found to help you get through that time and process that loss?

*Dr. Eric Goosby:*

In San Francisco we actually had one of our psychiatrist friends that did in-patient psych consults, and she really did create a cathartic conversations. But mostly it was just talking to other people who were facing the same burden--my colleagues, the other doctors and nurses who were also in front of this. It helped a lot. And our psychiatrist friend pointed that out, "You know I am not going to do this for you, but you guys are going to do it for each other." So we convened in weekly conversation where we acknowledged who died that week. We would have 12 to 20 a week out of the clinic that passed away. And then you have the in-patient unit, and it would just be that much more. You would know a third of them from just being in the clinic. I think that was the biggest intervention to decompress.

*Eileen Campbell:*

Building that community--that makes sense. You mentioned that there wasn't a major federal response to the disease until the mid-90s. Can you talk about the way that public attitudes towards HIV/AIDS during the 80's and 90's contributed to the delayed response by the American government?

*Dr. Eric Goosby:*

I would say it was largely avoided. President Reagan was in office at the time and for his first term did not mention the word "AIDS" even though he had friends in Hollywood that had AIDS--the actor Rock Hudson came forward in that period. President Reagan eventually created an AIDS commission that was set up and run by a general who went around to large cities in the United States and convened two to three day hearings to hear people give testimony about what was happening to them and what was happening in their community. That collective information then became the substrate for the actual legislation, the Ryan White Care Act.

So the commission, with staff from Senator Kennedy and Senator Hatch's offices, all of whom we're still in contact with, came with the commission and then wrote up the Ryan White Care Act. It was very general but the first title was focused on bringing resources to epicenter cities that were heavily impacted by HIV. And then the second title gave money to states to organize surveillance systems for HIV. And then the third title gave money to individual clinics that were especially heavily inundated and/or to dedicated AIDS clinics. So you have three titles that had three separate funnels of money that would come into states and cities that were most heavily impacted. Figuring that out was almost completely informed by my experience in San Francisco.

We had a large community component in the early 80's that came out of the San Francisco AIDS Foundation, the Shakti Project, and Project Inform, all of which played really foundational roles in defining what package of services and responses are needed in a community for it to optimize care of HIV-infected individuals. And we spread, in my mind, the San Francisco model to epicenter cities across the United States. We took an evidence base that came largely out of San Francisco, New York and Los Angeles and patched together the continuum of services we thought everybody in the United States should receive if they are HIV positive.

By doing that work, in part I decompressed some of the personal reaction I was having. But I approached it-- the Ryan White period-- as instead of seeing patients one at a time I was there thinking about them in larger numbers. It's called a doctor-patient relationship thought process. And I think that's worked pretty well to refine and better hone these specific interventions that Ryan White ended up paying for.

*Eileen Campbell:*

So by the mid 90's, AIDS treatment in this country had progressed dramatically. There was a cocktail of drugs that allowed people living with HIV to live much, much longer. You were overseeing

the delivery of this care through the Ryan White Care Act, in 25 different AIDS epicenters all over the country. But it was around the late 90's you had an opportunity to visit an AIDS ward in a hospital in Zambia. You've described this experience as a real turning point for you in your career. What did you see there?

*Dr. Eric Goosby:*

You're absolutely right. In the late 90's, I went to a hospital in Zambia operated by the Salvation Army. The medical ward was an open ward--no individual rooms, just people in a big room with the nursing desk in the middle, which is great for the nurses and doctors because you can see every patient without having to walk around. And while we were there, maybe a half dozen to a dozen people had grand mal seizures over the course of half an hour. All from a fungal infection, *Cryptococci meningitis*, which they had been admitted for.

In our country, you can treat *Cryptococci meningitis*. Largely 80% of the time there is a cure, even in an HIV infected person. But here there was no amphotericin available in the whole country--it's still very hard to get, I would add, because it can be so expensive. With these multiple people with grand mal seizures in beds with three to four people per bed, it just looked like total chaos. I realized that, not only did I understand that particular disease, but my work in Ryan White had been all domestic up until the point. I felt validated in focusing on the domestic response-- that was my charge. But in Sub-Saharan Africa, which carried the lion's share of the epidemic on the planet, they were getting almost none of the treatment. We had identified protease inhibitors in 1994, and had a few years' experience understanding that these drugs turned the infection around. In 1999 we weren't sure how long patients were going live yet, but we knew that they returned to what looked like a normal life expectancy--they went back to having no opportunistic infections, their energy was restored, and they were able to return back to work.

So we thought that this was going to be dramatic and lasting but we knew it wasn't a cure. Before going to Zambia, I thought my charge was the United States' domestic epidemic-- I thought, let me do that well. This was the first time I realized that I actually did have something to offer in these very resource-poor settings, where there was a lot of HIV, and no antiretroviral response. This was all about diagnosing and treating, which San Francisco had made me very good at. And I think that I realized at that point that looking to the international response was going to be something that I needed to do, so that was a big moment.

*Eileen Campbell:*

So this is a time where AIDS is sweeping over the African continent with such speed. I remember in the early 2000's, Stephen Lewis, who was the UN Special Envoy for HIV/AIDS, calling the statistics just hallucinatory. There were some countries like Botswana where the prevalence rate among young women were as high as 50%. And the science to treat AIDS, as you said, in the United States, existed. What was preventing those young women in Botswana or those patients in Zambia that you saw from getting the drugs that people were getting in San Francisco?

*Dr. Eric Goosby:*

Really, money. And then I would say trained, component knowledgeable providers. But it was money. In 2003, the guestimates are that-- at the most--about 50,000 people were receiving treatment in all 57 countries in Sub-Saharan Africa, which at that time made up 74% of the epidemic globally. And the 74% globally was concentrated in 22 countries of those 57. So you had a hugely lopsided deployment response.

And that disparity was talked about for the first time in the Vancouver International AIDS Conference, but occurred publicly in the Durban International AIDS Conference. And that challenge that was put out by Peter Piot (then Executive Director of UNAIDS) in his plenary and was picked up in a big way by everybody who was at that meeting, and then went right to policy makers, who could impact an expansion of the response. And this was right at the time when the discussion about the Global Fund to Combat HIV/AIDS, TB and Malaria started, in part in response to that challenge. I think a sequence of events occurred that basically defined the problem, solved the disparity, talked about the ethics of it, and the lack of ethics of it. And then, a series of efforts went towards identifying the drugs, moving them to cheaper formulations, generic formulations, single dose pill formulations, pediatric doses were worked out. And calculations, although not acted on yet, began to appear in the literature that tried to estimate what the cost would be to bring care and treatment to these populations.

The medical community was kind of divided. Leadership in the Center for Disease Control in the United States, and all of the major foundations that did global health work, all took the position that they should avoid giving resources to treatment and it should all go to prevention. So, step over all the infected, let them succumb to the infection, but try to prevent the influx of new infections as the main strategy. And that is a discussion that still has a lot of strong residual roots. There are still people who deeply believe that, even with the advent of treatment-as-prevention and studies showing that with anti-retrovirals you got a 98 % drop in your infectivity.

When Eisenhower came out of WWII, we were warned about the growing military industrial complex. Well we have a similar phenomenon with our international global multi-national NGOs that do truly wonderful work, and are full of wonderful people. But the bottom line of keeping a payroll going and keeping their organizations alive put an inherent conflict in their willingness to be and remain the primary implementer of these programs and not transfer that to the appropriate individual in country who is responsible for these patients. So most of these big programs fund academic medical centers, and multinational NGOs based in the north to do work in these countries and have blunted the capacity of ministries of health to manage their own programs, and I think is a fatal flaw. And it is one that we still have not adequately corrected.

*Eileen Campbell:*

So over the course of your career, you've had this opportunity to be a part of and witness these huge transformations in the way that entire nations and entire global communities respond to this disease. With the advent of treatment in this country changing millions of lives and what people could expect from their lives by receiving this life saving combination of drugs, and then in 2003,

with President Bush announcing the creation of the Presidents Emergency Plan For AIDS Relief (PEPFAR), this was the largest global health initiative in U.S. history and has now made it possible for millions of people to survive with this disease. Can you talk about, from your vantage point as a physician, as someone who has served in government during these times, the role of activist movements in making treatment possible and making that claim that this is a human rights issue, it's a social justice issue that treatment be made available to those patients you were describing?

*Dr. Eric Goosby:*

Yeah, I think it's breathtaking the transformation that was started in President Bush's willingness to take the leap and put huge amounts of resources toward this response. It is the largest public health response on the planet, in the history of the planet, by everyone's tally. It dwarfs the Marshall Plan Post WWII, and has now saved about 11.5 million lives just on the antiretroviral medications, not to mention babies who were prevented from contracting HIV and those whose health was protected in terms of not contracting HIV because of the prevention efforts. It's an incalculable benefit to humanity, and I think that the American people, karmically, are going to benefit from this. But it's not widely known so they can't just intellectually appreciate the contribution that their tax dollars have made to fighting a huge source of morbidity and mortality on the planet.

I think that it's also a model of how we should treat each other. Those who have resources and are wealthy in my mind--and President Bush articulated this-- have an ethical obligation to respond. And he is absolutely right. In my playing a small role in implementing that vision through PEPFAR programming, I have come to see that the ethics of this are clear, and you are ethically obligated to do something if you can do it. The people who need to struggle with that dilemma of "should I or shouldn't I engage" are those countries who do have the resources and are choosing by passively not acting to not do it. It makes me proud to know that the United States-- like no other country on the planet-- has stepped up to this challenge aggressively. HIV is something that will never be the same because of that commitment. We haven't done that for TB, and that's a whole other story, but I do think the HIV story is something to be proud of.

*Eileen Campbell:*

You have written in recent years about creating an AIDS-free generation. Do you think that's possible and what would it take of the average person to realize that vision?

*Dr. Eric Goosby:*

Well it is possible, and what I mean by an AIDS-free generation is that for those who are already infected, they don't progress to AIDS, they stay HIV infected without developing AIDS by getting an opportunistic infection or dropping their T- Cell count below 200. We can do that because we have the science to stop it. The introduction of anti-retrovirals prevents you from progressing to a diagnosis of AIDS, and as soon as you get your T-cells above 250 your risk of opportunistic infection drops way off, to just normal risk. So, that's what I mean by that. In terms of



pediatric HIV, we know how to completely prevent it. By putting the HIV-positive pregnant mother on anti-retrovirals, it stops transmission about 98% of the time. And then for other prevention interventions like preventing injection drug users from getting HIV and hepatitis, we know how to do that by not sharing needles. By putting those who are HIV positive on anti-retrovirals, we can stop that individual from being able to infect others.

So all of those interventions will stop people from progressing to AIDS, and will stop people from contracting AIDS in large numbers because the only way you can get infected is from a person who is infected. So if we have all of those who are living with HIV on treatment, along with the other prevention interventions--prevention from mother to child transmissions, using condoms, having safe sexual practices in general, treating sexually transmitted diseases, all of which are evidence based interventions that stop or drop transmission-- that's how we'll have an AIDS-free generation. So it's more than possible-- the science is there. It's really the implementation barriers and the political will that's needed to make the investment decision to get it done, and that's easier said than done but definitely doable. So I still think it's possible.

*Eileen Campbell:*

And it's happened before. This is where we come in as activists, right?

*Dr. Eric Goosy:*

Right! Yeah.

*Eileen Campbell:*

Well thank you again so much for your time Dr. Goosby you've been so generous with it. I'm so inspired every time we have the chance to connect. So thank you so much.

*Dr. Eric Goosby:*

You're welcome Eileen, it's nice to talk to you.