

TRANSCRIPT

The following has been edited for length and clarity. Any alterations are noted with brackets and ellipses.

Fátima Ptacek (FP): You had the chance to meet Elizabeth Glaser and you worked for her Foundation...

Dr. Warren Andiman (WA): Yes, I did.

FP: And, in its earliest phase?

WA: Yes, in the early to mid-eighties.

FP: I unfortunately didn't have the honor of meeting her, so would you mind telling me what she was like, and how her advocacy contributed to your research?

WA: I met her but I never had a really close relationship with her. So at the time in the early eighties, we already had begun to see kids with AIDS in New Haven, so I was already quite familiar with the terrible medical problems that these children and infants with AIDS had, and we were already seeing children who were dying of the disease or who were left with long term disabilities. . . . So I applied for grants through the Pediatric AIDS Foundation and I was successful in getting funded. Then, because I was already producing reasonable data, I was invited to serve on the [Foundation's] grants review committee, where I would have the opportunity to review other people's research and decide which could receive grants.

During those review sessions, where a number of pediatric AIDS researchers from throughout the country met together, Elizabeth Glaser visited us a lot in order to meet the scientists or pediatricians who were at the vanguard of this growing interest in pediatric AIDS. She came to a number of those meetings; we all had the opportunity to meet with her. The first time she came, she came anonymously. She was introduced to us as a "very important guest," and none of us knew who she was. In later years, it became acknowledged that she was Elizabeth Glaser, and that she and a group of her friends were interested in really building up the resources for the Pediatric AIDS Foundation. After those first few years, they began to invite us to this beautiful estate in Santa Barbara. She had two or three very close friends in Hollywood who supported her and were able to provide her with a donor base through their connections. . . .

FP: So, thinking about the times, I mean, when I hear the 1980s, I don't even know what that feels like. So what were some political or financial hurdles that you faced in research?

WA: . . . The biggest hurdle was that we had no medicines, no antiretrovirals, and we did not have all of the anti-infective medicines that we now have to fight the

opportunistic infections that patients developed because they had lousy immune systems. So we were confronted with sick children, nothing to treat the virus, and a limited number of medicines and agents to treat the infections. That was the initial crisis of impotence. We had to take care of these kids and provide them comfort, care, everything; but we weren't able to save those lives. Most of those kids died before the age of five.

The second problem was that not only the public, but also the healthcare providers, didn't know enough about [the virus] . . . We knew it could be spread sexually, that homosexual men were at high risk, and that IV [intravenous] drug users were at risk, but we didn't understand well enough why women were at risk, and we certainly didn't understand the ways in which the babies got infected. . . . Nobody knew, so there was tremendous concern about the potential infectiousness of anyone who contracted the infection—and that included the babies! So we had these babies in the hospitals, but what precautions did we need to take to protect ourselves? We had some idea, but we didn't know everything.

When the children came to the hospital when they were ill, [many] were not able to go anywhere when they recovered from their illness. Many of the mothers of these children lost custody, because many of them were using drugs or their sex partners were using drugs, which was a big cause for women contracting the disease. Normally, you could find foster parents who would take sick children. No foster agencies, anywhere in the United States, would allow these kids to go into the foster care system, because nobody knew what risk they posed to the families. . . . So they weren't adopted or fostered; they stayed in the hospital. . . . That was a huge problem until we understood more about how the virus was transmitted and then all of that [excess caution] disappeared. Ultimately, when all of the infectiousness was figured out and cleared up, then the foster care system absolutely opened up. . . .

The third problem was, as some of these kids got old enough for school, schools would not take them under any circumstances. Do you know about Ryan White? Ryan White was a hemophiliac in Indiana whose case was covered by newspapers all over the United States. He had been transfused with contaminated blood and he contracted HIV, and when parents and faculty learned of his diagnosis, they wouldn't let him into school. So it became a national story. He became the poster boy for pediatric AIDS stigma. He ultimately died, but he became an incredible spokesperson. He was so eloquent, he was very into arousing people's understanding of it.

. . . So that was the next thing, what do you do with these kids when they reach school age? And the way New Haven dealt with the problem—it was really sick. They couldn't go into regular classrooms, no one would let them in the regular classes. . . . My social workers and nurses really advocated like crazy and we would go and give testimony at the state legislature and board of education, and instructed them until everyone realized that you couldn't catch AIDS by sitting in a classroom . . .

FP: And how about in terms of political [advocacy]?

WA: The only advocacy we had to do was at the state level, never anything on the federal level, and it was just all about demystifying the virus and offering instruction. . . . A few times we had to advocate in Hartford for additional beds for AIDS patients when the hospital was doing renovation, or when we were asking the state to provide additional support specifically for AIDS patients because the population was growing and they consume a lot of money. . . .

FP: In your view, what do you think are the highest priorities in contemporary pediatric AIDS research?

WA: I would say the first thing is to work with the pharmaceutical companies to make sure that there are pharmacologic formulations of the drugs that can be easily given to children, like liquid formulations. For so many of these kids, taking pills—especially with combo medicines, those pills are really big, even the adults struggle with it—[is extremely difficult]. When you put a young child or teenager on a multi-drug regimen, which we uniformly use now, when the patient can't even really swallow the pills, adherence is a huge problem.

Once they get older and become more independent, adherence, or compliance with their regimens, becomes dismal. It's a terrible problem. How do you get teenagers or preteens to take medicines that come in these bad formulations that are nasty, these things that remind them every day that they are different? That's what the kids will tell us. "I am a teenager, I don't want to think about this. I want to have a normal life like all of my friends. . . ." So the easiest thing to do is not to do it

This terrible problem of not adhering means patients contract resistant viruses, so they won't get as far ahead of the disease as they want. . . . That is honestly one of the biggest problems. We don't have any young patients anymore though really, and there's no more mother-to-child transmission, at least not in New Haven. The last infected child at Yale was born in 1996. . . . It's unbelievable. I think it's pretty unusual to go for 21 years without an infection.

FP: Jake is 32 now!

WA: Oh, really? Oh, my God. That's incredible! That's so incredible. Do you have a picture of him or something? . . . Wow, his coloring is just like Elizabeth, she had reddish-brown hair. He looks so much more like Elizabeth than his father. I don't believe it, I just don't believe it. I hope he's still taking his medicine. I can't believe that. He was infected when he was a baby, and he's 32. I can't believe it. Can you forward this to me? I want to share that with all of my friends and colleagues, that's so unbelievable!

. . . By the way, many of [my patients], whom I've known their whole lives, they have children of their own. I'm like a grandfather now to all of these healthy kids. I took care of their mothers, knew them so well, and now we have four or five of the original 1980s and 90s group that have had children, and NONE of them are infected, not one, which just goes to prove that these young people—at least when they become pregnant—take their medicine and keep up with their appointments. . . . But the babies have never been infected, so I think it's sort of this message that “no child of mine will ever go through what I went through,” and they won't

FP: . . . I always think of things in terms of my lifespan, in my 16 years, right? To think of dedicating yourself and your life to a career, you got to see an entire transformation and lifespan of this disease and what it looks like.

WA: Exactly, that's what's truly unique about this disease, if you look at pediatric AIDS, it started probably with the first baby in around 1981. Now in most parts of the United States, the transmission rate is less than 1%. It was 20-25%% in 1980. At Yale, it's 0%. But in the 1990s, it was horrible. . . . There is no disease like this, there was no other one like it. It just came and shocked us. I never thought this would happen. . . . We never thought there would be a time where we would have to think about getting our patients internal medicine doctors, because they used to die before they turned 5. 25-30 years, there's nothing like this, and it's certainly not true with any other disease. And unfortunately, the statistics aren't the same in the rest of the world, which is the challenge. It's not a research challenge—it's a money challenge, a political challenge, and it takes infrastructure. If you have no way of getting to the hospital, you can't take medicine. If your husband is going to beat you up and throw you out of the house because you're HIV-positive, you can't tell your husband. And your husband doesn't tell you if he infected you. It's a huge problem outside industrialized countries. The stigma is still so huge, the cultural element is the major part, it defines who you are in a society, it's your value. But again, that's not really a research problem. The drugs and medicine are available, and all the manuals and instructions are available. To prevent mother-to-child transmission you do a, b, c, d, and e. . . . But if you have no way of implementing them, allocating the resources, parasitic diseases, cholera, typhoid, his is just part of the mix of the unavailability.

FP: I'd love to go back to the topic of transitioning, because I think it's so interesting. What does that process look like? When do you go from being a pediatric AIDS patient to an adult infected with HIV? What does that mean?

WA: First, we try to begin the conversation at around 16 or 17—at a time when they very well may be sexually active, and they have to start taking responsibility for their actions. That conversation is, “you're almost a grown up, you're going to be 18 and be a legal adult, we should think about the idea of having you take more and more responsibility for your own illness.” There's a checklist: can you make your own appointments, can you fill and refill your prescriptions, can you go to the pharmacy to

pick those up, and once you have obtained the medicines, do you know how to set up the pills and take them? Have you thought about getting a job, or having some form of financial independence? What kind of job would you like or are you interested in? Do you think you can work on a schedule? . . .

FP: So this is far less about medical preparation, and more about life skills and emotional preparation?

WA: Exactly, the only medical aspect is the medicine taking, can you call up for your prescriptions, et cetera.

FP: So there's no difference in the medicines they take once they become adults?

WA: Very little, if any. The dosage sometimes changes, but the medicine is exactly the same. The formulation may be a little different but no basically no difference. The other medical responsibility is making [and keeping] appointments with us. . . . Obviously, we call and remind like all doctors' offices, but they usually need multiple reminders. "If you need a ride, let us know and we can get you a ride. . . ." We pay for those things for our patients because we want them to come in, just tell us when you need it.

FP: I see that it's mostly about initiative and motivation then, it's about whether or not they decide they want to be on top of it.

WA: Right, they have to have that initiative. But the rest of it is all social. It's just about jobs, money management, do you know how to use a bank, deposit money, that kind of stuff. And then of course school. Most of our kids have finished high school, which to me is incredible. Do they want to go to college? Probably at least a third of them have gone to community colleges. . . . But we work through that too, have you thought about your education and continuing it.

The other thing is sexual behavior—to make sure they know what to do to avoid infecting someone else. . . .

And then after preparing them and figuring out if they have those basic skills, we introduce them to the adult clinic, which is right across the street. They don't have to go to a new place, but it's very scary for these kids. They're coming from a very sheltered pediatric environment when they come to our clinic. As the pediatric specialty clinic, it's so beautiful, all decorated, paintings on the walls and fish tanks and choo choo trains. And the nurses are so kind. The adult clinic is not like that, and the scariest thing is that they get a view into the future. You're 18 - 20 years old, but you can walk by and see a 60-year-old IV drug using AIDS patient. It's not pretty. It's scary. You see these old [people] who have had HIV—they don't look healthy or vigorous, they look drained. The exam rooms are smaller, the nurses aren't as cuddly, so a lot of them get scared, a lot of them don't want to break away from us. They won't do it. [They say], "you've taken

care of me my whole life, I know I'm 22, you have saved my life, how can you possibly ask me to trust a whole new group of people?" . . .

FP: And that's difficult because their whole lives are often about insecurity, and about being different.

WA: Right! It's not surprising, but we have a 25-year-old who has refused to leave. We have a young man who is 23 and has two kids, and he won't go either. He has two kids, he's a man, but says, "Dr. Andiman has taken care of me my whole life and I love my social worker Ann, she's gotten me through everything, and I won't do it."

FP: Well, hey—that must say a lot about your clinic, you guys are clearly doing something right. It's better that they do that than give up.

WA: Ha, ha, yes It's like sending your kid to college; it's hard and painful for us too. We have a few older folks who are still with us, who we keep but recommend all the time to go. We had a nurse practitioner who left 6 or 7 years ago, so when they found out she was leaving, they decided to transition over and they didn't need the pediatric clinic anymore, it was just that she was so spectacular they didn't want to leave. . . .

FP: She went above and beyond. She was a unique case, huh?

WA: Yeah, that's the way it goes around here. They're all like that, nurses and social workers alike. So maybe 20 together recently total have moved and transitioned over, and we help in any way we can, with the social worker and with the pharmacy. It's a little like babysitting until they take that leap.

FP: You mentioned the Ryan White Act, but I wanted to ask if there's any legislation that you would like to see that you think may be necessary or very helpful?

WA: There is a huge budget for AIDS, we can't deny that. . . . [But] I think there has to be much more money devoted to increasing infrastructure support and provision of antiretrovirals in Africa and in other poor regions of the world. I think it's part of our responsibility as a really rich nation to ensure that [low and middle-income countries have sufficient drugs and infrastructure], but also to do training, because obviously we cannot provide manpower continuously. . . .

FP: My last question for today is pertaining to young people. I found that for me specifically, it's very hard to be able to do hands-on work because I'm not a legal adult, I can't be "in the field," so what can young people do if they want to further EGPAF's mission or be more involved in a way that feels like it's making a real difference? I have a platform, I can post on social media and raise awareness, but what can an ordinary young person walking on the street do?

WA: I think most of it just goes back to education or peer-to-peer conversation in schools. I know that a lot of schools are doing it, but to make it mandatory and make certain that every teenager knows about what HIV is and how you contract it. It seems to me that it would always be put in the same category as other STDs. This is a sexually transmitted disease, you've heard about chlamydia, about PC, its just another STD but it has more serious consequences in that it's a lethal disease and you can get very sick. But learning how to protect themselves is the most important. . . .

FP: Well, thank you so much for your time!

WA: Good luck and any time, thanks so much.