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**Joey**

**Growing Up Positive**

By Sharon Lerner



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You may remember Joey DiPaolo from 1990, when parents protested his attendance at a Brooklyn middle school. Throughout his childhood, Joey spoke publicly about AIDS and his own HIV-infection. His mission was simple: to prevent future infections, stop discrimination against people with AIDS, and demand a cure. Today we continue our 5-part series about people infected with HIV at an early age. In this installment of "Growing Up Positive," Sharon Lerner reports that Joey's struggle has recently become more complicated. Now 23, he's ready to leave behind a childhood defined by AIDS - and is finding that's not as easy as it sounds.

When Joey DiPaolo was 4, he contracted HIV through a blood transfusion during heart surgery. At age 9, he appeared in an educational video for children, a tiny boy talking about the big bullies who picked on kids with AIDS.

Young Joey with tiny voice: They're really stupid because people have to teach them that they can't be afraid and everything. Because there's nothing to be afraid of. You can't get it from touching someone, from talking to someone, using same things as someone. So they're really weird. They should be taught a lesson about that.

As a small child, Joey didn't tell anyone about his infection. But gradually, he got tired of keeping his secret and his family approached a reporter with his story. On his first day of 6th grade, Joey's picture ran on the cover of Newsday with the headline: Now My School Knows I have AIDS. The next day, angry parents gathered outside his middle school in Brooklyn, to demand he leave the school. But Joey stayed - and the experience only made him more vocal. A year later, in 1992, he spoke to an estimated 20,000 people gathered in Times Square, at a rally that coincided with the Democratic National Convention.

Joey: I will be 13 in September and I have AIDS. I dream about the day when there will be no more AIDS, no more tears, no more pain, and no more dying...

Joey had to stand on a box to reach the microphone. Cute, upbeat, white - and infected through a blood transfusion - he was a perfect poster boy for kids with AIDS. He appeared on Good Morning America, Phil Donahue, Geraldo Rivera. HBO broadcast a special about his life. But Joey always seemed bent on using the spotlight to advocate for the



great bulk of kids with less TV-friendly stories, those who were infected at birth and through sex and drugs.

Camp ambience here

At 23, Joey has a giant AIDS ribbon tattooed on his leg, a silver stud in his left eyebrow, and the knowing demeanor of someone who's grown up in the public eye. For the past three years, he and his mother, Carol, have run a free summer camp for young people with HIV. The overwhelming majority of campers are poor, black and Latino teens.

Joey's camp, located in a cluster of wood cabins two hours north of New York City, is one of the few places where HIV-positive teens don't have to feel weird about their infection. Instead of hiding the pills that might tip people off to their condition, campers can openly gulp them down without worrying. They can flirt with each other. They can take archery lessons - or safe sex workshops.

[recording from safe sex workshop]: you take the tip between your fingers, roll it down, that's right... [laughter] [SINCE THIS IS AMBIENT, I LEFT THE CHOICES FOR IT AT END]

For Joey, camp is the crowning achievement of his childhood of activism. Growing up has been about surviving the virus and preaching tolerance for those who have it. But recently, Joey has begun to realize that he wants a future that isn't solely focused on AIDS.

Joey: 2, 5:23 6:51 I'm older now and I actually have to do something with my life. I graduated high school. I went to college for a little while. I took business, I've been around. I've done other things. College wasn't my thing as far as regular school, business and things like that.

Last spring Joey finally decided what he wanted to do: become a medical technician who draws blood. He made up his mind to be a phlebotomist.

Joey: I've been in a medical setting my whole life. Blood draws. Vital signs. Cat scans. MRI's EKGs, echoes. You name it, I've been through it all. I was actually always interested in being a phlebotomist, in drawing blood, I always really wanted to do that. 6:01 I've been stuck so many times so you know I'm not going to lie to people and tell them it's not going to hurt, because yes, you know, you're going to feel a pinch, it's going to hurt.

Drawing blood might seem an odd career choice for an HIV-positive person. But perhaps it's not so odd that someone who grew up fighting for the rights of people with AIDS would pick a profession that challenges expectations - and makes uninfected people just a little bit uncomfortable:

Carol: He had come home one day and said that he wanted to look into going to school for phlebotomy. Of course, the first thing I thought was, oh no, here it goes again - drawing blood - do we really need to do this? Can't you take accounting or something?

Carol DiPaolo is Joey's mother.

Carol: And when he made his decision, he was really ecstatic. I said to him, are you going to tell them your HIV status? And he told me that he had decided not to only because he felt that he didn't want them to make special exceptions or make it easier in any way. He wanted to do everything in his own merit.

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But just two months after he enrolled in a New Jersey phlebotomy school, Joey encountered a bump in his career path.

Joey: I got called into school saying that this was, you know, a normal student- teacher meeting. I look behind the head administration- not the head of administration- the director of the school, and on his desk was the computer and my name was typed into google.com and so I was like, ok, I know why I'm here now. Well, they found out I was infected. Legally, they're not allowed to kick me out of school because I was infected, but they wanted me to wear extended universal precautions, which was a blood protective outfit and blood protective shield when I'm drawing blood. I refused to wear it - I told them that there's no such thing as extended universal precautions, just universal precautions.

Joey left the meeting heartbroken - and called his mom:

Carol: I was sitting in the beauty salon and I had all these foils all over my head and the phone rings and it's Joey and he said to me - his first words were: ma, the only thing positive about that meeting was me.

Carol felt that Joey was being unfairly, and pointlessly, singled out.

Carol: To be honest with you, it's like, they didn't test any of the students for Hepatitis C or HIV. It just so happened that Joey's status they knew. And of course, with that knowledge, they wanted to treat him differently.

The meeting at Joey's school marked the beginning of the end of his phlebotomy training. Soon after, Joey decided he had no choice but to leave the school. He says that several of his teachers left their jobs, leaving him unable to continue his studies. He figured they left the school because of his HIV-status, though he can't prove it. School officials interviewed for this story said descriptions given by Joey and his mom about what happened are wrong, but that they cannot provide the school's side of the story for confidentiality and legal reasons. In the end, less than a year after Joey began training, he gave up on his career plan.

Joey: I'm not a quitter, but - I feel like I had my shot with phlebotomy. I could pursue it if I really wanted to. But. maybe, doing something else.

Carol: I have to say he's pretty frustrated. I don't know, he's kind of floundering around again, not knowing what to do. // I have to say it was like we were brought back to the early 90's, the late 80's. And part of me was hurt for him. And another part of me was very angry. I felt like in this day and age they should know better.

For his part, Joey is in limbo. And it's not just because of his career ...

Joey: Everyone tells me I have to do something, therefore I know I have to do something.

Joey's transition into adulthood hasn't been as smooth as he had hoped. For him and other HIV-positive young people, just growing up is a victory. Prevailing against the virus is a big, important battle. But, it's not the only one. And until there's a cure, many others lie ahead.

For WNYC, I'm Sharon Lerner.

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