

Polio Confidential: Stories from Those Who Lived It

Part 2 - My Journey After Contracting Polio



PODCAST 45

00:25

Dr. Jane Caldwell

Hi, this is Jane Caldwell. Welcome to the *On Medical Grounds* podcast, your source for engaging, relevant, evidence-based medical information. What you'll be listening to today is part 2 of a three-part series on polio, a serious disease that was almost totally eradicated in my lifetime due to polio vaccination programs worldwide. We'll be talking to polio survivors, healthcare providers who cared for polio victims, and a noted expert on polio and polio vaccines.

Today we'll be speaking with Janice Flood Nichols. Janice Nichols was on the cutting edge of polio vaccination development. In 1954, she was one of over 1.8 million children from the United States, Canada, and Finland who participated in the Salk polio vaccine trial, the largest trial of its type in history.

These kids were dubbed the "polio pioneers." Their study led to the successful production of a polio vaccination, which was licensed the following year. Prior to this study, Jan was diagnosed with polio as was her twin brother, Frankie. Her brother was lost to the disease while Jan survived. Ms. Nichols describes these events and more in her memoir, *"Twin Voices, a Memoir of Polio, the Forgotten Killer."*

Jan has a bachelor's degree in psychology from Seton Hill University and a master's in medical rehabilitation counseling from the University of Pittsburgh. She has used her education and writing as part of her commitment to the eradication of polio and the promotion of vaccinations.

Hello Ms. Nichols. Thank you for joining us today.

Janice Nichols

Thank you.

02:17

Dr. Jane Caldwell

First of all, tell me about your twin brother, Frankie.

Janice Nichols

I think I'd like to tell you about our polio story, and you'll learn about him to a certain extent just by that conversation. We were in first grade at the time, and it was fall 1953. Frankie was a typical little boy, super busy, super in love with especially baseball, but he had had a little cold, a head cold for a few days.

And Halloween was going to be that weekend and my parents wanted to make sure that he would be fine to go out Halloweening with all of our friends. So, my parents kept him home from school. And on the day before Halloween, Frankie developed a terrible time breathing. So, my parents rushed him to City Hospital for Communicable Diseases in Syracuse. He was given a spinal tap to determine whether he had polio or meningitis and he was immediately placed in an iron lung, which was a forebearer of today's modern ventilators. They're a cylindrical machine and a person's body, except for their head, is encased in this machine. And by alternating air pressure, it does the work of paralyzed lungs.

By the next morning, they had confirmed a diagnosis of polio. Because Frankie was so gravely ill, the doctors decided to bring me to the hospital and give me multiple doses of gamma globulin. It was the only thing that they knew at that time that could sometimes prevent a case if someone was not yet infected or lighten a case if possible. So rather than getting just the one shot, I received multiple shots, up and down, both arms and both legs, and then the one in the buttocks as well.

And I was so weak, and they had to put me in a wheelchair and bring me to my father's car. And the next night, at about 10:30 at night, Frankie died. He died on November 1st, 1953, which is All Saints Day in my faith. My family owned a funeral home in Syracuse, but they had requested permission to "wake" him in our own home. No one was ready to just turn Frankie over to anyone.

So, the county agreed, and Frankie was "waked" for two nights in our home. I insisted that I be present for everything. I had never been away from him, not even for a day, and I had to be with him up to the very, very end. And at night when the calling hours were over, they allowed me to spend just a little bit of time alone with Frankie in the room where his casket was held.

He loved baseball. So, at six years old, I figured, in heaven, he better have all his equipment. So, I actually put his ball bat and mitt under his little body. After the two days of waking, we had a funeral mass for him, which I attended. And then we all went to the cemetery to see his burial. That night, we went up to my maternal grandparents' home. And I developed a terrible headache. I've never had a headache or anything like that. So, my parents called our pediatrician who came to our house and examined me. He asked me to take my chin and put it down to my chest. I couldn't move at all. So, I was rushed off to the hospital. And for about the next four days, I remember nothing. Apparently, I had an extremely high temperature. The doctors could not tell my parents whether I was going to live or not.

But when I woke up, even though I couldn't move, the only thing that scared me was hearing a cough from a little baby down the hall. We were in individual isolation rooms, glass isolation rooms. And I had just never heard a cough like that. And I asked my nurse what was wrong with the baby. And she told me that the baby had whooping cough. At six, I knew nothing about that disease. But I've spent the rest of my life wondering whether that little baby lived or died.

Later on, that same week, my mother suffered a miscarriage. In the end, 12 young children from our small suburb and one mother were admitted to the hospital. Two children died, my twin, or three children really, my twin Frankie almost immediately and two of my friends later on because of complications. Two children had temporary paralytic polio. I was one of those kids. Both of us grew up. We made really good recoveries until post-polio syndrome started interfering a little bit with our lives some 40 years later. So that's my initial story, but it's affected my life forever. It influenced what field I went into, and it's influenced my long fight for over 20 years to finally eradicate this disease.

It's a terrible, terrible virus, but it does not want to give up. But we've got people all over the world who are more determined on this virus to finally get rid of this disease. But we have to have children vaccinated around the world in order to pull this off.

07:56

Dr. Jane Caldwell

Janice, thank you for that. That was an incredible story and incredibly sad. So, this, of course, was before the development of the preventative vaccine for polio. How was polio viewed by families back then?

Janice Nichols

Well, we were just little kids, so we did not understand how terrified our parents were. But as an adult, I learned just how terrified they were. They were willing to do anything and everything imaginable to stop this disease. We were kids born after World War II. Our parents had all fought in World War II, and they felt that the United States could do anything and everything, including develop a vaccine that would stop this disease. So, when the vaccine trial took place, decisions in terms of what schools were going to be affected, which areas, was made at a school district level. They allowed me to be in the trial because they weren't about to say no to my parents who had already lost one child, nearly lost me, and my mom had a miscarriage.

Today I would not be in the trial because we know more about double blind studies. We knew nothing about them then, but we were proud to be in the trial. And I don't think our parents were overly afraid. They believed in science, and they wanted to do anything possible to stop this terrible virus. Just before the vaccine trial was rolled out, there was a columnist on the radio, his name was Walter Winchell, and he got on the radio and told parents that the United States government was stockpiling little white coffins for all the children who would die if they took the vaccine. About 150,000 children were pulled from the study, but thankfully most of us were not pulled.

And I've always wondered if some of those kids who were pulled, did they become victims or survivors of polio because they didn't have the vaccine? We were proud to be a part of this whole thing. And they call us Polio Pioneers, telling us that we were not only helping our own generation, but we were doing something for all future generations of children. And to this day, when you meet a Polio Pioneer, we're still speaking very proudly of our experience.

10:53

Dr. Jane Caldwell

That's incredible. So where were the vaccines administered and how were you monitored? This is a really huge study. Did you go to a central place like a hospital?

Janice Nichols

No, we were administered the vaccine in our schools. And it was over 80 % of all the kids in DeWitt.

10:54

Dr. Jane Caldwell

And then how were you monitored after?

Janice Nichols

We got three shots, okay? And then they began to make decisions about all kinds of things. One of which is they knew who got the vaccine and who didn't get the vaccine. So, in the fall, parents were notified that their children had received the vaccine and would not need three more shots. If you were unfortunate and you just got a placebo, you got to have three more shots.

I received the actual vaccine. So, I did not need further shots. It took a year for the University of Michigan to actually go the thorough study to determine whether the vaccine was effective or not. We didn't have big computers at that point. They were doing everything by hand, you know, the old-fashioned math kind of stuff. And it took them a year, but it was determined that the vaccine was effective. In some ways more effective. There are three polio types, and the vaccine did better with some types than others, but it was determined to be a good vaccine. So, in 1955, the vaccine was licensed and all over the country, Canada and Finland, children started getting the vaccine.

At first, the children most vulnerable, which were kids aged from about first, second and third grade. And then after that, they increased the vaccine coverage to older and younger children. We had a serious setback soon after the actual licensed vaccine came out. And they found that about 220,000 people had been exposed to a vaccine where not all of the killed virus had been killed. And a few people died.

There were a few people who became paralyzed, but they immediately stopped the study, determined exactly what went on, corrected everything, and they actually started the vaccine program up again.

13:34**Dr. Jane Caldwell**

So, Janice, if I could stop you there, you're talking about the Cutter incident, correct?

Janice Nichols

Yes. Yep. So, what's amazing today, I don't know if we'd have a polio vaccine because with all the litigation that takes place about anything and everything today, I think people would have started mass suits. People would have become so terrified that they would have just forgotten this vaccine. Fortunately, that didn't happen back then. So, the program was reinstated and things went on the way it should.

13:38**Dr. Jane Caldwell**

So, Janice, as a child you had paralytic polio. Let's talk about the post-polio syndrome that you mentioned earlier. Could you describe that please?

Janice Nichols

Right. Yeah, I think I'll describe my paralyzed experience first. I had what was called temporary paralytic polio. And that's defined for anyone who after a few months is still having trouble with all kinds of polio symptoms, which I certainly had. When we started the vaccine trial, I was just beginning to kind of walk again.

And I was a very fortunate child. My parents could afford to give me private physical therapy, which I had for years in one form or another. First with daily therapy, then re-enrolling in every physical activity

imaginable. I started ballet classes when I was three. And my big goal in life was to put on those little ballet slippers again. So, I was dancing or kind of dancing, skating, you name it. I was doing everything imaginable. And I eventually became a very proficient dancer, skater, skier, I even cheered for a little while. So, I made a marvelous recovery. And then about 40 years later, all of a sudden, we all started having some weird symptoms and they took place very slowly.

So, at this point, I'm now 77 years old. I'm still walking on my own, but I'm walking much slower. I don't have the same stamina I once had, but I just, I'm determined to go on and do everything I can. It's a strange thing because you normally think, okay, if you have this, the more physical activity you have, the better you'll be. Well, post-polio syndrome likes to put in an extra little wrinkle. And if you overexert yourself, then you'll go backwards faster. So, you have a balance between staying active and yet not overtaxing your body. And that's the way we live.

I'm also fortunate that I'm married to an orthopedic surgeon who actually studied under one of the doctors that took care of me, one of the orthopedic surgeons. So, he's always kept abreast of anything and everything that's going on. And it's just something that we live with. But I think most of us tend to be pretty spunky people. And we're going to do our best to lead good, productive lives and fight back against this virus any way we can. And for me, it's encouraging parents to vaccinate their kids.

16:30

Dr. Jane Caldwell

So, for the last part of this interview, I'd like it to be dedicated to your brother, Frankie. What would you say to Frankie if he were still alive today?

Janice Nichols

I've thought a lot about that question you asked, and I really can't talk to him as someone who is alive today. All I can tell him is that I love him. I've missed him every day of my life, and he is the reason why I fight so hard to convince parents to vaccinate their children. No child in this world should have to ever, ever go through polio. No parent should ever have to face this.

But we have to believe in science and believe in what the experts are telling us, not what circulates the internet. So, my goal is to do something in his memory and honor, I guess. I love him. I am happy to see him someday, but I've got lots of stuff to still do down here. And I just hope that in my lifetime, we can finally say yes, we've finally eradicated this disease.

But I want to mention one other thing. Public health experts say that polio is a disease that's just a plane flight or ship away from the United States. It's kind of a stealth killer andcrippler. Over 90% of people who contracted polio have no symptoms at all. So, you can be spreading the virus and have no idea that you're spreading it, which makes it insidious. People can have the idea that nothing is going on. So, I just beg parents to please, please read and listen to factual information and not believe the naysayers because they are a very, very loud, and scary lobby in this country, and really around the world today.

18:30

Dr. Jane Caldwell

Jan, thank you so much for sharing your story with us today.

Janice Nichols

Thank you for having me.

Jane Caldwell

We've been speaking with Ms. Janice Nichols, author of *"Twin Voices, A Memoir of Polio, The Forgotten Killer"*. You can read a summary of her story and more than 100 personal accounts and case reports about diseases that vaccines can prevent on the website, Immunize.org.

And thank you for listening to the *On Medical Grounds* podcast. OMG is your source for engaging relevant, evidence-based medical information. We feature interviews with top experts along with complimentary teaching slides and continuing education credits on selected podcasts. At **OnMedicalGrounds.com** and on our OMG app, we provide perks to all posted podcasts by linking content so you can drink in more if you so choose.

Please be sure to click the subscribe button to be alerted when we post new content or download our app to get all of our podcasts, slides, and continuing education credits in one convenient location. If you enjoyed this podcast, please rate, and review it and share it with your friends and colleagues.

This podcast is protected by copyright and may be freely used without modification for educational purposes. To find more information or to inquire about commercial use, please visit our website **OnMedicalGrounds.com**