

## **Interview with Janice Flood Nichols, author of *Twin Voices: A memoir of Polio, the Forgotten Killer***

Today, Tyler R. Tichelaar of Reader Views is pleased to be joined by Janice Flood Nichols, who is here to talk about her new book, “Twin Voices: A Memoir of Polio, the Forgotten Killer.”

*Janice Flood Nichols was diagnosed with polio as a child, as was her twin brother. Her twin brother was lost to the disease, but Janice survived and became one of the polio pioneers who was given the Salk vaccine in 1954. She is committed to the eradication of the disease. She will tell us more today about her amazing story as told in “Twin Voices.”*

**Tyler:** Welcome, Janice. I’m honored that you could join me today. In the United States, it’s fair to say that polio is a forgotten killer, and you yourself personally survived it, so why do you feel the need to bring it to the public’s attention again by writing “Twin Voices”?

**Janice:** For many years, I had been under the false impression that polio had been essentially eradicated throughout the world. But, in 2003, a friend sent me the March 2003 edition of the “Rotarian” (the magazine for members of Rotary International). Her note to me was a simple one, “Jan, now you have to write your story.” She had always encouraged me to write, but I couldn’t tell the Flood Family’s story if its only purpose was to add one more polio memoir to the mix. This “Rotarian” pulled at my heart in a profound way. I was sickened to read that innocent children were still suffering from the killer and crippler.

I sat down with my husband, Dave, and told him that I wanted to write a book. As an orthopedic surgeon, Dave understands the lifetime impact of polio all too well. In fact, this saga of mine has sent him on his own quest. This past fall, he returned to school part-time to earn his Master’s in Public Health. Our son, Kevin, designed the website for the book and keeps it continually updated.

For four years, I’ve devoted nearly every day of my life to research and writing. Since the book was published in early fall 2007, I’ve devoted my time to “spreading the word” about polio and the need for eradication via presentations to students, civic groups, and service organizations. The book is a tool to reach people I can’t reach personally.

**Tyler:** What kind of reaction do you get from people when you talk to them about polio?

**Janice:** The reactions are varied. Individuals who remember the epidemic years recall their own stories—of being survivors, of knowing people who contracted polio, of how terrified their parents were of polio epidemics, of all the restrictions our parents placed on our activities in an effort to protect us. People born after the epidemic years are amazed that polio was such an issue before the vaccine was developed. Like me, most people have been unaware that polio continues to infect children and young adults in several Third World countries, and that all unvaccinated people (even those in western countries) remain vulnerable to the infection. Most people in my age group have been unaware that parents can receive waivers to opt out of vaccination for their children. People who are old enough to remember the polio epidemics are appalled by the short sightedness of such vaccine waivers. Every once in awhile, I meet someone who is under the impression that people who contracted polio in the epidemic years came from dirty homes. I like to correct their misperceptions: Some public health officials have described polio as “the clean people’s disease.” In Canada, polio is sometimes described as “the middle-class plague.”

**Tyler:** Janice, will you tell us a little bit about how it felt, especially as a child, to be someone with polio?

**Janice:** Polio was just a reality in my life. Because I made a complete recovery, I didn't even think of myself as a "polio survivor." If you read most polio memoirs, you'll learn that children were often shunned by those around them—people were terrified of polio. But, everyone around me just seemed to love me and accept me, so I didn't feel "different" even though I walked "funny" for a few years. Learning to walk again was very difficult, but learning to cope with Frankie's death was what consumed me as a little girl. I couldn't move on until I had concluded that Frankie was OK in Heaven. I was not so much a polio survivor as I was a little girl who had lost her birth-partner to the disease.

**Tyler:** Janice, will you tell us a little bit about how a person contracts polio, and also about the cure for it since I understand you were one of the polio pioneers in the test group who were first given the Salk vaccine?

**Janice:** Polio is a highly infectious disease caused by a virus. It's spread through fecal-oral contact, oral-oral contact, and contaminated food and water. Although polio has plagued mankind since ancient times, polio infection did not reach epidemic proportions throughout the western world until the late 19thC—early 20th C. More importantly, until the 20th century, polio was a disease that almost everyone contracted by age two, but only as a flu-like illness. It was our transition to modern sewer systems and a life-style that incorporated clean, single-family dwellings that allowed polio to morph into a horrific killer andcrippler. Because most people were no longer exposed to the polio virus and were largely protected from infectious agents, young immune systems were simply overwhelmed. Sadly, polio is a disease that prefers children and young adults.

Even today, most of the people who contract polio will experience what experts refer to as "abortive polio"—with no symptoms or symptoms limited to a flu-like illness. But, in less than 3-4% of people, the virus (for unknown reasons) enters the spinal column and attacks nerves that control muscle movement.

Early symptoms of polio include: fever, fatigue, headache, stiff neck, and limb pain. Paralysis and death can occur within a very short period of time. Death occurs in between 5-10% of polio cases, but that percentage can increase significantly in bulbar polio cases (individuals whose breathing and swallowing has been affected). Many polio survivors suffer from leg length discrepancies, curvature of the spine, limb deformities, and breathing problems. Contrary to popular belief, more than 50% of people who contract paralytic polio—people like me—recover completely, though a constellation of symptoms called post-polio syndrome has entered many of our lives of late.

Polio is a mysterious disease. For some reason, boys were more apt to be paralyzed than girls. Pregnant women were especially susceptible to the disease as were children who had had their tonsils removed. Epidemics were unpredictable: One year an area would experience many cases, the next year hardly any cases would be reported. No one could explain the capricious nature of polio—that made the disease all the more terrifying. Parents just didn't know how to protect their children. They followed every public health suggestion, but oftentimes it didn't do any good. Polio attacked whoever, wherever, whenever.

In sheer numbers, the United States was the western nation hit the hardest by polio, but no country was spared; we also have to remember that our country's population was larger than that of many other countries. In fact, during Canada's worst epidemic years, the per capita rate of infection was much higher than during our country's worst years. Our worst epidemic year was 1952—nearly 58,000 cases were reported.

**Tyler:** Janice, is polio now wiped out in the United States and the Western World? Do most children receive the vaccine at an early enough age to prevent the spread of the disease, or do we need to have concern of it become widespread again in the United States?

**Janice:** The United States was declared free of the wild poliovirus in 1979, but unvaccinated individuals remain susceptible to the disease if they come in contact with someone from another country carrying the virus. Viruses do not require passports to enter our country.

In the 1960s, our country and the bulk of the world switched to a different polio vaccine called the Sabin vaccine. While the Salk vaccine was a killed-virus vaccine, the Sabin vaccine is a live-virus (but weakened) vaccine. This vaccine was a better vaccine in many ways because it provided some immunity to community contacts who were not vaccinated. But, at the same time, the vaccine could (though very rarely) cause polio in a person who had received the vaccine or who had come in contact with a recently vaccinated individual. There are extremely rare instances of virus mutations causing circulating vaccine-derived polio.

Because of the Sabin vaccine related concerns, the World Health Organization has asked polio-free countries to transition back to the killed-virus vaccine. The United States did so in 2000. As of October 2006, 30 countries had transitioned to killed-virus vaccines. Because of conditions in many parts of the world, and because the live-virus vaccine offers advantages in polio infected areas, the oral live-virus polio vaccine must continue to be used until worldwide wild virus polio is certified. Public health officials have already begun making contingency plans if any cases of vaccine-associated polio occur because of circulating vaccine-derived poliovirus once the world is certified polio-free of the wild virus.

Infectious disease specialists have devised vaccination schedules to polio and all vaccine-preventable diseases based on when children are most susceptible to specific diseases. Sometimes, vaccine schedules must be altered for legitimate medical reasons, but it has become quite popular for parents to “second guess” vaccine schedules and to demand alterations. In my opinion, this is a dangerous trend. I am a person who believes the public health community has a vested interest in keeping children safe from disease and that their expertise, derived from several years of study beyond medical school, must be taken seriously by parents. It is also up to the medical community as a whole to answer parents’ questions fully, so as to dispel fears.

It is commonly believed that vaccination has saved more lives than any other medical advancement, though the medical field is always quick to concede that there are no guarantees in medicine, or in life for that matter. We are already seeing an increase in cases of pertussis (whooping cough), measles, and mumps in our country because of failure to vaccinate. I don’t want polio to make a comeback in this country. Again, it’s why I’ve written the book.

**Tyler:** Janice, I understand you lost your brother to polio. How did you and your family deal with that loss? Do you think your polio would have been enough to lead you to writing about the disease, or is your brother’s death a significant addition to that equation, especially considering he was your twin brother?

**Janice:** The death of a child changes a family forever. My parents went on, but I’m sure that a part of each of them died on November 1, 1953. My father was never able to speak of Frankie’s death, or openly cry about Frankie, until he was on his death bed. My mother pulled inward. Because I had to keep Frankie’s memory alive, I insisted that my parents tell me stories of our time together over and over again. I’m so thankful that they indulged my need, but I’m sure that it ripped them apart. I didn’t understand that until I became a parent myself.

I was brought up in a family with a strong religious faith. I was taught that we would never understand why Frankie had to die, or why our suburb of DeWitt, NY was hit so hard. In our first grade classroom of 24, eight children contracted polio. Two other DeWitt children died of complications several years later. My parents explained that spending my life focused on “why” would only bring bitterness and sadness. They told me that God had let me live for a reason, and that Frankie would always be by my side as my special guardian.

I don’t see “Twin Voices” as a book about Janice. I see the book as a story that uses our family’s experience (especially Frankie’s death) as a wake-up call to the world. Polio has always searched, and found, vulnerable children. I wanted people to see Frankie as a beautiful little boy, with a real personality, who may have had to die before the polio vaccine—but, one who would not have to die today.

I felt that my dual perspective, as polio survivor and surviving twin, offered a unique perspective to polio literature at a time when many young parents are questioning the necessity and safety of vaccines. Otherwise, I would not have written a book—I would have found another way to join the polio eradication fight. Polio has always influenced my life. It’s why I became a rehab counselor.

I’ve tried to be proactive in the book, providing information and references that parents may find useful. Public health officials are alarmed that “polio may well be just a plane trip away.” Since I submitted the manuscript for publication, the polio virus has been found in the sewer system in an area of Geneva, Switzerland. Recently, a twenty-two-year old student who had visited his family in Pakistan returned to Australia with a diagnosis of polio.

Any unvaccinated individual can carry the virus anywhere he or she travels. Any unvaccinated individual remains susceptible to polio. Any unvaccinated person can remain asymptomatic, but pass the virus to a vulnerable child who is unvaccinated for medical reasons or who is too young to have received the full series of shots... I had to do something to raise public awareness—I’m haunted by these realities. People born after the era of polio epidemics do not understand the power and devastation of polio.

**Tyler:** If a person did contract polio today, how would his or her experience be different in 2008 from someone who had the disease in the 1950s? Would the disease be easier to cure?

**Janice:** There is no cure for polio. Vaccination is the only way to prevent the disease. It seems foolhardy for parents to rely on the status of medicine in 2007 to treat a disease that can be prevented in the first place. Polio is not a disease to play around with!

**Tyler:** Tell us a little bit about how you structured the book and the special narrative voice you chose to use for it?

**Janice:** Writing comes easily to me, so I was surprised that I developed a “writer’s block” of sorts for about a month. Many people were giving me suggestions regarding style and format, but none of them seemed to fit. Then, I read a novel involving a complex medical/ethical issue that was told in multiple voices. All of a sudden something clicked. The multiple voice approach fit perfectly with my professional orientation as a rehabilitation counselor because serious illness or injury always affects many beyond the nuclear family. I wanted people to come to know Frankie, my parents, relatives, and friends as real people who all experienced our polio ordeal in different ways.

Frankie needed to tell his own story in order to convince people of the importance of vaccination and polio eradication—he needed to be the “star of the show.” I decided to have Frankie speak from Heaven based on my childhood perception of Heaven to demonstrate what children have to come to terms with when they lose someone they love. “Twin Voices” is a memoir of a disease, a disease with millions of children like Frankie and me, and millions of family and friends like those readers will meet in the book.

I wanted people to learn something about polio, the disease, but I’m not a physician and therefore could not write a medical textbook. Because I was fortunate enough to locate the medical resident who signed Frankie’s death certificate and because my husband is a physician, I realized that I could use their voices to provide medical information interpreted for a lay audience without overstepping my bounds. The personal relationship that I have developed with that resident, Dr. Alice (Jaros) Turek, has been a joy that I will always cherish. By adding historical perspective to each of the voices, I reasoned that I could tell a more complete story without boring people.

We live in a fast-paced society. If I kept chapters short and specific, and went back and forth between emotional accounts and medical information, I could keep people’s interest. I also wanted to give readers the freedom to put the book down if leisure time were running short, yet give them the option to pick the book up once again without losing its flow. Because of the way the chapters are organized, it’s relatively easy for readers to go back and find information they found especially interesting, such as the Salk vaccine trial, post-polio syndrome, twin dynamics, or current eradication issues.

I’ve been especially gratified that people who have read the book take more away from it than just another book about polio. Fathers seem to identify with my dad while mothers see themselves in my mother. One mother of twins purchased the book to help her daughter cope with the loss of her twin brother—that was perhaps the most rewarding comment I’ve received.

The book is a factual account of polio, but explores many things: the grief process, the twin relationship, human strength, faith, the power of kind medical care-givers, the power of friendship and family, advancements in medicine, etc. I’ve found that most people, like me, were unaware that polio continued to be a problem. I’m thankful that the book has served to educate people.

In the end, I hope people see polio as a terrible disease that can and must be stopped.

**Tyler:** Janice, I’m intrigued that you wrote part of the book in your brother’s voice. You mentioned earlier that you needed your parents to tell you stories about him so you would remember him. Did you find it difficult to imagine what your brother would say? How has your relationship with your brother changed as a result of writing “Twin Voices”?

**Janice:** I remember Frankie, and his personality, very vividly, though I can’t separate in my own mind what memories are derived independently, from those stories that were recalled by my parents. I was six-years-old when Frankie died—old enough to have permanent memories. My motivation to remember childhood memories was heightened by the fact that Frankie died. I just couldn’t let Frankie’s existence die along with his physical demise. Believe me, when your twin dies and all of his earthly possessions must be burned except for photos and three keepsakes, you work very hard to remember everything you possibly can. But, as I mention in the book’s Postscript, I could never have enough memories. I can’t remember anything about his food preferences, or what his “snuffles” sounded like—I wish I could.

Although my parents are both deceased, I have many relatives and friends who vividly remember Frankie. All of my relatives remember Frankie's "snuffles," temper, etc. But, because he was the quieter child, some of my relatives thought that I was the dominant child. Both of my parents always told me that although I was the more out-going child, I always deferred to Frankie. He was definitely the boss and I was the "little mother" who always took care of him if he cried, couldn't button his coat, etc. If you look at some of the photos in the book, you'll see the dynamics of our personalities coming through.

Frankie was a bright, spirited six-year-old. The events he talks about in the first two chapters are based solely on real events in our short life together... I wanted readers of the book to get to know Frankie as a real, flesh and blood child growing up in the '50s. I felt that if I spoke of Frankie and our times together in the third-person, his impact would be diminished. I could never do that. As a little girl in our double stroller, my mother used to tell me that I would often turn to people passing by, point to Frankie, and say, "See honey, see honey." I'm still that proud twin today.

Frankie "speaks" in four chapters: My Short Life on Earth, My Last Days on Earth, Heaven, and Heaven Update. Only the first two chapters are derived from my memories and those recalled by my parents. The two Heaven chapters are based solely on how I perceived Heaven to be for Frankie—I explain this in the book's Introduction. I went on quite a metaphysical and religious quest when I was a little girl. The last chapter describes Frankie helping a Nigerian boy to "cross over." I chose to include this chapter as a reminder that polio remains endemic (never eradicated) in Nigeria, and that twins continue to be separated because of polio.

My relationship with Frankie has not changed because of the book, though I've had great fun reminiscing about him. At times, memories have made me cry as well, but that's OK too—I have to believe that even after fifty-plus years, there may still be tears that need to be shed. Frankie is my twin and he died at a point where all I ever felt for him was love. I still feel the same love for him today. I think he'd be happy with this book project of mine. Although some might find my feelings silly, I think he's been guiding me along this book path for some time.

**Tyler:** Besides your personal experiences, what kind of research did you do and what information did you find that you found most fascinating?

**Janice:** My research is extensive. The book contains 40 pages of end notes and bibliography. My research will always continue. I'm committed to doing what I can, through this book and the speaking opportunities that I am being offered as a result of the book, to help with polio eradication. That commitment involves that I always stay current.

I don't think I find one aspect of research more interesting than the other. What I have found to be most upsetting is the amount of inaccurate vaccine information that is available on the Internet. I also find it disturbing that much of TV and the print media have not given equal time to vaccine proponents. We are blessed to have dedicated experts in the field of vaccine-preventable diseases. I pray that someday they receive an equal opportunity to educate the public. I also hope that parents address their concerns to qualified medical personnel—the consequences of basing decisions on hype could be deadly for their children.

**Tyler:** Janice, polio is forgotten in the United States, but it still exists as an epidemic worldwide. Will you educate us a little bit about the extremity of that situation?

**Janice:** In 1952, six-hundred thousand cases of polio were reported worldwide. In 1988, when the Global Polio Eradication Initiative was created, polio continued to affect 350,000 people in 125 countries even though the U.S. had been declared polio-free of the wild virus in 1979. The GPEI has set 2008 as the goal for global eradication. In 2007, 1278 cases were reported worldwide (down from 1,997 in 2006), but because of the nature of the poliovirus, it is now predicted that 10 million more children will be paralyzed by 2040 if eradication is not soon achieved. That statistic sickens me— it's why I've written the book. Moreover, the growing trend of parents to question the need for vaccination and the current philosophical waivers against vaccination that are allowed in several states, combine to make the public health community's fear that polio could be a "plane trip away" all too real.

Presently, a large funding gap threatens eradication efforts in spite of a recent \$200 million commitment from the Gates Foundation and Rotary International. Dimes and dollars raised the money for the 1954 Salk vaccine trial. Donations, large and small, are needed to complete the work that can only be accomplished through vaccination and worldwide commitment.

**Tyler:** Thank you for joining me today, Janice. Before we go, will you tell us a little bit about your website and what additional information our readers can find there about “Twin Voices”?

**Janice:** The book’s website is: [www.twinvoices.com](http://www.twinvoices.com). What I’ve attempted to do via the web page is to educate the public through a short text about the book and through links to good vaccine information sites, Post-Polio Health International, the Global Polio Eradication Initiative web page, and “Stand Proud” (a wonderful polio relief organization in the Democratic Republic of the Congo). Through these links, readers can find continually updated information. In addition, I provide a “polio fact” that I change weekly, a Reader’s Guide that can be printed in Adobe pdf or Microsoft Word format, and links to purchasing the book. I’m especially proud of two links that I have dubbed, “Community Outreach” and “Not-for-profit Campaign.” These two links explain what I’m trying to accomplish: I offer my services, free of charge, to any organization interested in having me speak on the topic of polio. I do ask that if overnight travel is necessary, that my travel expenses be paid for. The other link offers the book to any not-for-profit group at a 40% discount if the book is purchased (20 or more at a time) directly through the publisher and incorporates either a talk or book signing that is approved by the publisher. All groups are free to use the profit they derive anyway they choose because my goal of “spreading the word” is what is most important to me. All non-profit causes are worthy. If the group donates proceeds to a polio cause, I will make an additional private donation.

**Tyler:** Thank you, Janice. I’ve greatly enjoyed speaking with you, and I wish you much success in continuing to carry on your message.