

Eva Janzen Powell: Walking A Mile In Her Shoes

by Maren Symonds

Born and raised in the heartland of America, Eva Janzen Powell is the quintessential girl-next-door. Kind-hearted and demure, she became a wife and mother in her mid-twenties and looked forward to the simple joys of raising a family and growing old together. Yet an unexpected turn of events paved the way for this suburban housewife to have global impact. She became a passionate HIV/AIDS advocate whose life's work benefited persons living with AIDS and the researchers who save their lives.



In 1987, Eva's first husband was diagnosed with HIV/AIDS. Further tests showed Eva and her 7-month-old son to be HIV-positive. "It's hard to describe the shock that comes with the diagnosis. I was told that my son probably wouldn't make it, and that my chances for survival were slim. When I buried my husband a few months later, I purchased two extra spaces and got my affairs in order," she recalls. "Then a stubborn resolve kicked in. I knew that there had to be some reason and value behind living with HIV/AIDS. I was not going to let complications from AIDS be the reason for my death."

Eva's advocacy began when her son, Arlo, entered school. "When your child has a compromised immune system, it changes your relationship with the school. A cold or flu or outbreak of the chicken pox that puts other children in bed could send mine to the hospital," she recalled. "Arlo's vulnerability to infection forced disclosure of his status to the administration. It took a lot of work to change their process to provide immediate notification of a potential health hazard."

To her relief, the school honored the family's privacy while Eva's son was too young to understand his condition. When the administrators provided notice to other parents that an unnamed child in the school had HIV/AIDS, they scheduled two parent meetings and brought in the experts to talk about the disease.

"The parents were very nervous and upset. Even after the presentation, they asked questions like: 'What will happen if my child finds a bloody band aid on the floor?'" she said. "Then one mother got up and said she'd done her own research. She told everyone that it was a lot more dangerous for [Arlo] to be here than for the other children to be around him."

These difficult encounters gave way to productive conversations about health and safety standards for *all* children. Eva helped craft policies on universal precautions – e.g., making latex gloves readily available throughout the school campus – to minimize the spread of infectious disease.

In 1996, Eva became a charter member and Co-Chair of the Chicago Pediatric Community Advisory Board (CAB) for the Special Infectious Diseases Clinic. She also served on network advisory Boards for the Pediatric AIDS Clinical Trials Group (PACTG) and the International Maternal Pediatric Adolescent AIDS Clinical Trials Group (IMPAACT). Collectively, these groups brought scientists, clinicians, and patients together to bridge the gap between the arcane world of medical research and the common needs of patients.

"In the early years, we didn't have much of a voice in the development of treatment protocols. You were simply expected to adhere to a strict regimen and bring your child into a center every few days to draw blood. It was onerous for the parents and hard on the kids," she said. "It didn't help that [the practitioners] used code words that no one else understood."

Active community engagement helped break the language barrier by encouraging researchers and clinicians to use plain speech when counseling patients. At the same time, CABs helped patients and caregivers recognize the acronyms and get comfortable using them with their doctors. CABs were also responsible for the informed consent process which includes a bulleted outline to describe each study, its purpose, its treatment protocol, and the requirements for participation.

As consciousness of the disease assumed global proportion, Eva played a part in taking the CAB model to other countries where new research sites were being established. She served as a faculty member for training at four sites in South Africa (Johannesburg, Cape Town, Port Elizabeth, and Durban) and helped launch the program in Zimbabwe. Today, regional programs throughout Asia, Africa, and the Americas routinely collaborate on more effective ways to test and introduce new protocols and provide quality care for persons living with HIV/AIDS.



Johannesburg, South Africa
Research Site Staff and CAB Members
with Eva and Emily Barr, RN



Cape Town, South Africa
CAB Members from 2 Sites
Training with Eva

After serving on numerous Boards and action groups over the past 15 years, Eva is taking a breather to replenish her energy reserves and focus on family. She remains an advisor to several organizations and an active participant in the Women's Interagency HIV Study. Despite a dismal prognosis 23 years ago, Eva enjoys reasonably good health and a full life with an uncommonly supportive second husband. At 48, the travails of middle age may be more of a nuisance than living with HIV/AIDS.

"It still bothers me that people are so preoccupied with how one gets infected. It really doesn't matter. HIV is a human disease, and those of us who have it deserve no less care or compassion than persons suffering from any other ailment," she said. "Judgment isn't healthy for anyone."

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Eva Janzen Powell is a Community Advocate who has served on the Chicago Pediatric Community Advisory Board at Children's Memorial Hospital, the Ryan White Title I Chicago EMA HIV Services Planning Council, the Community Constituency Group (CCG) of the Pediatric AIDS Clinical Trials Group (PACTG), the AIDS Foundation of Chicago Board of Trustees, the DAIDS Cross CAB Working Group, and the International Maternal Pediatric Adolescent AIDS Clinical Trials Group (IMPAACT). She has also been on the faculty at the PACTG/Francois-Xavier Bagnoud Center (FXBC). Eva earned her Bachelor of Arts at the University of Illinois at Chicago in criminal justice and earned her paralegal certificate at Roosevelt University.

Headquartered in Redwood City, CA, Until There's A Cure® Foundation is a national organization dedicated to AIDS awareness and prevention education, care and services for those living with AIDS and vaccine development.