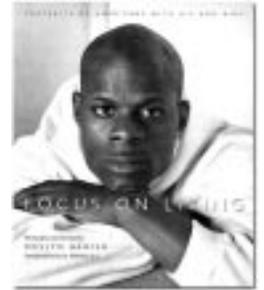


Focus on Living: Portraits of Americans with HIV and AIDS

Photographs and interviews by Roslyn Banish; introduction by Paul M Volberding, MD

Review by Richard Wolitz, MD



Amherst: University of Massachusetts Press; 2003. ISBN: 1558493948 (cloth); \$50.00 ISBN: 1558493956 (paperback); \$24.95. 288 pages

More than 900,000 Americans are now living with HIV. This statistic adds little to our understanding of their lives. *Focus on Living* is about 40 people, each with a story about living with HIV. They come from different parts of the country and from different economic, racial, and ethnic backgrounds. They are young and old, gay, straight, bisexual, and transgender. Each has a reason for participating in this moving project by San Francisco photographer Roslyn Banish, who has compiled riveting portraits with verbatim interviews. Each subject takes the stage, as it were, to give out a message—for example, the person whose partner died without leaving a will—or simply tells that person's story so that others might not feel so alone in their struggle. Thus, each participant leaves a legacy.

This book was begun before the introduction of highly active antiretroviral therapy, several subjects' lives have since changed dramatically: Instead of planning to die, they are deciding how to live—in some cases going back to work, retraining for a more interesting career, or starting a family. Their words and pictures will inspire you and will broaden your understanding of this disease and its impact on our families and communities. By allowing HIV-positive people from all walks of life to speak openly, this book seeks to remove the stigma that contributes to the silence surrounding this disease.

An excellent introduction to *Focus on Living* is provided by Paul Volberding, MD, Professor and Vice Chair of the Department of Medicine, University of California at San Francisco, and Chief of the Medical Service at San Francisco Veterans Affairs Medical Center. Dr Volberding states, "To the doctor, a person becomes a patient following a diagnosis. To the person, however, the diagnosis is only one event in the context of an entire life."^{1:pxxi} This book chronicles the transformations—large or small—that can occur in people threatened by illness.

The story of a young woman who is an incest survivor, drug addict, and mother of three children is remarkable: After discovering that she was HIV-positive, she kicked her crack cocaine habit through Narcotics Anonymous and regained custody of her children through hard work and determination. After enduring her own childhood of abuse and neglect, she encourages her children to maintain their education, to read, and to better themselves. She says, "When my kids come visit me, they don't just sit and watch

TV. We bake cookies. We read. We draw and write ..."

"... I want ... to show my children the importance of education, to teach them African-American history, and to let them know the meaning behind the word *NO*. I want to be there to give my seven-year-old daughter self-confidence, to teach her to love herself."^{1:p55}

Also included is the moving story of a devoted grandmother who takes custody of her HIV-positive daughter's children, one of whom is HIV-infected at birth. The strength and activism of this woman is humbling and inspiring.

One of the most touching stories in *Focus on Living* is the story of a Vietnam veteran living in rural Minnesota who must decide whether to move to a city where he might receive more support from social service agencies and other people who are HIV-positive, or continue to live in the countryside near where he was raised. He decides to stay and to be open and honest with his neighbors and family members. His Amish neighbors know that he is HIV-positive, and are not judgmental. With the town's help, he opens and directs a drug-abuse-and-alcoholism recovery center, which is still going strong. "Somewhere in all of this," he states, "the desire to find peace is the most important thing—peace with people, with the animals, to have that sense of peace inside me."^{1:p201}

In another chapter, Cleve Jones (founder of the NAMES Project AIDS Memorial Quilt) asks, "Is there a family left in this country that doesn't know someone with AIDS? People have come out about their HIV status and it's very much like the gay struggle in that we win when we are open and honest about our lives. ... The people that I think have made the difference have been ordinary people with AIDS who are so courageous about revealing their status to their world. By doing so, they compelled and required this country and our society to move forward."^{1:p15}

Contemplating the hard facts regarding the worldwide impact of the AIDS epidemic, we may easily despair and become lost in numbers. What will keep our compassion strong is to maintain our focus on the person: We must begin and end with the person. This is why we must pay attention to their stories. ♦

Reference

1. Banish R. *Focus on living: Portraits of Americans with HIV and AIDS*. Amherst: University of Massachusetts Press; 2003.

Richard Wolitz, MD, is a comprehensive ophthalmologist practicing at the KP San Francisco Medical Center since 1981. He has a special interest in treating HIV-associated eye diseases and has been an investigator in clinical trials for experimental drugs related to this field since 1984. E-mail: richard.wolitz@kp.org.