

# SISTERS IN THE STRUGGLE

A NEWSLETTER FROM THE WOMEN'S COLLECTIVE



## BEGINNINGS...



BY PATRICIA NALLS

**M**y story and the story of *The Women's Collective* does not begin with the opening of our new office space. It began years ago. I hope by sharing my story, that other women will feel that they can end the silence about their lives.

In many ways the birth of my daughter Tiffany in 1984 symbolized everything wonderful in the life of my family. After ten years of marriage, my husband Lenny and I both worked hard and had meaningful jobs. We owned our home. We had two other children, both healthy and happy. From the beginning Tiffany was a child who was very ill, she was hospitalized for numerous heart and liver operations. Frustrated with not knowing what was causing her medical problems, my husband and I took her to the Mayo Clinic to try to identify appropriate medical care to treat the problem with her heart. While at the Mayo Clinic Tiffany underwent yet another operation but the damage to her heart was so devastating that the surgery was unsuccessful.

For a period of two and a half years Tiffany underwent over ten operations. Then in 1985, Lenny developed a persistent cough. For a year, we went to various doctors, often he was sent home without a diagnosis. In October 1986, my

husband went to the hospital emergency room, doctors felt his symptoms, a low blood count, indicated that he had a bleeding ulcer. After several days in the hospital, the doctors did a complete medical history and he was asked questions about past drug use. My husband and I worked for Bread for the World, a lobbying organization on behalf of hungry and homeless people. Lenny was a good provider, husband, and father. He had not used drugs for over ten years. The doctor did an HIV test and it came back positive. My husband had full-blown AIDS. By then my daughter Tiffany was back in Children's Hospital and my husband was at George Washington Hospital Center. I was going back and forth between two hospitals, providing emotional support to Lenny and Tiffany. I also had two

children at home to take care of, both frightened and unsure of what was going on with their father and sister. A few weeks later I took an HIV test and discovered that I too was HIV positive.

There was no time to think about what my diagnosis meant; all I could think about was taking care of my children and my husband. The next months were extremely difficult. Both Lenny's and Tiffany's conditions became worse.

My husband died from an opportunistic infection and six months later my daughter Tiffany died; she was just three years old. At 29, I was a widow, a mother and a woman living with HIV. It is hard to explain to you the enormity of losing two of the most important people in my life. But at that time I had no time to think about it because I had two children at home who really needed me. I literally had no time to take care of myself, to think about my own diagnosis. I thought that I was going to die and so I focused on my son, Shawn, who was four and my daughter, Alana, who was eight. I had to take care of them and that meant I had to go back to my full-time job, because I had a mortgage, we needed food and clothing; the world did not stop.

At first I did not tell anybody about my status, I didn't want to hurt or frighten my family and friends. It took me about three years of isolation and silence about my status before I sought any emotional care. My physician was sensitive and a good doctor. Then my insurance changed and I was forced to switch to another doctor. Then someone told me about a wonderful woman doctor who was considered an expert on women and AIDS. Her name was Dr. Mary Young at Georgetown University. She was the first physician to do a gynecological assessment. I believe that one of the reasons I am still alive today is because of the care that I have received from Dr. Young. I am an equal partner with her in deciding my medical care. She has never just given me a bunch of pills and sent

me on my way after a two-minute check-up. She sits down and explains the medical options and she and I make decisions about my health care together.

While my medical care was taken care of, I was still in isolation. I chose to remain quiet about my HIV status because I did not want my two surviving children to suffer any discrimination or worry about losing me. While

I worked eight-hour days, and tried to maintain a "normal" home there were other underlying emotional issues that came from being so isolated. For three years, I felt shame and I was terrified that someone would find out. My children's grades suffered, they couldn't concentrate, and they were overwhelmed with grief and loss. So I took them to see a counselor, who recommended that I tell them what was going on. My family started coming to terms with my HIV status and the loss of my husband and daughter. I sought a support group, but back then, support groups for women were very rare so I was the only woman in the group. The issues for men and women with HIV/AIDS were different and I felt a degree of isola-

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tion in the support group. I was the only person who had children. I was in a constant panic about caring for my children, trying to make arrangements for them in case of my death. I also struggled with how to provide for them when I didn't feel well. I was the primary care giver. It was extremely difficult to live off of one income. My health began to decline and by 1990 our family income had declined by 80 percent. But I was committed at that time to helping my children function as normal children.

In 1992, I started attending a support group for women sponsored by the DC Women's Council. Although services there were very limited, the support group was important. It was then that I began to heal and to learn what I could do to have some kind of a life. I sought and received the support of family and friends. Then the D.C. Women's Council closed down and the support group ended. A core group of the women began to meet at my house. Soon more women were interested and I knew I had to find a larger space. At first we met at Brooks Mansion, but that facility was sold, then I went to St. Anthony's Church, in N.E., it was convenient, close to the Metro, they let us use their school cafeteria, and I cooked food for everyone. I saved my money and with the help of some friends and family I installed a 24-hour telephone line in my home. Women called often, day and night. In the support group women came together and we discovered that we were dealing with many of the same problems and issues. Women with HIV became each other's main sources of information about medical care and support. Yet many women still face barriers to care and are frustrated by the lack of services and resources available to women, especially poor women and women of color. We started helping each other, providing emotional support. I

found myself helping women get access to multiple services, taking them to doctor appointments, etc. I didn't know it then, but I was providing "case management."

The Women's Collective was invited to make presentations regarding HIV/AIDS prevention. Although there were many women who were dealing with HIV/AIDS, there wasn't a local organization dedicated solely to serving women. We decided to incorporate, but that would cost money and while some folks helped with the mailings, we needed money. When I had enough money I decided to get incorporated. In 1993, we became a 501(c)3. Using the skills I learned from Bread for the World on com-

munity organizing and as a recruitment coordinator, I started identifying contacts and referrals. Other people began to offer their support, helping us get the word out, referring women to us. A small core of folks, "angels," gave time, energy, and encouragement. Who better to help us – but us? The core of our mission is to help women empower themselves and each other.

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More and more women are affected and infected by HIV/AIDS. Many organizations still do not provide gynecological medical care, seldom do organizations provide child care services, transportation or even case management services that take into consideration the diversities and complexities of women's lives. Although currently some services are available to women, many women still face isolation, discrimination and victimization. Many women I know still have physicians who are not prescribing medications that will prevent opportunistic infections. Others are being put out of hospitals because they don't have financial resources to pay for their medical care. Others are caught in SSI limbo, unable to work, with low T-cells but denied any benefits and yet, somehow,

some way, these women find a way to not only take care of themselves but also take care of their children, their husbands and even, in many cases, their parents.

After I tested positive I figured I would die but I've been extremely lucky to have a good physician; but I think about the countless others, many of them my friends, who have died because of health care providers lack of will and lack of knowledge. Many women do not trust a health care system that ignores issues of confidentiality. Someone I know had her status revealed in a waiting room full of people.

Women are concerned about confidentiality particularly as it relates to their children's lives. One woman in my support group was in her late fifties when she was diagnosed; the doctors never suspected she was positive because of her age. Many women cannot afford care and can't get care until they are very ill or near death. Now that new drug combinations are available, like protease inhibitors, some women are finding that their doctors will not prescribe them because women are not considered good patients. I know women, women of color, who can't get access to the new drugs because of what they look like and provider's perceptions about their past. I know others who can't get a good physician who is knowledgeable about HIV/AIDS.

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But women are not sitting around waiting to die. Many of us have taken an active role in saving our lives. Many women participate in program planning groups like Ryan White Title I Planning Councils in their communities; trying to advocate for themselves and others. Unfortunately the needs of women with AIDS are consistently ignored. The voices of women living with AIDS must be listened to. Given the critical need for services and care we must listen to what women with AIDS have to say. Women with HIV/AIDS desperately need a continuum of care and services; sadly, at this point in the epidemic, such care is available only to some people with AIDS.

I have learned a lot from the past. As the executive director and founder of the Women's Collective, I wanted to share this story, because it shows how far we've come. My daughter Alana is now 20 years old and in college and my son Shawn is 16 and in high school. While I'm ecstatic about the new office space and expanding our services, I feel much sadness too, yet I know that my family and friends lost to AIDS will not be forgotten because it is their legacies that strengthen and carry me through. So this is dedicated to Lenny and Tiffany, Sara, Specious, Janice, Diane, Debbie and many many others, sadly, too many to list. I will never forget – never.

## DEDICATION

This newsletter is dedicated to Debbie Pendelton who passed on March 7, 1998.

The title of this newsletter comes from Debbie. she always reminded us that we were sisters in the struggle and you know what – she was right – we must work together. We have to be at every table where decisions about care and services are being made. At a recent policy meeting Debbie shared her life experience – she was nervous but she didn't let fear silence her.

This newsletter is dedicated to women like Debbie who won't let fear silence us anymore.

Nobody is going to save us – we must save ourselves and each other!