



Remembering NAPWA

February 21, 2013 By [Paul Kawata](#)

In the early days, death from HIV was quick and very ugly. It seems unbelievable, but there was a time when funeral directors would not cremate our dead, hospital staff would not bring food into the room, even some of our friends would turn their backs on us because they feared infection. It is a testament and the legacy of the LGBT community that we rolled up our sleeves and developed whole new infrastructures to respond to the epidemic. The continuum of care model was developed by us to take care of our friends. There were heroes, amazing men, women and children who stood up to discrimination and fought back against the stigma and lies surrounding this disease. The HIV community owes a great debt to our straight allies and the lesbian community who stood with us when so many others looked the other way. This epidemic was and is the test of a generation. Would you stand up and be counted or run away and hide?

The [National Association of People with AIDS](#) (NAPWA), the first national organization representing people living with AIDS has closed. We can point fingers or cast blame, but right now I want to remember the visionaries who started and built this important organization at such a critical time for our community. NAPWA's first executive director was [Stephen Beck](#), followed by [Mike Meridian](#), [Bill Freeman](#), [Terri Anderson](#), [Cornelius Baker](#) and [Frank Oldham](#). Ordinary Americans who stood up to be counted. I was lucky to be taken under the wings of so many early heroes. I learned to fight from [Michael Hirsch](#), compassion from [Bobby Campbell](#), running an organization from [Richard Dunne](#), and to dream from my friend [Paul](#). Many who survived this period have their own Michaels. That friend who gave them courage to do things they could never have imagined.

This is my story about Michael Hirsch. When I first came to Washington, I had no idea which way was up. Michael was the first person to take me under his wing. He was the quintessential New York Jewish gay activist who was the first executive director of the [New York PWA Coalition](#) and [The Body Positive](#). Michael could drive me crazy, make me angrier than I thought possible, and laugh until I cried.

He would infuse during meetings. He wanted to remind the world that HIV was about real people with real problems. Because of Michael I was accepted into the PWA community. He insisted I attend early organizing meetings that would later become the National Association of People with AIDS.

Michael wrote long diatribes about life, the movement, his frustrations and joy. They were intimate letters between someone who was dying and someone who would remember. He closed each letter with "Yours in the struggle".

When I got the call -- if you did AIDS work in the 80s or early 90s, you know which call I mean -- to come to the hospital for Michael while I was in Washington. I hopped on the shuttle to New York as quickly as I could and prayed to make it on time. The taxi ride from LaGuardia to Saint Vincent's seemed to last forever. When I rushed into the hospital, Michael's mother and sister were sobbing. My heart sank, was I too late? Just then Rona Affoumado, former executive director of the Callen-Lorde Health Center, found me and said, "Oh God, you made it. The family just decided to pull the plug." ...I wasn't too late

Rona escorted me into Michael's room. It was all pumps and whistles from the many machines keeping him alive. It had that unique smell, the smell of death. Michael was unconscious. The morphine stopped the pain so he could sleep. When they turned off the machines, there was an eerie silence. I held Michael's hand and told him how much I loved him. Just then his eyes opened and a single tear rolled down his cheek and he was gone.

The nurse later said it was a reflex, to me it was a sign. It was Michael saying goodbye and to always remember. I close all of my emails with "Yours in the struggle" to honor his life and the lives of so many we've lost.

Michael's story is the story of our movement. With NAPWA's closing, we've lost a national voice for PLWHA just as we've found a pathway to end the epidemic. The dream of an AIDS-free generation cannot happen without leadership from people living with HIV or AIDS. All of us fighting to end this epidemic must work to carry on and fulfill NAPWA's vision and ensure that people living with HIV or AIDS are front and center in the fight to end this epidemic. We must never lose sight of the fact that our fight is more than a battle against some abstract disease, but a struggle for our friends and lovers.

Goodbye NAPWA. I will remember your history, legacy and the leaders who made it possible.

Yours in the struggle,

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