



AIDS CARE AND TREATMENT

IN OUR NATION

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Bethsheba Johnson

Chicago, Illinois



Nurse practitioner Bethsheba Johnson is part of an entirely African-American medical staff that provides specialized HIV care at the Luck Care Center on Chicago's far South Side to a population that is 97% African-American.

It is one of few HIV clinics in the area that is staffed entirely by African Americans, which Bethsheba feels can be an advantage in that it gives her and her colleagues a better cultural understanding of their patients. The clinic is also a one-stop agency: It not only conducts clinical trials, which Bethsheba helps coordinate, but it provides its patients with a wide range of services, including primary care, adherence counseling, case management, mental health counseling, substance abuse counseling and support groups. Bethsheba also works with many of the female patients at the clinic.

According to Bethsheba Johnson:

“A common issue I see with women who are HIV positive is their devotion to taking care of their children. Our female patients are primarily mothers. They take care of their children first and neglect themselves. The age range is between 20 and 56. About 80% have heterosexual sex as their risk factor for HIV. The other 20% have injection drug use as their risk factor. Quite a few are single mothers with mental health disorders.



Approximately 55% have Medicaid/Medicare, 42% are Ryan White Care Act patients, and 3% private insurance. All of our Ryan White Care Act patients receive ADAP.

The biggest challenge I face is taking care of people with reduced resources, who must rely on Ryan White CARE Act funding. I see patients paying so much for their medication that they can't make ends meet. The Illinois AIDS Drug Assistance Program (ADAP) does not cover non-HIV medications such as antihypertensives, oral hypoglycemics, statins, etc. The need for these medications is mostly related to genetics and adverse drug events from HIV medications. It is also a big challenge trying to educate that -- without exception - - *everyone* is at risk.

Many of my patients would not be in treatment if it wasn't for Ryan White CARE Act funding – and there are many more who don't realize that benefits are available, and as a result they don't come in for care. Another 1 in 4 people in the Chicago area are not in treatment because they don't know they are positive – we could see quite an increase if the word continued to get out that everyone needs to be tested. Our current budget, including the Ryan White funding does not cover the needs of our patients. We often have to spend valuable time fundraising to help treat those who need Ryan White funding. Many times we find ourselves struggling to meet the demands. And we have to ask, 'who is going to care for these people when we've been flat funded for 5 years and now the president wants to reallocate funds to other regions?' I applaud the President and Secretary of HHS for wanting to make HIV/AIDS a top priority but the way they are going about it is not ideal – we need to increase the money and help those people in the rural areas but if you take money away from areas where there is high prevalence we are going to be facing the same situation we faced in the 1980s with people dying from AIDS at an alarming rate.”

Alice Myerson
Bronx, New York



Alice Myerson, CPNP, MSN, is the primary care coordinator of the Adolescent AIDS Program at Montefiore Hospital in the Bronx, NY. She is a nurse practitioner who specializes in the care of adolescents and young adults who are infected with HIV or who are at risk for HIV.

She has been a nurse since 1972 and a nurse practitioner since 1995. She has worked with persons with HIV infection since the beginning of the epidemic in 1981. She has seen the devastating effects of this illness on young people in the Bronx and has seen the remarkable resilience of youth who grapple daily with the complexities of this disease.

According to Alice:

“I treat young people with HIV infection between the ages of 13 and 24. Over the past 5 years we have changed the orientation of our program from one of palliative and aggressive support to a chronic illness model. It is no longer the expectation that youth with HIV infection will die prematurely. Rather it is our goal to teach young people how to live with a chronic illness, how to live full, productive and meaningful lives within the context of this illness.

Our program is now built on a multidisciplinary, transition model. We work as a team that includes social workers, medical providers, a psychiatrist and a nutritionist and a full time HIV counselor. We instituted a “Celebration of Life” festival this year to acknowledge the accomplishments of our young people who graduated from our program at age 24.

Our patients all have had incredibly difficult and challenging lives. 1/3 of our patients have perinatal HIV infection. The other 2/3 acquired the disease through sexual exposure; the young men acquired it in the main through male-male sex and the young women through male-female sex.

Out of 81 of our patients, 46 have had experience in the foster care system; 23 have experienced the death of their mothers; 46 have been suicidal at some point; 25 have had experience with the criminal justice system.

Clearly youth with HIV infection are vulnerable youth who have suffered extensive trauma in their lives. The trauma of childhood, indeed, the dismemberment of innocence and dream, leaves them with emotional scars and multiple mental health problems. With treatment and support, with the collective care of the small village of our program, many of our patients transform themselves and turn their lives around. 6 of our patients, for example, are attending college.

Our program relies on grants from both the federal and state government. Some of our funding comes from the Ryan White Care Act. Our grants enable us to provide comprehensive care to these young people with such complicated medical and social needs. Our medical care is built on the attention we pay to the social needs of our patients. Suicidal patients don't take their HIV medications. It is difficult to provide follow up to patients who are homeless.

The achievements we have made over the past decade rely on funding sources such as the Ryan White Care Act. We have made HIV testing routine among young people in the Bronx. High school students are aware of where to go for testing. We teach them the importance of sexual choice whether it is to use condoms or to defer sexual intercourse. We emphasize in our counseling the importance of relationships and self worth. We are innovative in our ability to get youth to come in for routine STD testing. We know that if we decrease chlamydia rates, we can decrease HIV rates. NY has been exemplary in the identification and treatment of pregnant HIV positive women. We have decreased the rate of perinatal transmission to less than 1%.

Of course there are many challenges that we continue to face, many difficulties that lie before us. But it is my belief that federal funding such as the Ryan White Care Act that allows both all communities to individualize their HIV programs is an imperative if we as a society are to continue to move forward in the 21st Century.”



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Mary Lynn Purcell
Decatur, Georgia



Mary Lynn Purcell is a 12-year veteran of HIV nursing who provides care under the Ryan White CARE Act for indigent patients at the DeKalb County Board of Health, a public HIV clinic in Decatur, Georgia.

Many of the patients she cares for lack insurance and are only able to receive care and treatment thanks to funding provided by the Ryan White CARE Act. Only about 5% have Medicare or Medicaid. "Being poor, out of work, no medical insurance, sometimes no place to live are common in our setting", she says. "If I can ease some of their fears and barriers and have my patients trust me, that is an accomplishment I am very proud of."

Some of her patients come from other states without making plans before coming here. According to Purcell,

"We have to explain that all states are not uniform in their Ryan White HIV programs; some states have more money than others. I remember telling one patient that she would be better off going back to New York, because she [wanted] housing, food, furniture, transportation and medications. But that may change if the new funding guidelines are enacted.

I am very thankful for the existence of the Ryan White CARE Act, but at times disappointed by the bureaucracy, because often the people who make the



decisions don't understand what it's like to be in the trenches. For example, the AIDS Drug Assistance Program (ADAP) often lacks standards in judging how much an individual pays. To me, a perfect ADAP would be to assess the uninsured individual and have them pay a portion on a sliding scale, based on their income or ability to pay. There are many HIV infected people that make just over the income requirement, but cannot afford a \$1200-\$1500 drug bill every month. People have to continue to eat, pay utilities, house/rent payments, etc. It seems the system is for the poor, not for the people working and contributing to society. I certainly believe the poor need help, but working people do too.

I would also like to see the ADAP program work with several local pharmacies to dispense medications. That would cut down on much of the confusion in the clinics. Patients would then also understand what it is like to call ahead and sometimes wait at a pharmacy. This is done in Baltimore, Maryland with much success, I understand. The same could also be done with services. I am not saying to completely eliminate clinics, but Ryan White could contract private doctors to see HIV patients and I think this could work well.

Our clinic is in a public health setting. There are sometimes barriers to signing up for ADAP. Patients are sometimes slow in bringing in the required paper work. At times staff is less than cordial to patients. I think all HIV providers should stop and put ourselves in our patients' shoes. This is a life and death situation and health care providers should do all that's possible to help these unfortunately uninsured individuals.

Hopefully, one day, there will be universal health care and all will be treated equally. Until then, the Ryan White CARE Act helps provide necessary care and treatment for HIV/AIDS patients and should be reauthorized and funded at a level that helps keep pace with the changing nature of this disease.”



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Joel Wesley Thompson, P.A.-C.
Charlotte, North Carolina



Although he has been a physician assistant since 1987, Wes Thompson didn't begin to focus on HIV until the early 1990s -- when one patient in particular changed his life forever. "It was spring of 1993. I was just learning about HIV," Wes recalls. "He was the third HIV patient I had met. I didn't recognize him at first, and then he said, 'Don't you recognize me?' And I realized I had known him 15 years earlier."

Wes says that, at that moment, he envisioned Christ knocking three times at Peter's door -- this long-lost friend, his third-ever patient with HIV. It was an image that, Wes says, told him to "pay attention." Wes realized that the missionary-type work he had sought all his life was right in front of him -- as a healthcare worker treating people with HIV. "We both cried, and it was then I realized that taking care of HIV patients was my mission field, my calling," he says. "I have never doubted it since."

Though Wes describes himself today as "not overtly religious or spiritual," he says that "each person's pursuit of their individual path to the holy excites me. I believe in a creative force that many would call God. The greatest gift is life in the here and now, and we must make the most of it. I tell my patients, 'Part of your health is going to be forgiving yourself. You did nothing wrong in getting HIV. I don't do guilt, so let's get that out of the way. If you don't have any guilt, you're way ahead of the game.'"

Wes learned his own lesson about guilt at age 19, when he was in college and struggling with his homosexual feelings. He had sought both medical and religious "cures" for his



homosexuality. Finally, believing he was an "awful reprobate," as he puts it, Wes was on the verge of taking his own life. But a voice in his head told him to stop -- that he was exactly who and what he was supposed to be. "A peace washed over me that I can't explain," he says, "and my tears turned to laughter."

And also, years later, into hope and healing for the HIV-positive people who would one day come to him for their care.

Today, Wes works at the Jemsek Clinic in Charlotte, North Carolina. His patients range from the transiently housed to the well-to-do. They include straight, gay, transsexual and a mix of urban, suburban and rural. According to Wes, the number of immigrant patients is increasing every week and he sees many poor patients and African-American women.

He comments on Ryan White CARE Act Patients:

"I see lots of patients with who pay for their care through Ryan White and the North Carolina AIDS Drug Assistance Program (ADAP). The rest are a mix of Medicaid, Medicare and private insurance. I see a few deaf patients where I use sign language and their issues are the same as those who can hear and speak.

Currently, I am serving on the American Academy of HIV Medicine Southeast Chapter Board of Directors, the Regional AIDS Interfaith Network Board of Directors, and on the Ryan White Continuous Quality Improvement Committee (CQI) for our local AIDS Service Organization, Metrolina AIDS Project.

Ryan White has been flat funded for the past 3 years while the number of patients without access to care has increased. The cost of care has increased exponentially. The president has recommended the Ryan White funding remain the same, i.e., flat funded yet again. Title I through Title IV is focused on healthcare with no emphasis on prevention, education or testing. Not only do we need to have the funding increased, we need to change the focus to emphasize prevention, education and testing.

Title I which was originally designated as emergency funding for a specific set of large metropolitan cities has continued at the same funding unchanged to those cities. For example, the number of cases in San Francisco has actually decreased but they are still being funded for people who have actually died. The southeast is leading the nation in the number of new cases of HIV and AIDS, and without any additional funding. This disparity in Title I funding should be corrected to accurately reflect who needs the monies.

On a personal level, the number of patients waiting to be enrolled in Ryan White is growing. There are so many that our local ASO is no longer able to maintain a list. We do not have the monies available to fund anything much beyond the cost of labs."