

# The Circle

Summer 2003, N° 10

leading lines advocacy outreach our history

## SURVIVING & THRIVING

by John Hatchett



"Sisters are doin' it for themselves," declared Annie Lennox and Aretha Franklin in a popular song a few years back, and if there were any doubt about that statement, one look at the AIDS community would put it to rest. The pandemic's disproportionate and devastating impact on women continues unabated worldwide, and though faced with tremendous economic, political and social disadvantages, positive women are not only "doin' it for themselves," they're doing it for each other and for the rest of us as well! From local neighborhoods to the halls of government, women are increasingly visible leaders in everything from prevention education and service delivery to community organizing and political advocacy. In this issue of *The Circle* we highlight just a few of the ways HIV+ women are asserting leadership to respond to the challenges of AIDS, including two organizations founded and run by and for women living with HIV: Catch a Rising Star (by Vanessa Johnson of Albany) and SMART University (by Susan Rodriguez and Petra Berrios of New York City). Both stories have at their core dynamic positive women working in creative ways to help other

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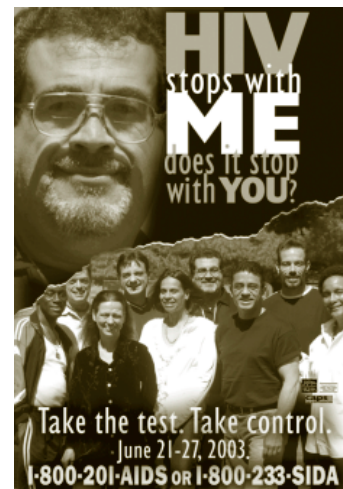
## IT STOPS WITH US!

**Editor's note:** Recently a committed group of advocates from the Albany area powerfully demonstrated Margaret Mead's aphorism to "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has." As LTI graduate Richard Hahn tells the LTI Circle, this small group of HIV-positive citizens saw a need for education locally, generated an idea, sought funding for it and made it happen, significantly impacting perceptions of AIDS and the need for testing in their community.

Several months ago a series of events occurred in the Albany area that profoundly disturbed members of the HIV community there. A local AIDS service organization, the Jim Perry House, which provides transitional housing for small numbers of men of color living with HIV, was proceeding with plans for relocation. In two proposed sites, however, community opposition exploded. A conventional NIMBY (Not In My Back Yard) response to public projects in residential areas was made uglier by ignorance and prejudice specifically aimed at PWHA (people with HIV/AIDS). One resident was quoted at a town meeting as saying, "if any of those people so much as spit on my lawn, I'll sue them for attempted murder."

Many community advocates would have been appalled and enraged by such blatant intolerance and discrimination, but a small band of activists in the Albany area

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## POWERFUL WOMEN

The *LTI Circle* recently asked several LTI graduates what it is like to be women advocates living with HIV.

advocacy

### **Yolanda Diaz**

Dean of Students

SMART University, New York, NY

*I like to empower women of color that have just been diagnosed. Becoming an advocate made me feel so much stronger. Sometimes it's hard waking up in the morning but after I'm up and outside I'm great. The end of the day the best part of the day when I can look back and realize that I met someone who just came out of detox and they are becoming empowered. I get a ton of energy from advocacy. I'm learning from other women all the time.*

### **Denise Drayton**

Director of Education and Prevention Exponents, Inc., New York, NY

*I love advocacy. Boarding the bus to Albany to do a legislative visit or shout for action at a rally is a rush. I'm especially pumped up when other HIV+ advocates are already on board, there is an air of excitement as we take off. We know we are about to make a difference and there is that sense of unity. It's my chance to hug those brothers and sisters that I have met over the years and to know that they are still out there fighting for the cause. I get to see leadership in action and I know that LTI has made a positive mark on my people. I feel blessed.*

### **Deshell Fields**

Peer Educator

Greater Buffalo Chapter of the American Red Cross, Buffalo, NY

*I don't really look at being a positive female advocate as being hard or easy. It's what I have to do if I want to live. I have good days and bad, but I don't look at them at all as being just HIV-related. I think being diagnosed early helped me to remain healthier, I'm lucky in that I haven't had much trouble adjusting to a medication regimen. I think relationships matter a lot, and I just don't mean romantic or dating relationships, but the kind of support friends and loved ones give, knowing someone's in my corner. Working has helped me, too. But mostly, I gain inspiration from knowing in my heart that I'm okay. I lost a really good friend this*

*year and that hurt. But I remember what we used to talk about and that strengthens me. I know whatever, I do I do because I want to. That makes me feel good. I'm learning to take care of myself.*

### **Denise Goodman**

Community Relations Coordinator  
Project Achieve, New York, NY

*For me it's a classic case of a love/hate relationship. I hate it because it would be better if there were no stigma or oppression attached to HIV infection. Why isn't HIV thought of as other diseases that are medical concerns deserving quality care and compassionate social support? I hate the fact that 2+ decades later we're (and me personally) still fighting against labeling, separatism by race, gender or sexual orientation, finger-pointing, ignorance and fear. I love it because advocacy liberates me (and hopefully others) from that same stigma or oppression. I simply refuse to buy into the assumption that there's something wrong or damaged about people living with HIV. Living with the virus helps me remember that this is about real people living real lives against unreal odds. With that in mind, I gain strength from my efforts and the efforts of my peers for our common cause.*

### **Vanessa Johnson**

Associate Director for Program and Resource Development  
Capital District African American Coalition on AIDS (CDAACA),  
Albany, NY

*One of the reasons I am alive, strong, and well enough today to tell about my own struggles and experiences with HIV is that peers too many to be named here have provided me with exemplary examples of courage, wisdom, and spirit. In particular it was the women I met in my first HIV support group for women who made me realize that one, I still had a lot to offer; two, I would not sell myself cheap; and three, I would not give into hopelessness. My quest to be the best advocate I can be is born of a desire not to die in silence and to let people know that I too want to enjoy a whole and fruitful life. Too many women living with HIV/AIDS are dying prema-*

*turely or dying a slow painful death alone. I was reached so I know someone or something can reach them too. We have to keep trying. And try I do because ever now and then someone really gets it and my spirit is lifted and it keeps me on this path another day.*

### **Anita Paige-Bowmen**

Case Manager

St. Johns Riverside Hospital  
(formerly Yonkers General)  
Hope Center, Yonkers, NY

*Being a woman of color, there are definitely not enough of us out doing advocacy. There are not enough women period doing advocacy. We have so many issues with children and being often single heads of households. We often let our own health go by the wayside or even down the drain! But what energizes me is letting other women with HIV know that they are not alone and that there is so much to go on for! The most satisfying experience I have as an advocate is the mentoring process: helping someone through their own process, their own becoming of themselves and a stronger realization of where they fit into the world as women living with HIV.*

### **Joan Warner**

Peer Educator

Osbourne Association, Bronx, NY

*I'm all about prevention. Whatever group or demographic needs my efforts, I'm there. It may be people over fifty, maybe people of color. When I do HIV advocacy, I feel like I look at other women and I see myself. For me, it's all about being able to give back some of the things that were so richly given to me. I look around and I see other women advocating and being activists and I'm happy to be a part of it. Of course, we need more women and people of all kinds to step up to the plate. One of my main things is, where have all the advocates gone? I enjoy advocacy. I like to be able to speak about the things we so desperately need as women, things have been put on the back burner for so long. Sometimes it's fun, sometimes it's not. It's always important.*



## CATCH A RISING STAR

Catch A Rising Star is a leadership development program for African American/Black women living with HIV/AIDS in the Capital District. It is a community capacity building program designed to encourage, support and increase the ability of African American/Black women to participate in the HIV community planning and service delivery process as community leaders and advocates. The program is a joint effort between the Capital District African American Coalition on AIDS (CDAACA) and the Albany Medical Center Ryan White Title IV Collaborative Project for Women, Children, Youth and Families.

Women who participate in the Catch A Rising Star program attend four one day training sessions, dealing with issues such as the impact of gender and sexuality on the development of leadership, how to share their life experiences via community presentations, conducting community outreach, learning basic HIV/AIDS facts, the importance of participating in planning and advisory groups, and forming a support network. After completing these training sessions, women are encouraged to continue their development by attending Community Advisory Board (CAB) meetings and LTI trainings.

For more information about Catch A Rising Star, please contact Vanessa Johnson, Associate Director for Program and Resource Development for the Capital District African American Coalition on AIDS (CDAACA). Vanessa can be reached by phone at 518-427-2957 or via e-mail at [vanessaj@nycap.rr.com](mailto:vanessaj@nycap.rr.com).

## SMART UNIVERSITY

They have been on the cover of *Poz* magazine as activists, and they organize a sewing circle as well. The women of SMART University contain fabulous contradictions. But one thing unites them, the goal of empowerment for HIV-positive women.

SMART, which stands for Sisters Mobilized for AIDS/HIV Research and Treatment, was initiated in 1998 in recognition of the need for an organization devoted solely to the empowerment of women with HIV disease, with a special focus on treatment education. In fact, SMART University is the only organization run by and for HIV-positive women in New York State! Founded by Susan Rodriguez and Lorna Gottesman, SMART University has grown with the help of its Program Director, LTI staffer Petra Berrios; from a small band of like-minded women into a stable organization with several staff members and a range of programs including SMART Voices, a literacy/GED preparation program, and ongoing cycles of treatment education classes.

SMART University will be having its first annual Power Walk on Saturday, September 13, 2003 in Midtown Manhattan. The walk will end at St. Vartan's Park on 35<sup>th</sup> Street and First Avenue with a women's health fair and entertainment. For updates, registration or information on tabling, go to [www.powerwalknyc.org](http://www.powerwalknyc.org).

For more information about SMART University and their programs, please call 917-593-8797 or email them at [smartuniv@aol.com](mailto:smartuniv@aol.com).

## POTLIGHT ON AFRICAN AMERICANS AND AIDS

*(continued from front)*

women discover their own power—to live and live well with HIV, or in other words, to survive and thrive.

We are also extremely excited to report that the LTI's Core training has now graduated over 1,000 people living with HIV/AIDS! Most of these are, of course, in New York State, but several dozen also hail from other states around the country, and several of them have begun to develop their own leadership training initiatives modeled after the LTI. One thousand is a nice round number, (and one that seemed inconceivable just a few years ago!), and it seems like a fine time to take stock of where we've been and where we need to be going, so the LTI is in the process of launching a comprehensive assessment of the training and capacity building needs of New Yorkers living with HIV. It's the first and largest survey of its kind that we know of, including plans to reach and learn from the widest possible range of PWHA around the state. If all goes as planned, the results of this assessment will provide invaluable information, a community snapshot, if you will, not only for the LTI, but also for a wide range of community groups to use as we strategize to meet the challenges of the next several years of this crisis. Come the fall, we'll be reaching out to literally thousands of folks (in one way or another), and of course, in order to make this work, we'll need your help! So watch this space for updates on the assessment process.

In the meanwhile, enjoy your summer!

# WOMEN & HIV TIMELINE: THE FIRST 20 YEARS

WOMEN & HIV TIMELINE

**1981** The first case of GRID, which will later be referred to as AIDS, is reported. Five women are among those diagnosed. Sandra Ford, a drug technician for the Centers for Disease Control (CDC), officially notes an increase in requests for pentamidine for the treatment of pneumocystis carinii pneumonia (PCP). A paper napkin will later be taped to Sandra's door stating: "In this office in April 1981, Sandra Ford discovered the epidemic that would later be known as Acquired Immune Deficiency Syndrome."

**1982** Women are sick and dying, falling through the cracks. Those women diagnosed with this illness are classified under the risk category of "prostitutes." An article in the *Wall Street Journal* states that male and female drug users are being affected by GRID. Mary Richards Johnstone, a wealthy woman from the affluent suburb of Belvedere, receives twenty units of blood from Irwin Memorial Blood Bank in San Francisco. She is later diagnosed with AIDS.

**1983** Liz Smith is the first popular columnist to write about AIDS. **Barbara Fabian Baird, of the National Institute of Health (NIH), becomes one of the first nurses to conduct AIDS research.** The Women's AIDS Network is established. The CDC adds female sexual partners of men with AIDS as a "risk group." The *New York Post* headline reads "L.I. Grandma Dead of AIDS." The story goes on to describe how Lorraine DeSantis dies from AIDS after receiving a blood transfusion in 1980.

**1984** Health and Human Services Margaret Heckler announces that Dr. Robert Gallo has found the cause of AIDS. She also announces the development of a diagnostic blood test to identify the virus and suggests that a vaccine against AIDS could be produced in two years. Caitlin Ryan, a social worker, becomes the first executive director of AID Atlanta. AID Atlanta is the oldest AIDS Service Organization (ASO) in the Southeast.

**1985 Elizabeth Taylor and Dr. Mathilde Krim co-found AmFar** (the American Foundation for AIDS research). Elizabeth Taylor hosts the first Hollywood AIDS fundraiser. San Francisco AIDS Foundation produces their first brochure about Women and AIDS. Bette Midler and Barbara Streisand appear in a sold out fundraiser for the San Francisco AIDS Foundation. Mother Teresa visits AIDS

patients at George Washington University after receiving the Medal of Freedom from President Reagan. A reporter from the *San Francisco Chronicle* publishes a front-page story about Silvana Strangis, a prostitute who is living with AIDS. For the first time, a woman is admitted to the AIDS ward at San Francisco General (Ward 5B). Frances Borchelt, an older adult from San Francisco, dies from AIDS after she received three pints of infected blood during surgery in 1983. Her family files a negligence lawsuit against Irwin Memorial Blood Bank.

**1986** Women represent 7% of U.S. AIDS cases. Marie St. Cyr, a Haitian-born social worker, becomes the first director of the New York based Women and AIDS Resource Network (WARN) after it is formed by several women living with and affected by HIV. Silvana Strangis dies after battling cryptococcosis. Caitlin Ryan is hired to co-author the first book on AIDS policy, *AIDS: A Public Health Challenge*. This book is distributed to all members of Congress, governors, mayors, and key public officials and served as the basis for many of the recommendations of the first Presidential Commission on AIDS.

**1987** 13.5% of NIH money is dedicated to women's health issues. **ACT-UP begins.** Women excluded from HIV trials unless on the birth control pill or IUD; no childcare, transportation or GYN care is available. Trial inclusion/exclusion criteria read: "No pregnant women and no non-pregnant women" allowed. **Surgeon General C. Everett Koop urges any woman considering pregnancy to be tested for HIV.** Princess Diana opens the first specialist AIDS hospital ward in England. The fact that she did not wear gloves when shaking hands with people with AIDS was widely reported in the press

and helped change attitudes towards people with AIDS. Madonna throws her first AIDS benefit concert and later records a song, "In This Life", about friends who had died from the disease. St. Louis University School of Medicine

produces *Strong Women, Positive Choices*, an award winning documentary on the lives of HIV+ women.

**1988** The New Jersey Women and AIDS Network is founded. Revised NIH guidelines suggests "by gender" analysis of data being collected in clinical trials however does not establish clear standards for women's inclusion. *Cosmopolitan* Magazine article written by a psychiatrist tells women that they can have unprotected

vaginal intercourse with an HIV positive man if they have healthy vaginas. The article also reports that "Most heterosexuals are not at risk" and further states that it is impossible to transmit HIV using the "missionary position." **Women named fastest growing population with HIV.** San Francisco AIDS Foundation develops a Women's Services Program. A 22 year old New Yorker, Alison Gertz, is diagnosed with AIDS. Alison's mother Carol comments, "Alison had gotten sick that summer, and they tested her for everything: lymphoma, Hodgkin's, you name it. But they never tested her for AIDS because nobody thought a heterosexual woman who's not a drug user would get it. We subsequently learned that she'd gotten it from a good friend, who she'd only slept with once." Dawn Averitt is diagnosed with HIV. She later becomes a national AIDS treatment advocate and the founder of WISE (now Project WISE at Project Inform). **Elizabeth Glaser, Susan DeLaurentis and Susan Zeeger co-found the Pediatric AIDS Foundation after learning that Elizabeth, her daughter Ariel and son Jake are living with HIV.**

**1989** Rebekka Armstrong, former Playboy Playmate, tests HIV+. NIH publishes further guidelines on Women's inclusion. Bruce Lambert writes an article on Alison L. Gertz, a 23-year-old heterosexual, affluent woman from a prominent family who is living with AIDS. In later years, a movie is made about her life. Amanda Blake, TV Star ("Miss Kitty") on *Gunsmoke* dies from AIDS. Sisterlove, Inc. is founded by Dazon Dixon as the first and oldest organization in Georgia to focus on the needs of women living with and at risk for HIV. BABES is founded by HIV+ women in Seattle under the philosophy that HIV+ women are uniquely qualified to understand and encourage one another.

**1990** **The First National Women and HIV Conference is held.** ACT-UP spearheads a massive protest at the Centers for Disease Control in Atlanta to expand AIDS definitions to include women specific diseases. Women with AIDS lead the demonstration; 94 are arrested. An estimate of women worldwide with HIV is at 3 million. Cook County Hospital (the only hospital with an AIDS ward in Chicago) refuses to admit women stating they have no women's AIDS ward. Gay and Lesbian activists set up a ward in the street in front of the hospital; 35 are arrested. Two days later, the hospital admits women with AIDS for the first time. National "Speak Out" by women with AIDS is held in

*"There will be a vaccine in a few years and a cure for AIDS before 1990."*  
Margaret Heckler.

# WOMEN & HIV TIMELINE: THE FIRST 20 YEARS

Washington, DC to protest the Social Security definition of disability, which discriminates against women and people of color. On March 7<sup>th</sup>, the CARE bill was introduced into the Senate and House. During a Budget Committee that same day, Elizabeth Taylor speaks forcefully in support of the bill during her testimony, playing a vocal and visible role in its introduction. Elizabeth Glaser, a woman living with HIV, speaks at a House subcommittee hearing on pediatric AIDS, where she is praised for convincing the formerly unresponsive Ronald Reagan to do a public service announcement on pediatric AIDS.

**1991 Kimberly Bergalis says her dentist infected her with HIV and requests that Congress mandate testing of healthcare workers.** Kimberly writes the American Medical Association (AMA) requesting mandatory testing of healthcare workers. She dies by year's end. WORLD (founded by Rebecca Denison) publishes their first newsletter, by and about women living with HIV. Mary Fisher, a prominent woman in Washington circles, is diagnosed with HIV. Women Alive is founded in Los Angeles by and for women living with HIV. Mother's Voices, a group founded by five mothers who had lost a child to AIDS, is founded by Suzanne Benzer.

**1992 Mary Fisher addresses the Republican National Convention** as a person living with AIDS and stated "I don't know what kind of reception my speech received. It was like an out-of-body experience. People told me afterwards that the room got completely silent while I spoke, which is unheard of at a convention. Afterwards, President Bush said I'd done a wonderful thing." Elizabeth Glaser gives a speech to the U.S. Democratic National Convention as a person living with AIDS. A full page ad in the New York Times reads "Women Don't Get AIDS. They Just Die From It." Over 300 grass-roots groups signed the ad. The CDC expands the definition of AIDS to include: bacterial pneumonia, TB and stage III cervical cancer. Recurrent vaginal candidiasis (yeast infections) was also added as a symptom of HIV. This is a victory for women living with HIV. AIDS Survival Project creates the first support group for women living with HIV in Atlanta. Three women attend the first group.

**1993 The "female condom" is approved.** Kristine Gebbie is appointed as the first national "AIDS Czar", director of the Office of National AIDS Policy. In response to protest by ACT-UP's Lesbian

Caucus, **Health and Human Services Secretary Donna Shalala forms a Lesbian AIDS Task Force.** Gena Corea's book, *The Story of Women and AIDS: The Invisible Epidemic*, is published.

**1994** The ACTG 076 study finds that pregnant women taking AZT reduce the risk of HIV transmission to their unborn child by two-thirds. The Public Health Service recommends that HIV-positive pregnant women use AZT to reduce mother-to-child transmission. Elizabeth Glaser, co-founder of the Pediatric AIDS Foundation, dies. Jocelyn Elders is fired by President Clinton for saying that masturbation should "perhaps be taught" as part of sex education. Rae Lewis-Thornton, an African American woman living with HIV, is featured on the cover of *Essence* magazine.

**1995** Actress Sharon Stone becomes AmFar's celebrity spokeswoman. Elizabeth Dole, president of the American Red Cross and wife of Bob Dole (then the front-runner for the 1996 Republican presidential nomination) halts publication of a highly anticipated HIV/AIDS training manual for 1600 Red Cross chapters nationwide when her "special team" of advisors from outside the organization convinces her its contents are too explicit and controversial. President Clinton appoints Dr. Alexandra M. Levin to the Presidential HIV/AIDS Advisory Council. Dr. Levin's research includes HIV-associated lymphoma, women and HIV, and the development and testing of a therapeutic AIDS vaccine.

**1996** The annual incidence in women diagnosed with AIDS begins to decline because of the success of antiretroviral therapies in the U.S. Rebecca Denison (founder and editor of WORLD) delivers twin girls, becoming one of the first HIV-positive women to talk publicly about her decision to become pregnant.

**1997 Women account for more than half of HIV cases worldwide.** In March, The NAMES Project Foundation presents a month-long online Quilt display on its World Wide Web site featuring panels made for women who have died from AIDS, in honor of National Women's History Month. 75% of cases are in women of color. **Sandra Thurman, former Executive Director of AID Atlanta, is named AIDS Czar.** Therapist Penny Chernow starts the first support group in San Francisco for older women with HIV. The National Conference on Women and HIV takes place in Pasadena, CA and chants of "Do

Research to Save Women's Lives" echo the conference halls. The Los Angeles Times publishes an article on the conference. Princess Diana, one of the first public figures to urge compassion for people living with AIDS dies in an automobile crash. Poet River Huston's book, *Portraits of Women Living with HIV*, is released. The book's idea was stimulated by River's own

HIV diagnosis and the lack of images of women living with HIV in society. *Catholic World News* reports that Mother Teresa plans to start a new AIDS Ministry in the United States. Her religious order, The Missionaries of Charity, currently run five hospices for persons living with AIDS.

**1998** In South Africa, Gugu Diamini, an AIDS activist, was beaten to death by her neighbors after revealing her HIV status on Zulu television. 45% of the cumulative HIV cases reported among Asian and Pacific Islander adult/adolescent females acquired HIV through heterosexual transmission. A cumulative total of 109,311 adolescent /adult females have been diagnosed with AIDS in the U.S. 63% of newly reported female AIDS cases are African-American women. African American women are three times more likely to die from AIDS than Caucasian or Hispanic women. Of the 6,051 new HIV cases reported in women, 8% (461) were among Latinas. The Global Campaign for Microbicides is founded at the XII International AIDS Conference in Geneva. The creation of the Microbicide campaign came about from key members of the women's health and HIV community deciding to work together to focus world attention on the critical need for new HIV prevention options, especially for women. AIDS researcher Dr. Mary-Lou Clements-Mann is killed in the crash of Swissair flight 111. **Kate Shindle wins the title of Miss America under the platform of HIV/AIDS education.** She travels all over the country on a national speaking tour entitled "On the Way to a Cure: Preventing HIV transmission in America." She also moderates a panel discussion on Women and AIDS at the 12<sup>th</sup> annual world AIDS conference in Geneva, Switzerland at the invitation of U.S. Health and Human Service Donna Shalala .

**1999** Mary Fisher makes primetime news announcing that she is stopping combination therapy due to the side effects.

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# WOMEN & HIV TIMELINE: THE FIRST 20 YEARS

Of new cases of AIDS reported in women, 68% were in ages 30-49, 18% were in ages 20-29 and 12% were in ages 50 and over. Overall, heterosexual transmission accounts for an estimated 62% of AIDS cases diagnosed among women between July 1999-June 2000. **The National Conference on Women and HIV is held in Los Angeles, CA. Over 1,000 women attend. This event is documented as the largest gathering of HIV+ women in history.** Worldwide over one million women died of AIDS, the highest number so far in a single year.

**2000** In the South, more women with AIDS report their exposure as heterosexual contact than injecting drug use and approximately 3-4 times more cases are reported from the South than from the Midwest and West. 45,000 women 15-44 years old are reported to be living with AIDS in the United States. 63% of women reported with AIDS are African American. Ofra Haza, Israeli singer, dies of AIDS. Coretta Scott King launches the AIDS Memorial Quilt to black colleges and Universities. **One of four pregnant women in South Africa are living with HIV.** The FDA (Food and Drug Administration) passes the Clinical Hold Rule. This allows the FDA to delay or suspend any clinical trial that's found to exclude women (or men) because of it's "reproductive potential." This dramatically increases the opportunity for women with HIV to take advantage of drug trials and other treatment research. Valerie Reeder-Bey along with her granddaughter Annisha Monic Wilburn publish "My Grandma Has AIDS: Annisha's Story." Valerie has been living with HIV since the late

1980s and is the co-founder of Heaven In View, Inc. "A Positive Force."

**2001** UNAIDS found that in India, women are often blamed by their parents and in-laws for infecting their husbands or for not controlling their partners urges to have sex with other women. At a conference in Chicago, conference attendee Judy Delmar states, "This disease does not necessarily behave the same way in both genders. It's just a different disease in women." (The statement was made in response to the need for women to be included in clinical drug trials and other AIDS-related research). An article written by Jane P. Fowler, on persons living with HIV over 50, is published in Positive Living. Jane is a woman living with HIV who was diagnosed at the age of 55 and is the co-chair of the National Association on HIV over Fifty. Dr. Mathilde Krim, Founding Chairman and Chairman of the Board of the American Foundation for AIDS Research (amfAR), receives the African-America Institute's Award for Individual Vision and Achievement. The Natural Family Living Magazine *Mothers* cover page article is "HIV+ Moms Say No To AIDS Drug; Special Report: HIV, Families & Medical Justice." Many of the articles describe the stories of several HIV+ women who chose not to use anti-HIV medications during pregnancy in order to avoid the possibility of side effects and toxins that could affect their unborn child. Another article describes one HIV+ woman's fight to breast feed her child despite her doctor's protest. Blood Ties-The Stories of Five Positive Women edited

by Salli Trathen is available in print. This book describes the lives of five Australian women who are living with HIV/AIDS. After six years as the director of the National Center for HIV, STD, and TB Prevention with the Centers for Disease Control in Atlanta, Dr. Helen Gayle resigns to become the Bill and Melinda Gates Foundation's senior advisor on HIV. U.S.

**U.S. Department of Health and Human Services releases "A Guide to the Clinical Care of Women with HIV", the first manual specifically written about the medical care for HIV positive women.** . Korrin Krause, a sixteen year old living with HIV, is fired from her job at the Quality Foods IGA in Wisconsin. A store representative stated that he did not want other store workers "to take this (HIV) home to our families." The Equal Employment Opportunity Commission has sided with Krause in May however a settlement has not been reached.

*Terri L. Wilder, LMSW is a licensed social worker who has provided social services for persons living with HIV/AIDS for the past twelve years. She can be reached at [tlwilder@mindspring.com](mailto:tlwilder@mindspring.com). Terri invites women who are interested in adding information to this history to contact her. Terri apologizes for any oversights in our history.*

*The history is dedicated to the countless powerful women who are living with and affected by HIV including: Kellie, Ilyse (who is the CEO of her own company), Jane P. Fowler, River, Marguerite G. Wilder, Regina Ann Goldsworthy Stott, Susan, Eva, Valerie Reeder-Bey, Annisha Monic Wilburn, Lois C. and yes, Cara.*

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## IN MEMORIAM

It is with great sadness that we inform you of the death of Delia Rodriguez, former assistant director of the LTI and tireless advocate. She passed away in her homeland of Puerto Rico on Friday, July 11th.

Delia's passion, humor and good spirit will be sorely missed.



# THE DENVER PRINCIPLES

**Editor's Note:** Twenty years ago this summer, the Denver Conference of 1983 (Second National AIDS Forum, held by what is now the National Gay and Lesbian Health Association) was held, at which a group called the Patients Advisory Committee, comprised of people living with AIDS, created and declared **The Denver Principles**, a declaration of the rights and responsibilities of PWAs (now PWHA). This meeting is commonly acknowledged as the birth of the self-empowerment movement for PWAs.

Although first largely connected to the experience of gay white men and the gay rights movement, the PWA advocacy movement has grown into a truly global movement committed to the rights of all people to healthcare, treatment and dignity.

This anniversary of the Denver Principles is a time to remember and honor those who have gone before us for their wisdom, courage and prescience in articulating both the responsibilities of governments and nations to people in need, but also the responsibilities of those in need to each other and their communities.

This anniversary is also an opportunity to ring the changes that have taken place in the last twenty years, not only in terms of treatments available and global awareness but also in terms of the strengths that come from diversity, tolerance and mutual dependence and independence.

## **THE DENVER PRINCIPLES** *(Statement from the advisory committee of the People with AIDS)*

We condemn attempts to label us as “victims,” a term which implies defeat, and we are only occasionally “patients,” a term which implies passivity, helplessness, and dependence upon the care of others.

We are “People With AIDS.”

### **RECOMMENDATIONS FOR ALL PEOPLE**

1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact.
2. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

### **RECOMMENDATIONS FOR PEOPLE WITH AIDS**

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.
2. Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.
3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.
4. Substitute low-risk sexual behaviors for those which could endanger themselves or their partners; we feel people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status.

### **RIGHTS OF PEOPLE WITH AIDS**

1. To as full and satisfying sexual and emotional lives as anyone else.
2. To quality medical treatment and quality social service provision without discrimination of any form including sexual orientation, gender, diagnosis, economic status or race.
3. To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.
4. To privacy, to confidentiality of medical records, to human respect and to choose who their significant others are.
5. To die—and to LIVE—in dignity.

## RESOURCES FOR WOMEN WITH HIV

- ▶ **IRIS HOUSE** (NYC) Support groups, individual counseling, case management, treatment and prevention education, advocacy, childcare services and emergency intervention for HIV-positive women and their families. Services offered in English and Spanish.  
**212-423-9049**
- ▶ **JUST KIDS** (NYC) Support groups, treatment information, holistic and alternative therapies, childcare assistance, advocacy and conflict resolution services for at-risk children and their parents. Also has a national hotline connecting parents to parents.  
**800-341-1880**  
or **212-627-3390 x51**  
e-mail: [justkids@mhv.net](mailto:justkids@mhv.net)
- ▶ **LESBIAN AIDS PROJECT** (NYC) GMHC—Support groups and information.  
**212-367-1355**  
e-mail: [hotline@gmhc.org](mailto:hotline@gmhc.org)
- ▶ **LIFE FORCE** (Brooklyn) Support groups, treatment and prevention education, referral services, harm reduction, advocacy and counseling for those who are HIV-infected or affected.  
**718-797-0937**
- ▶ **WOMEN AND FAMILY SERVICES** (NYC) GMHC Harm reduction, education, support services and special events for women and families infected with or affected by HIV/AIDS.  
**212-367-1363**  
e-mail: [hotline@gmhc.org](mailto:hotline@gmhc.org)
- ▶ **WOMEN IN NEED** (NYC) Offers housing assistance and support for women at several residences throughout New York City.  
Manhattan: **212-582-8680**  
Bronx: **718-402-0067, 718-733-8880** or **718-933-2600**  
Brooklyn: **718-771-3088**

## IT STOPS WITH US!

(continued from front)

decided they would do something about community perceptions of people with HIV/AIDS.

Spearheaded by LTI graduates Mark Hayes, Richard Hahn, Perry Junjulas and Vanessa Johnson, [for more on Vanessa's advocacy efforts see the article on *Catch A Rising Star* on page 3], a plan was launched to educate the community about people with HIV while at the same time encouraging people to be tested.

"We knew we wanted to make as big an impact as possible," says activist Richard Hahn. "We wanted to do something really visible that, while it wouldn't respond directly to the ignorance we saw recently, would share a positive message about PWHA and encourage people to learn as much as possible about HIV and their own health status."

It was decided to seek funds for a public advertising campaign to encourage people to get tested as part of National HIV Testing Day on June 27<sup>th</sup>. The idea was to dovetail the campaign with "Take the Test Week," an initiative organized by a group of nine service providers—The Capital Region Take The Test Coalition—encompassing Albany, Rensselaer, Saratoga and Schenectady counties. It included a week-long series of community events and 26 separate locations where people can be tested during the last week in June.

"We thought it would be very powerful to combine our attempt to educate the community about people with HIV with the Take The Test Week's message," Richard explains. "We decided to create a blanket campaign that would cover the four county region for the entire month of June with 80 percent market saturation of advertising on the bus shelters and internal bus cards. We also decided that the campaign would feature self-identified local community members living with HIV so that people could see our diversity."

Additionally, the group also decided to use the slogan "HIV stops with me, does it stop with you? – Take The Test – Take Control," to promote testing while simultaneously reinforcing the message that, as Richard says, "PWHA are part of the solution, not part of the problem, and the biggest danger in HIV is people who are infected and unaware of their status."

With the plan in hand, Mark Hayes, co-chair of the Community Awareness sub-committee of the Ryan White HIV CARE Network of Northeast New York, drafted a \$20,000 proposal to the Community AIDS Partnership of the Capital Region for funds to run the campaign, which were awarded in January. The Community AIDS Partnership is a private not-for-profit agency that sponsors the annual AIDSWalk in the Capital Region.

Project WAVE (War Against the Virus Escalating), a nonprofit organization working to reduce HIV transmission in communities of color, added their support to the prevention campaign by having some of the posters placed on billboards around town and working with local radio stations to get the testing message out. Through Project Wave's excellent collaboration/negotiations with Lang Media and Clear Channel Communications, the billboards will continue to be placed on unused inventory throughout the year and JAMZ 96.3FM will continue to encourage urban hip-hopper's to seek testing as well.

"It got so you couldn't go anywhere in the area without seeing one of the posters," Richard says. "It was extraordinarily empowering. The press were great in interviewing people who appeared in the campaign, and it was clear we were really changing perceptions of PWHA in the area." In fact, even the federal Centers for Disease Control and Prevention (CDC) took notice and reported on the campaign!

"What was most moving to me," Richard continues, "is that we had no trouble getting PWHA in the commu-

## UPCOMING CONFERENCES

### JULY

#### NATIONAL HIV PREVENTION CONFERENCE

JULY 27-30, 2003 ATLANTA, GA

Sponsored by the Centers for Disease Control and Prevention (CDC) and the National Minority AIDS Council (NMAC)

**Tel:** 800-277-6313

**Web:** [www.2003hivprevconf.org](http://www.2003hivprevconf.org)

### AUGUST

#### 6<sup>TH</sup> ANNUAL STAYING ALIVE CONFERENCE: TWO DECADES OF POSITIVE LEADERSHIP

AUGUST 15-17, 2003 DENVER, CO

Sponsored by the National Association of People with AIDS (NAPWA)

**Tel:** 202-898-0414, Ext 121

**Email:** [cdebnam@napwa.org](mailto:cdebnam@napwa.org)

### SEPTEMBER

#### UNITED STATES CONFERENCE ON AIDS

SEPTEMBER 18-21, 2003 NEW ORLEANS, LA

Sponsored by the National Minority AIDS Council (NMAC)

**Tel:** 202-483-6622

**Web:** [www.namc.org](http://www.namc.org)

#### 4<sup>TH</sup> NATIONAL CONFERENCE ON HIV/AIDS AND AGING: PREVENTION, CARE AND MANAGEMENT OF HIV OVER FIFTY

SEPTEMBER 5-6, 2003 SCOTTSDALE, AZ

Sponsored by National Association of HIV Over Fifty

**Tel:** 617-233-7107

**Web:** [www.hivoverfifty.org](http://www.hivoverfifty.org)

nity to agree to be part of the campaign, that we represented the full spectrum of people living with HIV in the posters – Black, White, Latino, Gay, Straight, male, female -- and that we showed that we were a powerful positive force in and of the community, while at the same time providing a clear message to promote testing. I think it was pretty cool."

We think so too. Congratulations to all the advocates involved!