

WOMEN & FAMILIES NETWORK

Welcome to the first issue of the Women and Families Network Newsletter

The mission of the Women and Families Network is to address the needs of Minnesota women and families affected by HIV through collaboration, advocacy, training and resource sharing. We have been meeting since March 2002 to brainstorm how we could use this network to improve the quality of medical care and social services for women and families affected by HIV. We are still in the process of defining our goals and objectives for the future. This effort is expanding upon the good work of the Women and Families Work groups which has existed in many forms during the past seven years.

We encourage participation in the network by consumers, providers and anyone else who is concerned with the needs of women and families affected by HIV. For more information on the network and to find out how to get involved contact: Sarah Senseman, (651) 602-7570, ssenseman@westsidechs.org.

This issue of The Women and Families Network Newsletter begins with Terri L. Wilder's: "Twenty Years of Women Living with HIV: Past, Present and Future". This moving and informative timeline brings the 20-plus year history of women and HIV to life and makes it clear why we need to continue to fight for the needs of women and HIV to be recognized.

We hope that this newsletter will provide up-to-date information and resources for both service providers and people affected by HIV. Please send your comments, submissions, and requests to Ribka Berhanu, (612) 373-9175, rberhanu@mnaidsproject.org. We look forward to working with you in the future!

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Twenty Years of Women Living with HIV: Past, Present and Future

By Terri Wilder, LMSW

Since the beginning of time, women have had to fight for recognition. Women had to fight to vote. Women had to fight to work. Women even had to fight to wear the clothes they liked.

Twenty years ago women were fighting off unusual symptoms. Twenty years ago women were fighting to be diagnosed. Twenty years ago women were fighting to stay alive.

Today, women are fighting to be recognized in the AIDS epidemic as if it were 1981. The fight is not over and is perhaps just beginning. We (infected and affected) must gather our strength and remember those who have gone before us. We must never go back to 1981. We must run our lives as if we are the female CEO of our own company. We must meet with our "Board of Directors" for input. We must set a twenty-year strategic plan for "Women AIDS Inc." We must be the most important person in our life.

I invite you to read this humble history of Women and HIV and decide what you can do to add to the history of HIV and Women. As you process your vision of the future, keep in mind that the final paragraph of this story should include the following words: *cure, women, AIDS, and forever.*

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The mission of the **Women and Families Network** is to address the needs of women and families affected by HIV through collaboration, advocacy, training and resource sharing.

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The Women and Families Network Newsletter is distributed as a free community service. To subscribe please contact: Sarah Senseman at (651) 602-7570 or ssenseman@westsidechs.org

NEWS YOU CAN USE

HIV-Positive Women Receiving Lower Quality of Care in Minnesota

The Minnesota HIV Services Planning Council is the official body that oversees how Ryan White dollars are spent statewide. Part of their work is to conduct needs-assessments and evaluate funded programs. Recently, they funded a study to assess the quality of care received by HIV-positive Minnesotans. This study tried to determine if there were any disparities in the quality of health care received by different groups (by race, gender, geographic location) of the people living with HIV. The study revealed that women appear to be receiving lower quality of medical care in Minnesota. Please refer to the full report for a description of study limitations and recommendations.

The study found the following good news:

- All pregnant women (7) received appropriate therapy and counseling for antiretroviral therapy.
- All patients on antiretroviral medications were on two or more drugs; the majority were receiving 3-4 drugs. No patient was on monotherapy. A high percentage of patients were on antiretroviral therapy.
- Most patients are receiving prophylaxis treatment for PCP and MAC as indicated by CD4 levels.
- Race and geographic location among men did not appear to be factors in quality of care.
- Men who have sex with men are getting the highest quality of care based on the indicators used in the study.
- Providers are ordering viral load and CD4 indicators on a consistent basis. There were no statistical differences between any groups when examining these indicators for 2000 and 2001.

The study found that women appear to be receiving inferior quality of medical care in Minnesota:

- Women receive antiretroviral therapy less than men. Of the 174 people sampled in this study, 89 percent of the men were on antiretroviral

therapy as compared with just 68 percent of women. The gap widened when it took into account only those with CD4 counts less than 350 and viral loads greater than 10,000. In that scenario, 93 percent of men and only 54 percent of women were receiving antiretroviral therapy.

- Women's gynecologic screening is either not documented well or is not being done at an acceptable rate. In this study, only 52 percent of women had medical chart documentation of a pelvic exam performed in 2000. The CDC and the Agency for Health Care Policy and Research recommend that HIV-positive women receive a complete gynecologic evaluation including a pap smear and pelvic examination annually if their results are normal and more frequently if they have any of the following: previous abnormal pap smear, HPV infection, previous treatment for cervical dysplasia or symptomatic HIV infection. White women appear to get less gynecologic care than non-white women and have higher rates of abnormal pap smears.
- Women appear to receive PCP or MAC prophylaxis at lower rates than men. PCP prophylaxis is the prevention of PCP (Pneumocystis Carinii Pneumonia), and MAC prophylaxis is the prevention of MAC (Mycobacterium Avium Complex).

The study also presented some recommendations related to the care of women with HIV:

- A pilot education program was suggested to educate women on what to expect from health care providers.
- A more in depth study of the women in this report was recommended to further explore these disparities.

The report is entitled: HIV Medical Care in Minnesota According to HIVQUAL2: A Baseline Study of Quality of Care in Minnesota, Department of Human Services HIV/AIDS Programs, Prepared by: Diane Knust, MSW, June 2002.

You can request a copy of this study by contacting Mary Doyle at (612) 728-7517

Women Patients Showing Signs of Post-Traumatic Stress Disorder

HIVplus (Oct/Nov 2002)

Nearly two thirds of a group of 41 HIV-positive women studied at Stanford University reported symptoms of post-traumatic stress disorder linked with their efforts in seeking medical care, according to a study in the June issue of *AIDS Patient Care and STD*. A survey of the women showed that 42 percent were likely to have the condition and 22 percent were likely to have partial post-traumatic stress disorder.

Surprisingly, 59 percent and 78 percent of the women in the two respective categories were not receiving any type of psychiatric treatment. The Stanford researchers note that previous studies have shown that severe trauma and post-traumatic stress disorder symptoms can lead to faster HIV disease progression, lower CD4-cell counts, and an increased risk of contracting AIDS-related opportunistic infections. Based on their findings, they recommend that all HIV-positive patients be screened and tested for post-traumatic stress disorder.

Women Are Found to Be Most at Risk for Drug-Related Rash

HIVplus (Oct/Nov 2002)

Researchers at King's College Hospital in London have discovered that women are more likely than men to develop an allergic rash when treated with non-nucleoside reverse transcriptase inhibitors Sustiva and Viramune, according to a study in the July 26 issue of the journal *AIDS*. The study included an analysis of the charts of 285 people treated with Viramune between 1997 and 2000 and of 52 people treated with Sustiva between 1999 and 2000. Of the women in the study, 14.6 percent developed a drug-related rash compared with 3 percent of the men. "Factors that predispose women to this are unclear and warrant further exploration," the research team wrote, but they theorized that steroid hormones, oral contraceptives, menstruation, pregnancy, and sex-related differences in the body's metabolism of anti-HIV drugs could be factors for increased rash risk.

AIDS Drugs During Pregnancy Don't Harm Fetus, Study Finds

New York Times (6.13.02)

American doctors routinely prescribe antiretroviral drug cocktails to pregnant women infected with the AIDS virus despite nagging fears that the medicines might result in premature or low birth-weight babies. But those fears are largely unfounded, according to a study made public today. The study, involving 3,266 expectant mothers infected with the virus, HIV, found that those who took the drug cocktails were no more likely to give birth to premature or low birth-weight babies than those who did not.

The research was started by the National Institutes of Health after studies in Europe suggested that the medicines might pose a risk. Experts said the findings, which appear in the current issue of *The New England Journal of Medicine*, should reassure women and their doctors. "There was always this little back-of-the-mind concern," said Dr. Anthony Fauci, director of the National Institute for Allergy and Infectious Diseases, one of two branches at the N.I.H. that paid for the research. "A chance was taken in treating those women. This study shows that, in retrospect, it was a good decision."

The study did, however, suggest an association between a certain class of AIDS medicines, protease inhibitors and very low birth-weight babies. But the authors said that finding, based on data on a small subset of women in the study, was not solid and required further study. "The numbers were quite small," said Dr. Ruth E. Tuomala, the lead author of the study and an obstetrician-gynecologist at Brigham and Women's Hospital in Boston. It is possible, Dr. Tuomala said, that only the sickest women were treated with protease inhibitors, and that "the severity of the illness is responsible for the lower birth weight, as opposed to the drug itself."

The Centers for Disease Control and Prevention estimate that 6,000 HIV-infected women give birth every year and that 300 to 400 babies are born with the virus. One of the biggest public health successes of the AIDS epidemic has been the use of antiretroviral medicines to reduce the spread of the virus from mothers to infants. The move toward treatment began in 1994, with publication of a landmark study showing that the antiretroviral drug

AZT sharply reduced mother-to-infant transmission, by as much as 70 percent. More recently, studies have shown that the drug cocktails can reduce transmission even further.

The National Institutes of Health study analyzed data from seven large studies involving pregnant women with HIV to assess the risk of such complications as premature delivery, low birth weight, stillbirth and low scores on the Apgar test to determine a newborn's state of health. The analysis compared 2,123 women who received antiretroviral therapy with 1,143 who did not. Among the treated women, 16 percent gave birth prematurely – defined as prior to the 37th week of the standard 40-week pregnancy – compared with 17 percent of the untreated women. The percentage of low birth-weight babies, those born weighing less than 2,500 grams, was the same in both groups, 16 percent. The Apgar scores and rates of stillbirth were also nearly identical. As a result, experts say, the study is not likely to change medical practice, which has been to treat HIV-infected expectant mothers as if they were not pregnant, on the theory that taking care of the disease is best for both mother and child. "The goal is to treat the woman and to do it as safely as you can for the fetus," said Dr. Mary Young, who treats patients with HIV at Georgetown University Medical Center. Dr. Young said she avoided one popular protease inhibitor, Sustiva, because it was known to cause birth defects in animals, and another, Crixivan, because it caused kidney stones in adults and, she reasoned, might do the same in a fetus. Dr. Young said research on the medicine in pregnant women had been scant, however, and "we are kind of flying blind."

But there have been some studies that suggest the antiretrovirals may cause harm. In 1998, Swiss researchers published a study of 30 women that found those who received so-called combination therapy had a higher risk of premature delivery. A larger European study also suggested that protease inhibitors increased risk of prematurity. Those studies prompted the institutes' research. "They were very small, uncontrolled studies, and everybody knew that," Dr. Tuomala said. "But nonetheless, you couldn't erase this." ■

Clinical Trials in Minnesota

THE FOLLOWING IS A LISTING OF RESEARCH STUDIES AVAILABLE AT THE MINNESOTA AIDS CLINICAL TRIALS UNIT

More detailed information about each study can be found at our web site listed below. Women are an important part of our work as we try to find new information about how HIV and its treatments impacts them differently than men. This is extremely important as rates of HIV in women continue to increase but most of the research and medication studies have been done with men. Given the fact that our bodies are very different, we need this information to ensure that women are being given the most effective information and treatment possible.

For more information about MN ACTU clinical trials, please contact a study nurse at: Phone: (612) 625-1462 Fax: (612) 625-1923, email: minnactu@umn.edu or visit our web site at <http://www.lamp.med.umn.edu/actu> To learn more about HIV research, basic HIV science and how it impacts you, the MN ACTU also invites you

to become a part of our Community Advisory Board (CAB). We meet the 2nd Thursday of the month at the Minneapolis Urban League at 2100 Plymouth Ave from 12 - 1:00. Lunch is provided. Each CAB meeting includes an educational presentation to help you know more about HIV disease and it's treatments. This group is a mixture of HIV professionals and people living with the virus in an informal atmosphere. We encourage women to attend so their voices can be heard and we can make sure that the answers to your unique HIV healthcare needs are found. The October CAB meeting presentation will be focused on HIV and Hispanic immigration issues and will be given by professionals from Westside Community Health Center. In November, we will learn about how HIV affects people differently according to their age. To register to attend a CAB meeting, please call Debra at (612) 626-3205.

Current Studies Open at the Minnesota AIDS Clinical Trials Unit

Study 1 - A5095

PI-sparing medication regimen for people starting their first antiretroviral regimen. Medications are Combivir, Trizivir and Sustiva – some may be placebo but participant will be on at least 3 real medications.

Study 2 - A5102 Treatment Interruption study:

People who have HIV RNA below 50 and CD4 cells greater than 500 will be randomized to take either their current ARV treatment plus three cycles of IL-2 (each 5 days every eight weeks) OR current ARV treatment alone during that period. At the end of that period if CD4 count remains greater than 500, people will come off all ARV treatment and remain off until their CD4 count goes below 350 on two consecutive visits. (The visits are every month to check CD4 counts).

Study 3 - A5082 "The lipodystrophy study":

People who have a high waist to hip ratio and have a high fasting insulin level will be randomized to Metformin (Glucophage) and/or Rosiglitazone (Avandia) to see if it improves the insulin level and the waist/hip ratio.

Study 4 - A5030 CMV-Valgancyclovir study:

People who have CD4 less than 100 and HIV RNA greater than 400 and have been exposed to CMV at sometime in their life (most of us have) will be followed every eight weeks to see if CMV virus is growing in the bloodstream. If it is, will be randomized to Valgancyclovir or a placebo to see if that prevents people from becoming sick with CMV (it can show up in the eyes, or the stomach and bowels, etc.

Study 5 - Naltrexone study:

Study designed by Minneapolis doctors based on "bench science" information that Naltrexone seems to increase the actions of two ARV medication in the test tube. Now people will be randomized to very small doses to see if it makes any difference in people taking ARV medication.

Studies Opening Soon

Study 1 - A5159 "HIV negative":

Evaluation of interactions of HIV drugs and heart medications in HIV-negative people. This study will last 34 days with HIV-negative people taking study drug for 26 days. Three all-day or overnight stays will be required. People completing the study will receive \$1000.

Study 2 - A5079 "Testosterone gel study":

Evaluation of effect of testosterone gel or placebo on abdominal obesity in HIV positive men who have a mild to moderate reduction in testosterone levels. Must not have used any testosterone product within 12 weeks of the start of the study. All subjects on study treatment at the conclusion of the double-blind phase will be eligible to receive open-label testosterone for and additional 24 weeks.

Resources for Talking to Kids about HIV and Sex.

The Minnesota AIDS Project is proud to announce the opening of our family resource library. This library has a number of materials developed to help families affected by HIV and AIDS talk to their children about the effects of the disease. We also have books, videos and pamphlets on the following topics:

Dealing with HIV in the family • Living with HIV • Parents talking to children about sexual health • Children's books and videos on sex and HIV • Videos and books for teens about sex • Materials and curricula for schools, teachers and HIV educators • Studies on teen sexuality • HIV resource guide for Minnesota

Here is a partial list of the resources available with ordering information. Stop by the **Minnesota AIDS Project** at 1400 Park Avenue South, Minneapolis to browse through our collection.

It's So Amazing! Robie H Harris

It's So Amazing is an amusing and colorful children's book on sex and sexuality. A curious bird and squeamish bee discuss bodies and babies, adoption and families, puberty, masturbation, homosexuality, HIV and sexual abuse. [\$15.99]

Come Sit By Me. Margaret Merrifield

Come Sit By Me, set in a multicultural daycare, is about Karen and her friends. One child, Nicholas, is often sick and absent from school. Eventually the children find out that Nicholas has AIDS. When Karen's parents hear that the other children are leaving Nicholas out, they help organize a meeting to address the fears of both caregivers and children. [\$5.99]

You Can Call Me Willy: A Story for Children About AIDS. Joan C. Vimiero

This book is the story of a young girl living with HIV and her struggle with discrimination. Willy Jones is 8 years old. She loves baseball, lives with her grandmother, and had AIDS. Willy talks about her illness and exhibits exceptional strength and courage as she learns to cope with the symptoms and the side effects of treatment, to put up with classroom taunts, and to find fun and friendship. [\$8.95]

Be a Friend: Children Who Live with HIV

Speaking in their own words and pictures children with HIV and AIDS tell how it feels to be different from other kids, how they face rejection if people learn they are sick. They think about loved ones they have lost and what heaven will be like. [\$6.95]

My Grandma Has AIDS: Annisha's Story.

Valerie Reeder-Bey and Annisha Monic Wilburn.

With her granddaughter, Valerie has written this children's book to help kids understand that it is safe to live with, kiss and hug someone you love who is infected with HIV.

[To receive a copy contact Ribka Berhanu, 612-373-9175 – FREE]

Pedro and Me: Friendship, Loss, and What I Learned. Judd Winick

Judd Winick pays tribute to his Real World roommate and friend Pedro Zamora, an AIDS activist who died of the disease. His cartoon memoir tells the story of their friendship and serves as a vivid memorial to a bright-eyed and gifted man who made more of his 22 years of life than most of us could make of 80. [\$10.50]

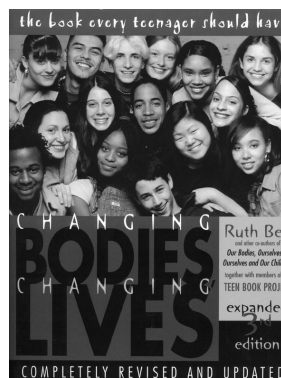
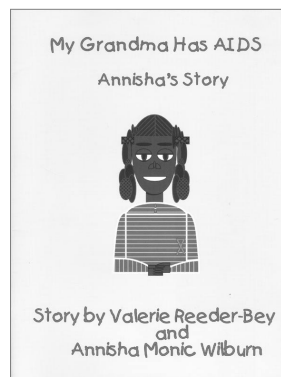
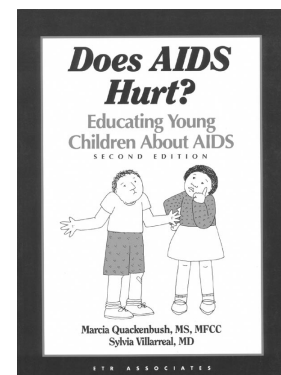
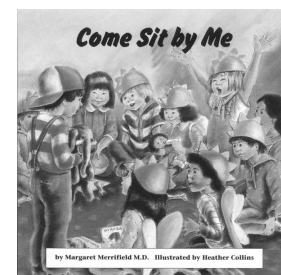
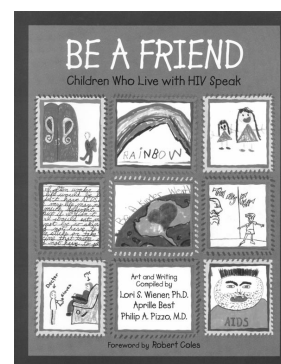
Changing Bodies, Changing Lives: The Book Every Teenager Should Have. Ruth Bell

Written by the authors of *Our Bodies, Ourselves* in collaboration with the Teen Book Project on teenage health problems and concerns. [\$16.80]

Adolescents and HIV Video Series

Four videos designed for adolescents with HIV and youth at risk of HIV. Topics include: adolescents talking about what it is like to live with HIV, getting the facts about clinical trials and sexual health education.

[To receive a copy contact: Ribka Berhanu, 612-373-9175 – FREE]



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Twenty Years of Women Living with HIV: Past, Present and Future

By Terri Wilder, LMSW

1981

The first cases of GRID, which will later be referred to as AIDS, are 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 know 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

Secretary of 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 Barbra Streisand appear in a sold out fundraiser for the San Francisco AIDS Foundation. Mother

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

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 percent 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 percent 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-positive women.

1988

The New Jersey Women and AIDS Network is founded. Revised NIH guidelines suggest "by gender" analysis of data being collected in clinical trials however do 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 reports "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-positive. 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

Security definition of disability, which discriminates against women and people of color. On March 7th, 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.

ates the first support group for women living with HIV in Atlanta. Three women attend the first group.

1993

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. 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

“Rae Lewis-Thornton, an African American woman living with HIV, is featured on the cover of Essence magazine.”

of women living with and at risk for HIV. BABES is founded by HIV-positive women in Seattle under the philosophy that HIV-positive 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 Washington, DC to protest the Social

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 is founded by Suzanne Benzer and four other mothers, each of whom lost a child to AIDS.

1992

Mary Fisher addressed 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. AIDS Survival Project cre-

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

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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 percent of cases are women of color. Sandra

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 percent 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 percent 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 percent (461) were among Latinas. The Global Campaign for Microbicides is founded at the XII International AIDS Conference in Geneva. The microbicide campaign was the result of 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.

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-positive 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 percent of women reported with AIDS are African American. Ofra Haza, Israeli singer, dies of AIDS. Coretta Scott King launches the AIDS Memorial Quilt at black colleges and Universities. One of four pregnant women in South Africa is 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 is found to exclude women (or men) because of their "reproductive

“In South Africa, Gugu Diamini, an AIDS activist, was beaten to death by her neighbors after revealing her HIV status on Zulu television.”

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 people living with AIDS.

Kate Shindle wins the title of Miss America under the platform of HIV 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 12th annual world AIDS conference in Geneva, Switzerland at the invitation of Secretary of U.S. Health and Human Service Donna Shalala.

1999

Mary Fisher makes prime time news announcing that she is stopping combination therapy due to the side effects. Of new cases of AIDS reported in women, 68 percent were ages 30-49, 18 percent were ages 20-29 and 12 percent were ages 50 and over. Overall, heterosexual transmission accounts for an estimated 62 percent of AIDS cases diagnosed among women between July 1999-June 2000. The National

potential." This dramatically increases the opportunities 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 people 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 American Institute's Award for Individual Vision and Achievement. *The Natural Family Living Magazine* Mothering cover page article is "HIV-positive Moms Say No To AIDS Drug; Special Report: HIV, Families & Medical Justice."

Many of the articles describe the stories of several HIV-positive 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-positive 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. The United States 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.

2002

Women, Cure, HIV/AIDS, forever.

Terri L. Wilder, LMSW is a licensed social worker who has provided social services for people living with HIV/AIDS for the past twelve years.



You can contact Terri at tlwilder@mindspring.com. She invites women who are interested in adding any 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 Scott, Susan, Eva, Valerie Reeder-Bey, Annisha Monic Wilburn, Lois C. and yes, Cara. ■

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Women and Families Network:

Who we are and where we want to go

Title IV

Background and Accomplishments

The Title IV program of the Ryan White Care Act is located in the Comprehensive Family Services Branch of the HIV/AIDS Bureau's Division of Community Based Programs. The Ryan White Care Act is the biggest federal program providing primary medical care and supporting services to Americans living with HIV. Title IV of the Care Act focuses on providing comprehensive, community-based, and family centered services to children, youth, and women living with HIV and their families. Title IV program services include primary and specialty medical care, psychosocial services, and logistical support, as well as outreach and prevention to provide a continuum of care for at-risk populations. Title IV systems of care enhance access to and linkage with clinical research supported by the National Institutes of Health and other organizations for their client populations.

The HIV projects of the Title IV program have proven effective in organizing and improving patient access to a comprehensive system of health and social services, particularly for the most vulnerable populations.

Title IV projects are identifying HIV-positive pregnant women, making it possible for

them to receive new therapies that have proven to have a high success rate in preventing the transmission of HIV to newborns. Through Title IV projects, clients have been able to participate in clinical trials that give them access to state-of-the-art treatments. These treatments have produced a significant drop in reported deaths among Title IV client populations.

(Taken from the HRSA HIV/AIDS Bureau Web site <http://hab.hrsa.gov/programs/factsheets/titleiv.htm>)

Title IV

Minnesota

As a Ryan White Title IV grantee, West Side Community Health Services is working to develop a comprehensive, coordinated care system for women, youth, infants, children, and families. This system ensures that individuals and families affected by HIV will receive all the kinds of care that they need in order to access and stay in medical care. One of the primary ways that this is achieved is via a service provider and consumer network. Title IV grantees develop networks of providers who address the multiple needs of people living with HIV/AIDS and their families. These services range from primary medical care to social services. This network of providers creates formal and informal partnerships to facilitate referrals, avoid duplication of services, and to provide cross-training and support. In Minnesota, this network is the recently formed Women & Families Network, and is co-coordinated with the Women & Families Systems Advocate at the Minnesota AIDS Project.

The second component of developing a coordinated system of care depends on consumer involvement. Title IV grantees rely on feedback from Consumer Advisory Boards and consumer network members to guide their services, and enlist consumers, when possible, to be involved in network activities. ■

WOMEN & FAMILIES
NETWORK

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Resources for talking to kids about HIV and Sex.

Just Hold Me While I cry: A Mother's Life-enriching Reflections On Her Family's Emotional Journey Through AIDS.

Bobbie Stasey

A mother's story of surviving the emotional challenges of having a son with AIDS. In this autobiography she shares her feelings about the medical system, her son's homosexuality, and her fears. [\$12.95]

Finding Our Voices: Talking With Our Children about Sexuality and AIDS. Mother's Voices

This 36-page parent's guide, available in English and Spanish, offers parents practical advice for talking to their children about sexuality and AIDS. [To order a copy call 1-888-MVOICES or write to Mothers' Voices at 165 West 46th Street, Suite 701, New York, NY 10036. Individual copies: \$5.00.]

Families are Talking. SEICUS

Newsletter containing information to help all parents and caregivers talk to their children about sexuality and related issues. [Order this newsletter and other SEICUS publications online at <http://www.siecus.org/cgi-bin/catalog.pl> The newsletter can be downloaded for free, or individual copy: \$1.00]

Filling the Gaps: Hard to Teach Topics in Sexuality Education. SEICUS

This manual provides lesson plans, worksheets, fact sheets and handouts for teachers and educators who teach sexuality education. The manual covers eight "hard to teach" topics: abstinence, condoms, diversity, pregnancy options, safer sex, sexual behavior, sexual identity and orientation, sexuality and society. [Order this and other SEICUS publications online at <http://www.siecus.org/cgi-bin/catalog.pl> - \$20.00]

HIV/AIDS: A Challenge To Us All. Pediatric AIDS Foundation

Video and booklet designed to help parents or teachers set up a school meeting about HIV/AIDS. (Available in Spanish) [For order a free copy call 310-395-9051 – FREE]

Stop by the **Minnesota AIDS Project** at 1400 Park Avenue South, Minneapolis to browse through our collection.

Someone at School has AIDS. National Association of State Boards of Education

A complete guide to education policies concerning students with HIV. This guide offers all the information and recommendations schools need for educational, health, sports, and confidentiality policies related to HIV. [This guide can be downloaded for free at: http://www.nasbe.org/HealthySchools/Safe_Healthy/sasha.html

Order a copy by calling 1-800-368-5023 or by writing to National Association of State Boards of Education, 277 S. Washington Street, Suite 100, Alexandria, VA 22314 - \$15.00]

A Time to Speak: Faith Communities and Sexuality Education. SEICUS Debra Haffner

A booklet containing information to help religious congregations address sexuality issues. [Order this manual and other SEICUS publications online at <http://www.siecus.org/cgi-bin/catalog.pl> - \$13.00]

Children, Families, and HIV/AIDS: Psychosocial and Therapeutic Issues.

Nancy Boyd-Franklin (Editor), Gloria L. Steiner, Mary Boland (Editor), James M. Oleske

This book presents a family-focused, culturally sensitive and systems-coordinated approach for the provision of effective service delivery and care to families and children affected by HIV/AIDS. [\$25]

Does AIDS Hurt? Educating Young Children About AIDS:

Marcia Quackenbush, MS, MFCC and Sylvia Villarreal, MD

Suggestions for Parents, Teachers and Other Care Providers of Children to Age 10. Good book for educating young children about HIV. [\$7.00]

Online Course on "Adherence to HIV Therapy for Children, Youth and Families"

The National Pediatric & Family HIV Resource Center is pleased to announce an online CME/CEU program "Adherence to HIV Therapy for Children, Youth and Families." This online course is intended for pediatricians, family practitioners, advanced nurse clinicians and nurse practitioners, social workers, case managers as well as generalists in these professions.

The goal of this continuing education offering is to assist healthcare providers in supporting medication adherence for children, youth and families with HIV infection.

Category I CMEs and Nursing CEUs are available FREE.

All participants are eligible to receive a certificate of completion. Visit our web page www.pedhivids.org/online.

CD-ROM: "Women, Children and HIV: Resources for Prevention and Treatment"

Prevention and Treatment Resource Available for Women & Children: The second edition of the CD-ROM, "Women, Children, and HIV: Resources for Prevention and Treatment," jointly produced by HIV InSite and Global Strategies for HIV Prevention, is now available free of charge. The disk contains more than 300 documents, including overviews, research articles, fact sheets, training manuals, and policy reports, intended for a diverse audience of professionals and community members around the world. For copies, please contact Maud Zimmerman at GSHIV@hivinsite.ucsf.edu with mailing address and number of copies requested. For those requesting multiple copies, please include an explanation of how you plan to use and share them.

Public-Private Partnerships: A New Model for Community Mobilization Against AIDS

November 21, 2002 • 2 - 4 pm

This live broadcast and webcast will discuss a variety of public-private partnerships engaging the private sector as a mobilizing agent and educational resource for community-based HIV prevention. Business and Labor Respond to AIDS, The National AIDS Fund Community Partnerships and AIDS Act Now are model programs addressing policy development, management/leadership training, employee education, community and family engagement, and public and private sector resources for HIV prevention. Viewers may fax in questions before and during the broadcast.

To view live webcast go to: <http://www.cdcnpin.org/broadcast/>

Local satellite broadcast site: MDH Distance Learning Center, 130 E. 7th Street, Metro Square Annex, 3rd Floor, St Paul MN 55101

Contact Lorraine Colford, phone 651-215-0460 or email: lorraine.colford@health.state.mn.us to RSVP

Free, Walk-In Legal Clinic for Refugees and Immigrants in Minneapolis

The Equal Justice Legal Clinic is a free, walk-in legal clinic for refugees and immigrants. Services provided include legal advice with discrimination and hate/bias crimes, immigration, safety issues, problems getting welfare and services, problems with landlords and housing, domestic violence.

Walk Ins from: 3 - 5 pm on Thursdays

1730 Clifton Place, Suite 200, Minneapolis, 55403

Telephone: (651) 291-0173

Call if interpretation is needed. Workshops on issues that affect refugees and immigrants are held once a month.

Some support and emergency services are provided to clients who utilize the clinic: lock changes, transportation for immigration hearings, employment, finding housing. Please call to inquire about these services.

Are you or your clients experiencing difficulty with immigration issues related to HIV/AIDS?

You can consult with an attorney at the Minnesota AIDS Project Legal Clinic

Attorney Michele Garnett McKenzie of the Minnesota Advocates for Human Rights

Tuesday, October 14, 4:30 - 7 pm

(by appointment only.)

To make an appointment call the Legal Program at (612) 373-2426

The legal clinic is held at the

Minnesota AIDS Project

1400 Park Ave South, Minneapolis.

HIV positive persons or those affected by HIV may sign up for a half-hour consultation. Individuals will receive advice and information only. If representation is needed, appropriate referrals will be made.

Gender inequality drives the HIV/AIDS epidemic

So what we can do about this? Learn how organizations and individuals from around the world have responded to the challenge. Access the latest tools that can help us take action on gender and HIV/AIDS. Read the arguments for approaches that empower and transform gender relations. All in the Cutting Edge Pack on gender and HIV/AIDS!

The pack has three parts:

- **Report outlining key issues by Vicci Tallis of Project Empower, South Africa, with support from Alice Welbourn, pioneer of Stepping Stones approach.**
- **GAD In Brief bulletin - featuring articles by Promundo (Brazil) and the International Community of Women Living With HIV/AIDS (Thailand and Zimbabwe).**
- **Collection of Supporting Resources - Summaries of key texts, case studies, tools and guides, and information about organizations, web sites, and courses.**

The Cutting Edge Pack on gender and HIV/AIDS is downloadable free from the BRIDGE web site at <http://www.ids.ac.uk/bridge/>

Or you can order the Cutting Edge Pack on Gender and HIV/AIDS through the IDS virtual bookshop at: <http://www.ids.ac.uk/ids/bookshop/index.html>, or from ITDG, 103-105 Southampton Row, London WC1B 4HH, UK (tel: +44 20 7436 9761; fax: + 44 20 7436 2013; email: orders@itpubs.org.uk).