# **WOMEN ALIVE**

# **KNOWLEDGE IS POWERFUL # ACTION = LIFE**

**SPRING 2005** 







**Dedication** 

A Personal Story

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**Dear Debbie** 

"Never doubt that a small group of thoughtful people could change the world. Indeed, it's the only thing that ever has."

**Margaret Mead** 

# Our newsletter is dedicated to Georgette Harrison

(September 23, 1942 - March 27, 2004)

My mother was a Strong, Independent Black Queen who said what was on her mind, but of course in a loving way.

When I, received the letter from my ex-boyfriend stating that he tested positive for HIV from prison, my mother was the first person I told. She was the one that held me and told me that it was going to be o.k.. My mother encouraged me to get tested, so

when my test results came back Positive once again she was there for me, she didn't judge me, nor did she point any fingers telling me "I told you so." Instead she was herself a loving person who accepted and loved her daughter who tested positive for HIV.

My mother has been my backbone and support through all my endeavors that I have encountered

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# Spring 2005

### **BOARD OF DIRECTORS**

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Toll Free National Hotline 1.800.554.4876 Hotline hours 11 a.m. - 5 p.m. PST

#### **NEWSLETTER**

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Alicia K. Avalos Carrie Broadus Precious Jackson Debra Johnson, MPAS, NP, PA-C

### **Contributors**

Alicia K. Avalos Lorraine Brown Precious Jackson Debra Johnson Betty Knox Nancy S.

# Letter from the Editor

#### Newsletter Subscribers!

I want to thank you personally for your past support of Women Alive's newsletter. Our last newsletter was updated to better reflect the services and resources available to women living with HIV/AIDS.

We continue to look for articles from women who are living with HIV/AIDS, and would like to tell their stories. I hope you enjoy the new format, and are interested in continuing your subscription or becoming a new subscriber.

Women Alive NEEDS YOUR SUPPORT! Please fill out the bottom portion of the newsletter subscription page and enclose the appropriate payment.

We look forward to hearing from you!

Best regards,

#### Alicia K. Avalos

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through life. She was there for me until she took her last breath at 4:15pm on Saturday, March 27, 2004.

Through her love, strength, and support, I have been able to walk through fears that I never thought I could do. My mother was a shining star which GOD used to get his message out she had 17 years of being clean and sober in Narcotics Anonymous.

My mother was a blessing to a lot of people. When she passed away in her home, she was surrounded with family and friends who truly loved her.

Mommy, I love you, and I know you will watch over me every step of the way.

**Precious** 

Any individual's association with Women Alive or mention of an individual's name or publication of an individual's photograph should not be, and is not, an indication of that person's health status.

women alive

# About Our Newsletter

Women Alive Newsletter is a publication of Women Alive Coalition, Inc. which is solely responsible for its content. Our newsletter is supported by funds received from the Office of AIDS Programs and Policy, the State of California, Department of Health Services, Office of AIDS, and the U.S. Department of Health and Human Services, Health Resources Services Administration, the Ms. Foundation and private donations from subscribers.

If you have articles you would like to submit to the Women Alive Newsletter, or if you just want to help, please contact the Women Alive office during business hours. Articles submitted for publication become the property of Women Alive. We encourage writers to attend the editorial team meetings. The editorial team makes all decisions about the content.

Please note: Information and resources included in our newsletter are for informational

purposes only and do not constitute any endorsement or recommendation of, or for, any medical treatment or product by Women Alive.

With regard to medical information, Women Alive recommends that any and all medical treatment you receive or engage in be discussed thoroughly and frankly with a competent, licensed, and fully AIDS-informed medical practitioner, preferably an HIV specialist and/or your personal physician.

Opinions expressed in articles in the newsletter are not necessarily those of Women Alive.

Any individual's association with Women Alive or mention of an individual's name or publication of an individual's photograph should not

be, and is not, an indication of that person's health status.



# womenalive

# women alive mission statement

Women Alive is created by and for women living with HIV/AIDS. We understand the pain and fear, how easy it is to hide, how difficult it can be to come to terms with this disease and reach out. Women Alive is the means we have created to help us connect with each other, exchange treatment information, bring others like us out of isolation, and take charge of our lives, our care, and our destiny.

# National Resources for Women Infected or Affected with HIV/AIDS

### African Services Committee, Inc. HIV Law Project

429 West 127th Street New York, NY 10027 Telephone: 212.222.3882

Email: annem@africanservices.org

#### **AIDS Services of Austin, Inc.**

7215 Cameron Road Austin, TX 78752

Telephone: 512.406.6150

Email: women.rising@asaustin.org

#### Aniz, Inc.

233 Mitchell Street Atlanta, GA 30303 Telephone: 404.521.2410 Email: ZinaAge@aol.com

### **Capital District African American Coalition on AIDS (CDAACA)**

388 Clinton Avenue Albany, NY 12206

Telephone: 518.427.2957 Email: cdaaca@cdaaca.org

#### **Christie's Place**

2440 Third Avenue San Diego, CA 92101 Telephone: 619.702.4186

Email: brosnan@christiesplace.org

#### **Courage Unlimited**

P.O. Box 363780 North Las Vegas, NV 89036 Telephone: 702.453.3855

Email: courageunlimited@cox.net

### **Helping Everyone Receive Ongoing Effective Support** (HEROES)

P.O. Box 1259 Columbia, LA 71418 Telephone: 318.649.2106 Email: avemon@aol.com



161 Williams Street, 17th Floor New York, NY 10038 Telephone: 212.577.3001 Email: vzelrnjn@verizon.net

#### Ms. Foundation for Women

120 Wall St., 33rd floor New York, N.Y. 10005 212.742.2300

info@ms.foundation.org

### Mujeres Unidas Contra El Sida (Women United Against AIDS)

1142 W. Woodlawn San Antonio, TX 78201 Telephone: 210.738.3393 Email: tinyyoli@aol.com

### **New Jersey Women and AIDS Network**

7 Spring Street New Brunswick, NJ 08901 Telephone: 732.846.4462 Email: mshoward@njwan.org

### Sisterhood Mobilized for AIDS/HIV **Research and Treatment** (S.M.A.R.T.)

PMB #117 217 E. 85th Street New York, NY 10028 Telephone: 917.593.8797 Email: smartuniv@aol.com

### **Southwest Boulevard Family Health Care**

340 Southwest Blvd. Kansas City, KS 66103 Telephone: 913.722.3100 Email: Micki56@juno.com

#### The BABES Network

221 Southwest 132nd Street

Seattle, WA 98146 Telephone: 206.242.2716 Email: mpatmig@yahoo.com

#### The Women's Collective

The Winter Building, Suite 200 1436 U Street, NW Washington, DC 20009 Telephone: 202.483.7003

Email: pat@womenscollective.org

#### **Twin State Women's Network**

P.O. Box 882

Bellows Falls, VT 05101 Telephone: 802.824.9654

Email: mboltswn@twinstatesnet-

work.org

### **Virgin Islands Community AIDS** Resources & Education, Inc. (VICARE)

P.O. Box 223235 Christiansted, VI 00822 Telephone: 340.692.9111

Email: carolynforno@hotmail.com

#### Women-Alive Coalition

1566 S. Burnside Avenue Los Angeles, CA 90019 alicia@women-alive.org

### **Women's Lighthouse Project**

P.O. Box 460905 Glendale, CO 80246 Telephone: 720.331.0408

Email: womenslighthouse@aol.com

### **Women's Project**

2224 Main Street Little Rock, AR 72206 Telephone: 501.372.5113 Email: fdavidson@aol.com

#### Women's Resource Center

P.O. Box 5122 Columbia, SC

Telephone: 803.771.0785 Email: kimfitz@bellsouth.net



# Facts You Should Know

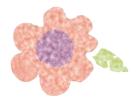
- Nearly one million Americans are living with HIV and more than 40 million people around the world are infected.
- Women account for a growing share of new AIDS diagnoses in the U.S. rising from 8% of AIDS diagnoses in 1985 to 27% in 2003.
- African American women accounted for 67% of estimated female AIDS cases in 2003, but only 3% of the U.S. female population.
- Latina women accounted for 16% of estimated female AIDS cases in 2003, and 13% of the female population.
- Most female AIDS cases were diagnosed between the ages of 25 and 44 (71%).
   This indicates that many were likely infected several years earlier.
- In 2002, teen girls accounted for half 51% of HIV cases reported among those ages 13 19, young women ages 20 24 accounted for 37% of HIV cases in their age group.
- Most AIDS diagnoses among women are due to heterosexual transmission (71% of estimated new AIDS diagnoses in 2003) followed by injection drug use (27%)
- Among younger women, ages 20 24
   heterosexual transmission accounts for
   79% of estimated new AIDS cases and 61%
   among teen girls, ages 13 19.
- The HIV Cost and Services Utilization Study (HCSUS), the only nationally representative study of people with HIV/AIDS receiving regular ongoing medical care for HIV infection, found that women with HIV were disproportionately low-income.

- Nearly two-thirds (64%) had annual incomes below \$10,000 compared to (41%) of men.
- Most women with HIV/AIDS receiving medical care have children under age 18 in their homes (76%), which may complicate their ability to manage their own illness.
- Women with HIV were more likely to postpone care because they lacked transportation (26%) or were too sick to go to the doctor (23%) than men (12% and 14%)

On line references: www.kaisernetwork.org







# How to Become More Involved

- Get educated about the virus, the disease and the statistics affecting your community and of the world.
- Be aware of your status, get tested!
- Stay involved in the political process because research dollars and funding are at stake.
- Spread your knowledge to those you love and the friends you care about and whomever you feel will benefit from the information.
- Volunteer your time at a local AIDS Services Organization

# Policy Brief

#### **A Personal Story**

My name is Lorraine Brown I have been infected with AIDS since 1986. I am a heterosexual African American woman infected by my husband. I am an advocate for women, children, and families. I started disclosing about 6 months after finding out.

One reason I came out was I needed my family's support. I am a single mother of two girls who at times could be a handful. I told my sister first and it was through her and her support that made it easier for me to disclose to the rest of my family members. At first, they did not have any reaction and had to find out more about the disease. Just like myself we thought it was a gay disease. My family steps in when I was too sick and could not do for myself. Nevertheless, it has been the main instrument behind the understanding, of why I was infected and how it happened. Many women believe that being married or in a long-term relationship saves them; I can say it does not. How many spouses come home and tell you they have slept with someone else? Through my disclosing, it has given our family the awareness and education behind my own status and has brought us much closer due to it. It has also allowed other family members to disclose their status for support in our family. I am just one out of three who are infected in our family.

With having family members who engage in high-risk behaviors, it has made them think and learn about protecting themselves. I always wondered what people thought of me after they found out about my status. However, I also never stop telling, mainly because I want people and other women like myself to know it can happen to them. I would encourage them to be tested and how it makes them more aware of the behaviors

just behind testing. For example my sister, who is married, was having marital problems and I got her to realize that there are other things going on that she needed to protect herself from before she ended up walking in my shoes. She was tested and the fear of the results was so powerful, that she left her husband due to the highrisk behaviors he engages in.

Now the difference between advocating and activism is how much time you want to put into the effort or cause, and sometimes can make a big difference in how and what you may limit yourself as far as involvement. Activism is being in the front line direct with the politicians affecting protocols, procedures, policies and Medicaid and Medicare etc. that are of value for your family and the community. It is important to be prepared, direct and to the point. An advocate is what you do everyday when you express how something makes you feel whether it be about the care you receive or even the way you are being treated. What is important is to make sure you are going to get the care you need. In addition, it is different for different people. Know what your cause is. What is it that you want to get out of it? Moreover, what is important to you?

I am an advocate; and it has helped myself and family realize that I am worthy of myself and that I first have to love myself before anyone can accept who I am or what I am or for that matter what I have. I disclose not to make friends, but to save another from being infected. I like to make a difference with methods that have worked for others and me. I advocate for others to participate on advisory boards, planning council meetings and talk to them about why it is important for them to be active in the community.

Sometimes being at the right place at the right time can make a huge difference in someone's life. Always remember you are the CEO of your health and you have the right to fire and hire who you want to be a part of your health treatment.

I encourage women especially to become empowered, to strive in making goals, become more active in their care, and lead a productive life. More and more, women are becoming the number one population in the country infected by HIV, 1 out of 4 infected everyday. In addition, most of them being heterosexual. This is not just a gay disease; this disease affects all of us in the community. It is everyone's problem. Let your voice be heard and make the communities out there become aware of what is the real deal.

# When disclosing remember these four important things:

- 1. Know the reason why you want to tell them.
- 2. Have someone with you who is supportive, so they can support you if you are rejected.
- 3 Prepare yourself for rejection.
- Remember that even with rejection, something good can come from it. You have left someone with education, with information that they may have otherwise not had.

With the numbers increasing, we need to open our eyes to the real picture. Let us reach out and join with determination, persistence, and ambition; we can strengthen one another through education and awareness.

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Women Alive recognized at L.A. City Coordinator's Office World AIDS Day Documentary Premier "Women Alive: Living with HIV"

Women Alive, along with Minority AIDS Project & East Los Angeles Women's Center were honored at the Los Angeles City AIDS Coordinator's World AIDS Day Event for continued service to women living with HIV/AIDS in Los Angeles County. The City of Los Angeles AIDS Coordinator's Office conducted a series of events for World AIDS Day 2004, in conjunction with its twenty sister cities. The focus of this year's event was the UNAIDS Theme. Women, Girls, and HIV. The goal of the office was to produce a



Carrie Broadus, Executive Director at City of Los Angeles World AIDS Day Event 2004

powerful video documenting the lives of women living with HIV/AIDS.

The video showed that the sister cities are joined together in the fight against HIV/AIDS, which does not discriminate by geography or culture. Women Alive staff, clients, and board members participated in the documentary and were able to put a face to the epidemic and create awareness among the African-American and Latina/o communities.

For further information on the video Women Alive: Living with



Women Alive staff at the City of Los Angeles World AIDS Day Event 2004.

HIV, please contact the Los Angeles City AIDS Coordinator's Office at 213.485.6334 or visit their website at www.lacityaids.org

# Women Alive welcomes visitors from the International Visitor Leadership Program



Women Alive had the honor of hosting women and men from seventeen different African Countries who were participants in the International Visitor Leadership Program, and who are working to combat the spread of HIV/AIDS in their countries.

The International Visitor Leadership Program brings participants to the United States from all over the world each year to meet and confer with their professional counterparts and to experience the U.S. first-hand. The visitors who are current or potential leaders in government, politics, the media, education, and other fields, are selected by American officials overseas. More than 200 current and former

Heads of State, 1,500 cabinetlevel ministers, and many other distinguished world leaders in government and the private sector have participated in the International Visitor Leadership Program.

It has been reported previously by *AIDS and Africa*, that at the national level, the 21 countries with the highest HIV prevalence are in Africa. In at least 10 African countries, prevalence rates among adults exceed 10 percent.

The Department of State directs the program in cooperation with a wide range of non-profit organizations operating under cooperative agreements. The program also relies on the commitment and skills of over 95 community-based organizations across the



Women and men from seventeen different African Countries were represented during the site visit at the Women Alive house.

country.

For further information on the International Visitior Leadership Program contact:

National Council for International Visitors 1420 K Street, NW Suite 800 Washington, DC 20005 Phone: 202-842-1414 Fax: 202-289-4625 www.nciv.org

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# Writer's Corner



### **Poems & Writings**

I am a Woman! A positive woman! A woman who looks at life and finds joy at the Sunrise.

A woman who hears her children's voices and is grateful for one more Day.

A woman who speaks to her friends, only to reinforce the importance of Unity.

A woman who looks up to notice the Glory of a Day, the Blue of the Sky, the Song of the Birds, the Color of the World.

Being Positive has made me just that!

#### by Nancy S.

I was thinking that there are many things that you should know because you are growing. I don't want to keep any secrets or anything from you. You are growing and I would like to have good communication with you. I want to talk about HIV. This is a disease that many people are afraid off because they don't know about it. This is a disease that is transmitted by having sex without using a condom to protect yourself from sexually transmitted diseases and by sharing needles with people that are HIV Positive and from mother to her baby when the mother is infected but there is only a small probability for the baby to become infected. The only body fluids that can infect a person are blood; semen, vaginal fluids and breast milk only if the mother is infected. In the 1980's some people got infected by blood transfusions because in the hospitals the blood was not checked for HIV or other infections. People did not know that they where infected and gave their blood and got many people infected that way.

I would like to educate you because I don't want nothing like this happen to you. I want you to know that its not only HIV but there are many other diseases you can get when you don't protect yourself. You are growing and any mistake that you make can cost you a lot. That's why you need to keep your eyes wide open and if you have any questions please ask me or our brother. Don't be

Calling All
Writers

For Newsletter

We're Looking for material from people who are HIV-Positive Alive

Poetry
Short Stories
Testimonies

Women Alive Coalition 1566 S. Burnside Avenue Los Angeles, CA 90019

Contact
Alicia
323 • 965 • 1564



www.women-alive.org

Share Your Stories!

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ashamed to ask anything, if we don't know the answer we will look together for it.

What I am trying to tell you is that I already went through a bad experience because I did not take care of myself and I had no one to educate me on safer sex. You may know that I'm working for an HIV agency and I'm learning a lot from it. If I knew then what I know today, I would have not put myself at risk of anything that would hurt my health and I would have done things differently. I'm telling you this because I made a mistake that changed my life. I trusted the wrong person and now I'm HIV-positive. I will do anything in my power to prevent this from happening to you. I want you to know that I'm taking very good care of my health and not to worry about me.

#### **ANONYMOUS**

# WHAT MATTERS MOST by Betty Knox

Life is all about love.
Because God is love, the most important lesson he wants us to learn on earth is how to love. Learning to love unselfishly is not an easy task. It runs counter to our self-centered nature. That is why we're given a lifetime to learn it.

God wants us to be in regular, close fellowship with others, to develop the skill of loving. Love cannot be learned in isolation. We have to be around people, irritating, imperfect, frustrating people. Life without love is really worthless. God says relationships are what life is all about.

Love leaves a legacy. How we treat other people not our wealth or accomplishments is the most important and enduring impact we can leave on earth. Its not what you do, but how much love you put into it that matters. Relationships take time and effort, and the best way to spell love is T-I-M-E.

#### YOU ARE NOT AN ACCIDENT By Betty Knox

You are not an accident. Your birth was no mistake or mishap, and your life is no fluke of nature. Your parents may not have planned you, but God did. He was not at all surprised by your birth. In fact, he expected it.

He deliberately chose your race, the color of your skin, your hair and every other feature. He also determined the natural talents you would possess and the uniqueness of your personality. Because God made you for a reason, he also decided when you would be born and how long you would live.

Most amazing, God decided how you would be born. He never does anything accidentally, and he never makes mistakes. Every plant and every animal was planned and every person was designed with a "purpose in mind."

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# Ms. Foundation: Women & AIDS Fund Convening

The Ms. Foundation is a leading advocate for the issues that touch women's lives, from reproductive

rights and violence in our communities to gaining access to resources to care for our families' wellbeing. The Ms. Foundation actively seek solutions for these issues. supporting cutting-edge

initiatives and organizations to ensure that women and girls have the tools to lead safe, healthy lives, gain economic self-sufficiency, and hone their leadership skills. To meet these goals, the Ms. Foundation awards grants, conducts public edu-

cation, and provides training and assistance in three main areas: Economic Security; Health and Safety; and Girls, Young Women, and Leadership.

Recently, grantees of the Ms. Foundation's groundbreaking Women and AIDS Fund (WAF) came together in Los Angeles for the annual WAF convening. This was the only national meeting of HIV-infected and affected women. Participants gathered to share their work and receive training on how to make their grassroots organizations more effective. The convening brought two representatives from each grantee organization to a two-day skills building session, and allowed time for grantees to network with each other, Ms. Foundation staff and Advisory Board members. The Women and AIDS convening has been critical to the success of the grantees' work. Many of these women work in isolation throughout the year. The convening is a way for the women to reconnect to their sisters nationwide who face similar challenges strive to achieve like goals, and need the same encouragement to press on. This year's grantees shared best

practices, which included successful strategies on organizing, board develop ment, fundraising, and media relations. Participants represented diverse groups from across the country.



Women Alive Treatment Adherence Educator Norma Guerra and Executive Director Carrie Broadus at the Ms. Foundation Women and AIDS Fund Convening in December 2004.

CO TO

For further information on the Ms. Foundation, visit their website at www.ms.foundation.org or contact them via telephone at 212.742.2300

# Women Alive Bulletin Board

#### Latinas Activas Support Group (Spanish

language)Transportation (one way), childcare, light meal, and raffles. For more information call 323.965.1564 and ask vided and light meal. For more information for Norma or email her at norma@women-alive.org

Dentro del Alma y El Corazon (Spanish language mental health support group). Transportation (one way) procall 323,965,1564 and ask for Elsa Garcia

Mental Health Support Group (English) Transportation (one way) and light meal provided. For more information call 323.965.1564 and ask for Renee Moseley or email her at renee@women-alive.org

Hetero Too Support Group (English and mixed) Transportation (one way) provided, light meal & raffles For more information call 323.965.1564 and ask for Precious Jackson or email her at precious@womenalive.org

#### **Treatment Adherence & Education**

If you have questions about your medical care, treatments and/or lab work, and/or if you need someone to go with you to your doctors appointment anywhere within Los Angeles County. Our Treatment Adherence Educators can be of assistance to you. For further information contact our toll free hotline number 1.800.554.4876 or contact precious@women-alive.org or norma@women-alive.org (Bilingual English and Spanish).

#### **Peer to Peer Support and Advocacy**

If you have questions on how to access services and need emotional support, our peer to peer program is for you. One on support services as well as support group services and resources available for HIV + individuals. For further information contact alicia@women-alive.org (Bilingual English and Spanish)

#### **Mental Health**

Therapeutic support group for women with HIV/AIDS. Specialized counseling is available for the whole family. Whether it's mom, the kids, a male partner or a family member who are having a hard time coping with HIV, help is available. Therapy for those that are HIV Positive is offered. Group is facilitated by a licensed therapist. For further information contact renee@women-alive.org (Bilingual English and Spanish)

#### Sisters Alive Health Educator Training

If you are interested in learning more about HIV/AIDS and prevention information, The Sisters Alive Health Educator Training is for you. Learn about prevention, STD's, and domestic violence, and share it with others in your community by becoming a community educator. Completion certificates are awarded at the end of the training. Agency requests are welcomed: For further information contact gail@women-alive.org (Bilingual English and Spanish)

#### **Medical Updates**

Women Alive hosts regularly scheduled medical updates with a focus on what's new for women with HIV/AIDS. Educational dinners are an excellent way to stay up to date with information on medications to treat HIV infection. To reserve your seat at the next update contact precious@women-alive.org. or norma@women-alive.org (Bilingual English and Spanish)

#### Women Alive Voices with a Message National Hotline

Are you an HIV+ Woman? Do you feel alone? Need information, help, and support? Our hotline is staffed by HIV+ women who can help you. Call us today at our toll free hotline number for positive women and become a part of our community. Hotline hours of operation Monday - Friday from 11am to 5pm (PST). Please call 1.800.554.4876. (Bilingual English and Spanish)

> For further information on any services offered through Women Alive, please visit us on line at www.women-alive.org

#### **Volunteer Opportunities**

Women Alive is always looking for volunteers to assist with administrative work, fundraising, and special events. If you would like to become a Women Alive volunteer, please contact gail@women-alive.org

#### GET ON BOARD!



Our Board of Directors meetings meet on a bi-monthly basis. If you live in the Los Angeles Area and are interested in becoming a Women Alive Board Member contact carrie@women-alive.org

# Treatment Corner

# VITAMIN AND MINERAL CHECKLIST

The following is a list of recommended vitamin and mineral supplements for persons living with HIV disease. Certain supplements can interact with HIV medications, so make sure to discuss your vitamin and mineral supplement plan with your doctor before beginning or making any changes to your current regimen.

# Basic multivitamin/mineral supplement

Everyone with HIV should be taking a basic multivitamin. Recommended dosage: one tablet, once or twice daily

#### **B-Vitamins**

You need extra B vitamins when your immune system is under extra stress from HIV. Recommended dosage: 25-50mg

#### **Beta Carotene**

It is called "provitamin A", it is converted into vitamin A in the gastrointestinal tract and is considered the non-toxic version of vitamin A. Beta Carotene is an antioxidant and is needed for fighting infections.

Recommended dosage: 10,000-20,000 IU's

#### Vitamin C

It is an antioxidant and can boost the immune system. Recommended dosage: 500-1000mg (if possible, take half in the morning and half at night)

#### Vitamin E

It works in harmony with vitamin C to strengthen and increase antioxidant effects of both vitamins.

Recommended dosage: 400-800 IU's

#### Selenium

It is an antioxidant and helps keep your gut healthy. Selenium deficiencies have been shown in studies to be an independent risk factor for survival. Recommended dosage: 200mcg

#### Calcium

Some of the HIV medications may lead to bone mineral loss. Brittle bones will be an issue as people living with HIV get older. Take your calcium with vitamin C rich foods like orange juice to help increase absorption. Recommended dosage: 1000-1500mg (if possible, take half in the AM and half in the PM)

#### NAC (N-acetyl cysteine)

NAC is an antioxidant that helps to increase glutathione levels in the body. Glutathione is also an antioxidant that is needed to keep the immune system functioning well. Low glutathione levels have been shown to be common in all groups of HIV+ individuals. Recommended dosage: 1000-2000mg

#### Magnesium

Low levels of magnesium can cause fatigue, dizziness, and depression. Recommended dosage: 300-400mg

#### **Zinc**

Levels of zinc have shown to be low in about a third of people living with HIV. It is important for wound healing, prostate gland function, and a healthy immune system.

This fact sheet is produced by the Women Alive Treatment Education & Advocacy program in cooperation with the Office of AIDS Programs & Policy-Los Angeles County, Department of Health Services

#### TO PHENOTYPE? OR GENO-TYPE? THAT IS THE QUESTION...

#### What is resistance testing?

Resistance Testing refers to two new types of tests that are being used by a number of researchers and health-care providers in the search for better ways to treat people infected with HIV/AIDS.

The first one called a Genotypic test, examines the HIV taken from a patient, looking for the presence of certain genetic mutations that are known to cause resistance to medications.

A Phenotypic test directly measures the actual sensitivity of a patient's

HIV to certain drugs. To do this, phenotypic tests measure the amount of a particular medication needed to inhibit HIV in a test tube.

#### How might these tests help me?

It is the hope of doctors, and people living with HIV that using these tests will allow them to make better treatment decisions. For example, knowing what medications you might already be resistant to, could save both time, money, and possibly the heartache of taking a bunch medications that could be destined to fail from the start. This is especially important to someone whose combination therapy may have already failed, or someone who may have been infected with resistant virus.

#### What are the pros and cons?

Unfortunately these tests are not without fault. They are being done on an experimental basis. They are quite expensive and the data can be hard to interpret.

### How can I get more info?

Drop by, or call one of the Women Alive Treatment Advocates. They will be happy to give you more detailed information.

For further information email precious@women-alive.org or norma@women-alive.org or call our office at 323.965.1564

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# 2005 Conference Schedule

## May 2 - May 4

Washington, DC

AIDS Watch '05: Grassroots Advocacy Day

www.napwa.org

### **May 18**

National HIV Vaccine Awareness Day www.niaid.nih.gov

### **June 12 - June 15**

Atlanta, Georgia National HIV Prevention Conference www.2005hivprevconf.org

#### **June 27**

National HIV Testing Day www.hivtest.org

# **July 24 - July 27**

Rio de Janeiro, Brasil IAS '05: Third Annual International AIDS Society Conference on HIV Pathogenesis and Treatment www.ias-2005.org

# August 19 - August 21

Los Angeles, CA Staying Alive '05: National HIV Positive Leadership Summit www.napwa.org

# September 21 - September 24

New Orleans ICAAC '05: 45th Annual Interscience Conference on Antimicrobial Agents and Chemotherapy www.icaac.org

# September 29 - October 2

Houston

USCA '05: U.S. Conference on AIDS www.nmac.org

### October 6 - October 9

San Francisco 43rd Annual Meeting of Infectious Diseases Society of America www.idsociety.org

### October 15

National Latino AIDS Awareness Day www.latinoaids.org

### November 17 - November 20

Orlando, Florida ANAC '05: 18th Association of Nurses in AIDS Care Conference www.anacnet.org

#### **December 1**

World AIDS Day www.worldaidsday.org

# **December (TBA)**

NATAF '05: North American Treatment Action Forum www.nmac.org

Conference dates, locations, and times are subject to change. Visit conference websites for complete and up to date information.



# DEAR DEBBIE

#### Dear Debbie,

I started dating someone who told me (after 4 weeks) that he has had herpes for 26 years. By the time he told me, we had had oral sex on several occasions and I had swallowed semen . He has not had a breakout in 18 months. Can I only catch herpes from him when he is broken out...or is he contagious 100 % of the time? Please help. I can't find this answer.

Thank you so, so much.

L

#### Dear L,

Genital herpes is the most common cause of genital ulceration in United States. Herpes (HSV) type 1 is usually found on the mouth (cold sores) and HSV 2 is generally found on the genitals (but not always). Infection with HSV is lifelong because the virus lives in the nerve root ganglia (that is why it always infects the same spot). There are antibody tests that can be done, but they really serve no purpose, because either you have it or you don't! (unless you are pregnant) Transmission generally only happens when there is direct contact with an infected lesion or secretions, but new studies suggest that transmission can also happen during asymptomatic viral shedding (the virus is present, but there isn't an ulceration present). So the important thing is to always protect yourself by using a condom. 20-25% of sexually active young adults in the US are infected with HSV-2 with approximately 5-8 outbreaks per year in the beginning and then decreasing to less than two per year after 5-8 years. The time it takes from the exposure to an outbreak can be a few days to a few weeks and can last 3-5 days. A treatment is available, Acyclovir and it can be used for both a treatment or to prevent outbreaks. I hope this helps. Thanks for writing.

D.J

#### **Dear Debbie:**

I have been researching a paper on ethical issues involved in offering invitro fertilization services to couples with HIV and have not been able to find much information on the topic. What information I have found has

been either old or not from reliable sources. I hope you can help me answer some of the following questions, or direct me to where I might. The CDC web site has not been that great of a source, believe it or not. All the in vitro clinics I have contacted refuse to return my e-mails.

#### **Debbie's Response**

There is very little information available about artificial invitrofertilization, mostly because of the fear of HIV infection. My understanding is that Japan probably has the most advanced research on this subject and have the transmission rate down to 1:3 million. The fear is that if the woman becomes pregnant (and she is HIV- )and also becomes HIV+, the baby has a higher probability of also becoming HIV+ because of the high viral replication that occurs when a person is going through Seroconversion (HIV- TO HIV+). In the State of California, it is against the law to conduct invitroferitlization between Sero-Discordant couples and yet in New York there is one invitrofertility clinic that is offering services at a very high rate of \$10,000 dollars or more. It is a very delicate subject and that is probably why you have not heard back from anyone. More information is becoming available in the last several vears about Invitrofertilization and HIV transmission. In one study reported in the American Journal of Perinatology. 20(6):305-11, 2003 AUG. Out of 25 discordant couples who underwent invitrofertilization there were no documentation of seroconversion in either mom or babies at 3 months. The clinics which provide Assisted Reproductive Technology (ART) are guided by general guidelines set forth by The American Society for Reproductive Medicine and its Ethics Committee.

What is the latest estimate of rate of transmission between an infected pregnant woman and her child? I have read between 1% and 4%.

Before ART, the transmission rates ran between 19 and 43% depending on the cohort or article you read about. The transmission rate with ART is down to about 2-4%, in other words the mother has about 98% chance of having a healthy, non-HIV infected fetus. New data about pregnancy also discusses that if the HIV RNA can be

decreased to < 1000 in a women within controlled viral replication, that there is a significant benefit.

With the latest drugs now in use, what is the life expectancy of a child prenatally infected with HIV? Is it the same as an adult, about 20 years? I have read some articles which say it is shorter because HIV interferes with the growing up processes, especially during adolescence.

I can tell you that even before all of the current drugs that are available, many children born with HIV are now young adults thinking about getting married and having children. The exact number of years is still unknown, I have read some literature that suggests > 30 years if the patient takes their ART and remains undetectable. Certainly there are less medications available for children than adults, but it is slowly changing. It is dealing with the difficulties of trying to get a young child to take their medications every day that is the most complicated.

Do you know if invitro clinics in the USA offer their services to HIV infected couples? (It is usually one or the other, I have never heard of both parents being infected and seeking IVF). Do you know if the technique developed overseas called sperm washing has been approved for use here in the USA? That technique along with Intro Cytoplasm Sperm Injection are said to bring the risk to the uninfected mother down to about zero. Do you know if any health insurance companies, the few who offer limited coverage of IVF, allow HIV positive couples to seek IVF?

There have been cases of two HIV infected males trying to find a surrogate woman who would consider becoming pregnant, but there again is not a lot of information. Sperm washing has to do with the assumption that HIV is located in the cells around the sperm, not the sperm themselves. So you wash as much of the surrounding cells amd fluid away from the sperm as can be done with the assumption that the risk of HIV transmission becomes less of a risk. Yes, sperm washing is being done in the United States; again it depends on the state and the law around HIV & invitrofertilization.

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continued from page 13

Again the Japanese are much more advanced then we are here in the United States.

#### **Reference Abstracts:**

- 1. Establishing a clinical program for HIV Seropositive men to father seronegative children by means of In Vitro fertilization with Intracytoplasmic Sperm Injection. AM J OBSTET GYNECOL. 2002 OCT; 187(4):1121
- 2. Reproductive Assitance to HIV-Discordant Couples--The German Approach. EUROPEAN JOURNAL OF MEDICAL RESEARCH. 6(6):259-62, 2001 JUN27.
- **3.** Infections in IVF: Review and Guidelines. HUMAN REPRODUCTION UPDATE. 6(5):432-41, 2000 OCT-SEPT.
- **4.** Gestational Surrogacy for HIV Seropositive Sperm Donor: What Are The Ethics? JOUR OF THE AM MED WOMENS ASSOC 58(3):138-40, 2003 SUMMER.
- 5. Obstetric Outcomes of HIV Serodiscordant Couples Following Vitrofertilization with Intracytoplasmic Sperm Injection. AM JOUR OF PERINATOLOGY? 20(6):305-11, 2003 AUG. I hope this helps you answer some of the questions, There is a lot of controversy over this subject and a state to state difference on what is available and where.

#### Dear Debbie.

How can you tell if you have overdosed on Vitamin B6 and what can you do about it?

#### N

#### Dear N:

Pyridoxine (vitamin B6) is not safe in large doses. Large doses can cause a peripheral neuropathy (pain, numbness or tingling in your feet or hands) despite the fact that vitamin B6 is a water-soluble vitamin (the body doesn't store vitamin B6, what you don't use is cleared out of the kidneys). In a study done in 172 women of whom 60% had neurological symptoms, which disappeared when B6 was withdrawn and reappeared in 4 cases when B6 was restarted. The symptoms were paraesthesia (numbness), hyperaesthesia (pain, tingling),

bone pains, muscle weakness, numbness and fasciculation (fine muscle spasms), most marked on the extremities and predominantly bilateral (in both feet) unless there was a history of previous trauma to the limb. Vitamin B6 is usually given along with the TB medication ionized (IHN) but in lower doses of 10-50 mg per day. The majority of vitamin B6 toxicities occurred in individuals who were taking 90-100mg or more over time. B6 is essential in preventing neuropathies when taking INH, but taking too much can also be bad and cause neuropathies. I hope this helps? Let me know if you need further information.

#### **Debbie**

#### Hi Debbie,

I've been HIV-positive for 18 yrs and just started to take meds in April 2002. I had something called the Burning Mouth Syndrome, and thought it had to do with having HIV, come to find out its part of being pre menopausal...but it did make me go on meds anyway... I shouldn't have waited so long, but I felt great...until the menopause kicked in...((sigh)). My t-cells were 27 and I felt horrid. I am also going though my changes...I went 16 months without a period, and then had it for 2 months in a row for 6 days. Now it's been 3 months and no period again... My question is...Why my sex drive is down... I am very dry in the vaginal area and it's hard for me to have sex. In fact, I don't even crave it... I was wondering if it's the meds or going though menopause. I want to be sexual with my partner again, but haven't the urge... What do I do to change that???

# Thank you, **Dead In Bed**

#### Dear Dead in Bed,

I know how you feel; going through menopause can be pretty tough. As your hormones change, so does your vaginal moistness and sex drive.

The jury is still out in regards to offering hormone replacement due to the recent findings in a large clinical trial. The results of the study suggests there is an increase risk of developing breast cancer in those women who took hormone replacement (estrogen/progesterone). At this point in time, the arm using only estrogen

replacement in women who have had hysterectomies is still ongoing. But for those of us who still have our uterus, using estrogen without progesterone is not an option. Estrogen only can increase the risk of developing endometrial cancer (sometimes we just can't win). There are a couple things that you can do, the first would be to use a vaginal cream with estrogen to help treat/prevent vaginal atrophy or use a water based lubricant each time you have sexual intercourse (with a condom).

There have been several reports that suggest that women who are HIV infected may have more problems with their menses and/or may experience early menopause. Menopause is not a side effect of your antiretroviral therapy, but I think as time moves on and we learn more about women and HIV, ARV may contribute to changes in our hormones. But at this time there isn't any literature that I know of that supports ARV causing hormone imbalance in women. There is more and more literature that suggests that HIV and possibility ARV may adversely affect men and their ability to sexually function, but there is little information about women and HIV.

Lastly, many women experience a dip in libido while their hormones are changing. Talk to your healthcare provider and ask them about some of your options. If you need to gain weight, you may think about a low dose of nandrolone (male hormone which has less 2nd sexual side effects). Nandrolone at 50-100mg every 2 weeks can increase your libido and help you to gain muscle mass. Other suggestions include taking care of yourself, eating good balanced meals, take a vitamin once a day, decrease your stress, exercise, stop smoking and be compliant with your ARV. I hope this helps. Let me know what you decide to do and how it works.

#### **Debbie**

\*\*Distribution of information is funded by the County of Los Angeles, Department of Health Services, Office of AIDS Programs & Policy, but such funding implies no endorsement of treatments or verification of the medical or scientific accuracy of the information.\*\* Women Alive Coalition 1566 S. Burnside Ave. Los Angeles, CA 90019 deardebbie@women-alive.org Please note: Information and resources included with our newsletter are for informational purposes only and do not constitute any endorsement or reccomendation of, or for, any medical treatment or product by Women Alive. With regard to medical information, Women Alive reccomends that any and all medical treatment you receive or engage in be discussed thoroughly and frankly with a competent, licensed, and fully HIV/AIDS informed medical practionter, preferably an HIV specialist and/or your personal physician.

#### Dear Debbie Question or Concern

- 1. If you want a direct response to your question, please include your name and address.
- 2. Confidentiality, your name or any other information that you may include on this form, will NOT be released within the column or to any individual. It will remain confidential.
- 3. Once Women Alive receives your question, it will become the property of Women Alive and will not be returned to you.
- 4. The response to your concerns may not be directed to you individually, if many other women express the same concerns. It may be a generic (addressed to everyone) response.
- 5. Please keep your question short and clear. Please write clearly.
- 6. Remember, all questions are important and if you thought of it, so have many others.

	Name:				_
	CD4 count: (Optional)				_
	Address:				_
	HIV RNA: (Optional) Age:				_
	Medications:	:			_
Con	cerns:				

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# **MEMBERSHIP INVITATION**

Women Alive offers full membership to Women Living with HIV/AIDS and to those affected by HIV/AIDS. Women infected/affected by HIV are encouraged to join our team of volunteers. I would like to participate in or do the following:

Write articles in Spanish	Do phone trees	Distribute ma	ail and newsletters
Typing and office needs	Economic Development	Policy	
Join the editorial team	Do E-mail Blasts	Advocacy Tr	raining
Public speaking	Attend leadership trainings	Community	organizing
Please contact me at the nun	nbers below		ned and want to nember of Women Alive
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