WOMEN ALIVE

KNOWLEDGE IS POWERFUL • ACTION = LIFE • SRING 2003

Newsletter

"The New Faces of Women Alive Coalition"

"Self-help means to grasp our potentialities, discover our resources, accept responsibility for our life and live it in the way we ourselves decide. Self-help means starting a process of change - from being a passive recipient to becoming an active participant in one's own life."

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WOMEN ARE FINALLY BEING RECOGNIZED AS PART OF THE AIDS PANDEMIC. WE, AS WOMEN INFECTED AND AFFECTED BY HIV AND AIDS, ARE BEGINNING TO JOIN TOGETHER EFFECTIVELY TO SEE THAT OUR SPECIAL NEEDS ARE MET. WOMEN ALIVE IS INTENDED TO INFORM WOMEN AND TO HELP US FIND EACH OTHER FOR ENCOURAGEMENT AND SUPPORT. WE HOPE YOU ENJOY THIS NEWSLETTER AND WILL CONSIDER GETTING INVOLVED IN ITS PUBLICATION.

in loving memory of

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Please note: Information & resources included with your 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 and 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.

This issue is dedicated in memory of:

Jon Glanz,
Shanae Jordan (daughter),
and Dessie Jackson (grandmother)

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NEW VISION

By Carrie Broadus

Patterns of domestic violence are very similar to the spread of HIV in women. In domestic violence, the woman is often isolated, has no control over the situation with her and her partner, she is often unaware, abused, and continues to stay in the relationship because she cannot see a way out. With HIV, the woman similarly has no say or control with condoms, she is either not aware or may have an idea that here partner is cheating, but again does not have a say in when he comes home or where he goes. She usually does not have the knowledge about how the virus is transmitted or that she is at risk of becoming infected because she is monogamous in her relationship. Often the woman is aware of who has infected her if she is positive, but will not turn the person in for all of the same reasons a physically battered woman resists turning in the father of her children, or the man who provides her economic stability.

In knowingly transmitting the virus to his partner, the male is declariing his control over his female partner. Statements are made to the effect of, "No one is going to want you now", conveying the message that the woman has now become "unclean".

In the same sense, social condition and religion has put the woman at a disadvantage. She is always made to feel that she must be monogamous, trust her partner, and taught to feel that someone else will be there to protect her, rather than instilling the belief that she is capable of taking care of herself. Further, as in domestic violence, there is much emotional trauma in getting a diagnosis or finding out that a partner has not only been unfaithful, but has also infected her with the disease. And many times women who are infected by their primary partners often suffer in silence, and it is not until they become sick that they come forward to recieve help.

> We are more than just a body. We are mind, body and spirit.

Some will say, "It is the woman's fault, she should know better; she should learn how to negotiate safer sex with her male partner." However, the

(*continued on page 7*) *

women alive 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.

How I Learned To Love Myself

By Precious Jackson

Hi my name is Precious. I want to tell you a little about myself so you can get to know me a little better.

I was raised by my grandmother and step-grandfather in South Los Angeles. Due to my parents' drug addictions at that time, they felt it was best that my grandmother raise me.

I had a sheltered life, so you know what that means. My grandmother loved and cared a lot about me, she did the best she could, as she knew how. I still grew up feeling less than adequate and unworthy. I felt ugly, and I was thin. I remember when I was in junior high school, there was this black girl walking down the hallway who was thick and already developed. When she walked by me I could hear her jeans go "swish-swish". I though that if my jeans could do that, then all the boys would like me and I would get the attention that I wanted. I just wanted to fit in with the "in-crowd" and to be accepted.

When we became sexually active, he stated up front,"I don't use condoms, so don't ask." And of course, I didn't.

I felt different because most of my friends lived with their parents, and I didn't. My parents would pick me up on weekends, and those were the days I wished for all the time while growing up. My mother and father were so loving and caring when I was with them. They weren't strict and they were open-minded, so I felt free to tell them things that I couldn't tell my grandmother.

My grandmother didn't allow me to make decisions about anything, especially when I was a teenager and even until my adult life. I remember how my father and grandmother always had arguments about me. They would argue about how she wouldn't allow me to make my own decisions, or go out with my girlfriends to the mall or movies. She always called them "fast ass heifers". I am not putting down my grandmother at all, I love her dearly, and I know she did the best she knew how.

I learned co-dependent behaviors early on as a child, and it carried on into my adulthood. There was a void in my life and I couldn't figure it out. I always felt that if I could get a man, he would complete me - mind, body and soul. Each time I went into a relationship, I felt like this was it, and when it wasn't, once again I was out there, hurt and mad. For years, I would jump in and out of relationships thinking that I had found love, but what I found was heartache and pain. I would allow men to use and abuse me, because i didn't want to feel rejected or make them upset by hurting their feelings. Whenever they wanted me to have sex with them, even when I wasn't in the mood, I did it anyway. Most of the time I just wanted to cuddle, but I didnt know how to express myself back then. So each time I fulfilled their needs I felt torn up inside, but I didn't know how to stop.

It seemed the older I became, the worse my neediness and desire for love became. In 1996, when I was about 25 years old, I met a man who was light skinned, fine and tall. He also had his own place, a car and a deep sexy voice. I just knew I had found my husband. When we were dating I had asked him if he had ever taken an HIV test. He told me that he had, and it came back positive.He then told me that he had taken another test, and that it had come negative. Back then I didn't think anything of it because some tests were coming back inconclusive.

A year and a half into our relationship, he became a ward of the California Correctional Center. In May of 1998, I received a letter from him stating that he had tested positive for HIV antibodies and was HIV+. At the time I was living with my mother, who had been clean and sober for nearly 14 years. After reading the letter I knew I was HIV+ because we didn't use protection at all. Back when we were together and sexually active, he had stated to me up front, "I don't use condoms, so don't ask." And of course, I didn't ask.

I told my mother about the situation, and she encouraged me to go get tested. I will never forget how she held me as I cried like a baby. "Baby, we are going to get through this together," I remember her saying. With those words of encouragement, I went and had a test. I recieved my results a week later, and my test came back positive. I was HIV+. After my diagnosis I went through more drama, and once again my self-esteem and self-worth were at the floor. I was tired of going through all the drama, and I wanted to do something about it. I went to therapy and started working on myself to get rid of all my personal baggage. That's when I discovered I didn't know how to love myself, and that I was looking for people, places, and things to fulfill my needs.

Today, I am still working on myself and learning how to love and accept me. It is only through the grace and mercy of God, who I have allowed to be the head of my life. Through my spiritual journey, I found that God, not men, places or things, complete me.

■

WHAT ARE HIV+ PERSONS' HIV PREVENTION NEEDS?

unknown

why prevention for HIV+ persons?

Every new HIV infection involves an HIV+ person. The Centers for Disease Control and Prevention (CDC) estimate that there are 600,000-900,000 people living with HIV in the US. Yet very few prevention interventions have been directed to HIV+ women and men. People who are HIV+ deserve to have interventions to help them stay safe and play an active role in stopping the epidemic.

In the past few years, advances in the treatment and care of HIV+ persons have helped many people enjoy increased health and longer life. For many, this allows for a renewed interest in sexual and for some, drug using activity. More sexually active and drug using HIV+ persons means the possibility of more new infections.

why haven't we done more of this?

In the past, prevention efforts had not been directed toward HIV+ persons for fear of "pointing the finger" or blaming HIV+ persons for the epidemic. Although AIDS has become less stigmatized in the US, in some communities there is still serious stigma experienced by HIV+ persons. AIDS activists and HIV+ persons have also feared laws criminalizing sexual risk behaviors and further prosecution of injection drug users. (IDUs).

Prevention efforts for HIV+ persons have focused on protecting one's own health from the possibility of reinfection with untreatable strains of HIV. Few efforts have addressed altruism-the responsibility of HIV+ persons to not transmit the virus to others and the opportunity for HIV+ persons to actively contribute to ending the epidemic. Prevention efforts need to address both issues: taking responsibility for one's own health and the health of one's partners, children, other family members and community.

why would someone infect another?

Most HIV+ persons are concerned about not infecting others and have made efforts to prevent transmission. Yet there has not been much support for HIV+ persons to gain the necessary skills and tools to adopt new, safer behaviors. Couples where one partner is HIV+ and the other is HIV negative often wrestle with issues such as how to maintain sexual satisfaction and trust. For some couples, the risk of losing commitment and intimacy in a relationship is more threatening than the risk of transmitting HIV.

A precondition of reducing your risk is knowing you're HIV+ and getting help. There are an estimated 200,000-250,000 Americans unaware that they are infected with HIV. It is imperative to help HIV+ persons get tested before they unknowingly infect others. Finding out HIV status can also allow early access to life-prolonging treatment and services.

disclosure

Incorrect assumptions and denial of responsibility between partners can lead to risky behavior. Many HIV negative persons are unaware of their partners' status or risk behaviors and may make assumptions that they are not at risk for HIV because they are married, in a relationship, their partner looks healthy, or simply because their partner did not ask to use a condom. HIV+ persons may make the same assumptions that their partner is also HIV+ because the partner didn't ask about serostatus or suggest using condoms. Likewise, there may be a difference of opinion on who's responsible for keeping safe, the HIV positive person, the HIV negative person, or both.

Disclosure can be a way of beginning a discussion about safer sex or drug use. Yet disclosure of one's serostatus is difficult for many HIV+ persons, especially women, who may fear stigma, rejection or violence from their partners.

Practicing safer sex with all partners and always using clean needles is one way of preventing transmission without having to disclose status. However, in many communities where this is not the norm, simply using a condom can disclose HIV+ status, even without saying it.

HIV is a disease that is often mistakenly associated with careless sexual behavior. However, many HIV+ persons become infected within a loving relationship. In one study of HIV+ men and women, 41% reported becoming infected by a spouse, significant other, or long-standing friend. Research has shown that people are often more comfortable disclosing and practicing safer sex with partners outside of their main relationship.

what are barriers to prevention?

Often, the same factors that led someone to become infected are also barriers to preventing transmission. Many HIV+ persons face complex issues that can affect their ability to engage in safer sex or drug-using behaviors. Depression, substance use and abuse, history of violence and abuse and sexual compulsivity are all issues that may need to be addressed. Many of these issues cannot be addressed in a prevention program and may require referral to longer-term counseling or other social services.

Legal, political, and environmental factors can be barriers to HIV prevention among HIV+ persons. For example, the lack of access to sterile syringes and needle exchange programs, as well as laws prohibiting possession of syringes, hamper the ability of IDUs to engage in safe behaviors. Fear of arrest for carrying drug paraphernalia has been associated with sharing syringes and other injection supplies.

what's being done?

In 1998, the CDC funded five Health Departments to create demonstration projects providing primary HIV prevention for HIV+ individuals.

*

California, Los Angeles, San Francisco, Maryland, and Wisconsin have begun a variety of programs that address a wide audience including: HIV+ women, men of color who have sex with men, IDUs, youth, female sex and needle sharing partners of IDUs, and incarcerated men and women.

Interventions include: HIV, STD and TB counseling, testing and treatment; referral and linkage to care; prevention case management; HIV+ peer "buddies"; outreach via social networks; mass media and internet marketing; partner counseling and referral services; skills building; and community level forums and social events.

There are an estimated 200,000-250,000 Americans unaware that they are infected with HIV.

campaign

AIDS Action Committee in Boston, MA, created an ad campaign that targets HIV+ gay men with messages aimed at opening discussion about transmission and promoting responsibility. Posters with messages such as "Ask. Tell." "Let's stop new infections now." and "If you're positive, think about transmission." were placed over urinals in gay bars and sex clubs. A survey of men leaving the bathrooms found that 70% could recall two or more of the messages.

couples

Couples counseling for sero-discordant couples (*where one partner is HIV+, the other HIV-*) has proven highly effective at reducing new HIV infections. One program for heterosexual women and men provided couples counseling in combination with social support. As a result, condom use increased and no new HIV infections were reported among the couples. Couples counseling can help ease communication and provide support for both the HIV+ and HIV- partner in straight and gay/lesbian relationships.

what needs to be done?

HIV+ persons are a unique population in that they require both care and prevention, which requires better coordination between these two worlds.

- Health care providers need to be trained to deliver HIV prevention, as seroconversion can provide a strong motivation to change risky behaviors.
- HIV prevention programs need to address HIV+ persons and include STD, hepatitis and TB screening and treatment as well as referrals to drug treatment, family planning and mental health services.
- HIV+ persons' partners, children and families must be included with support and education.
- We need more effective HIV testing and counseling strategies.

don't know

There is currently an unacceptably high number of persons who do not know they are HIV+ unknowingly infecting others. The social network approach (*encouraging HIV+ persons to provide information and outreach to peers who might be positive*) is one way to create a more efficient and targeted approach to HIV testing and counseling for those at greatest risk.

There are many things we don't know about the relationship between new anti-HIV drugs and HIV transmission. How much do they affect a person's infectiousness and how does that affect transmission? Is re-infection or super-infection a valid concern? These questions need to be researched, and the answers disseminated widely so that HIV+ persons can make informed decisions about preventing transmission of the virus.

If you have tested HIV positive, reach out and get some help. If you don't know your HIV status, take the test - it's free and confidential.

If you need a prevention for positives program to help you reduce your chances of transmitting virus to others, please call: Women Alive Coalition: 323.965.1564. Ask for Gina! n

"HIV STOPS WITH ME"

By Adriana M. Pentz

You see there faces on billboards, bus shelters, and posters outside the laundry mats and beauty supply stores, but who are they?

The spokesmodels for the "HIV STOPS WITH ME" social marketing campaign sponsored by Positive Images, are REAL people in Los Angeles County living with HIV, who are committed to preventing the spread of HIV/AIDS in their community. Women Alive's Treatment Advocate Precious Jackson, along with 5 other HIV positive men, women and transgenders are sharing there journey's, hopes and challenges in becoming a leader in this fight. The campaign is designed by Better World Advertising and funded by the U.S. Centers for Disease Control and Prevention and the County of Los Angeles, Department of Health Services, Office of AIDS Programs and Policies. It consists of a website, newspaper and magazine ads, postcards, billboards, and transit media.

In a Campaign assessment done by AIDS Project Los Angeles, 59% of the individuals surveyed feel that "HIV Positives have a responsibility to end HIV". In this campaign, the HIV spokesmodels are doing so through personalized messages and images that people understand.

On May 7th, the "HIV STOPS WITH ME" media launch will take place at Unity Fellowship Social Justice Center. Several other media launches will take place throughout the Los Angeles area over the next couple of months, and the spokesmodels will be there live to provide information and interact with their community.

To find out more about when the spokesmodels will be in your community, information about the sites, or to provide input about the campaign: feel free to call us at Women Alive (323-965-1564) or visit the campaign website at: www.hivstopswithme.org

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A Celebration of Life

For our friend and co-founding member of WAC, Justina Thompson

In Loving Memory of
Shanae Monique Jordan
April 3, 1974-October 10, 2002

"And he will wipe out every tear from their eyes, and death will be no more, neither will mourning, not outcry, nor pain be anymore. The former things have passed away."

—Revelations 21:4

obituary

Death is not a tragedy for those who have faith, for they are passing from a world filled with struggles and disappointment to one which is finer and better.

Shanae Jordan, passed through the veil called death into the life which is everlasting on Thursday, October 10, 2002.

Shanae grew up in Pasadena, where she attended Grover Cleveland Elementary School, continued to Wilson Middle School and Washington Middle School. In 1992, she graduated from John Muir High School. She furthered her education at Citrus Community College in Glendora, California. Her quality traits were making new friends and giving her heartfelt assistance to everyone she encountered.

Life is very uncertain, and we ought to be ready for death whether it comes soon or late.

If there are tasks that need to be performed, let us be busy at them; if there are kind deeds that ought to be done, let them not be delayed; if there are bad habits, let us overcome them; if there are those who are downhearted, let us help them lift the load.

Shanae leaves to cherish her memories, her precious children Raven Jones and Duriah Jones, her devoted parents Herman Jordan, Margaret Jordan, and Justina Thompson; sisters Regina, Nancy, Karen, Tamika and Enjoli, brothers Rodney, Everette, Jasper, and Alphonso; best friends Shindonna Henderson and Leilani Kisa-Alvarado. A host of nieces and nephews, aunts and uncles, and relatives and friends.

How precious are the friendships we have formed through the years, and how the sharing of sorrow lightens our burden. Thank God for those who come with flowers and other expressions of sympathy.

The flowers soon fade, but the love they represent is never ending. Some people never realize how many friends they have until sorrow comes and bereavement thus becomes a blessed experience, even as Jesus taught when he said;

"Blessed are they that mourn, for they shall be comforted."

---

forever in our hearts

God looked around his garden and he
Found an empty place.
He then looked down upon this earth and
Seen your tired face.

He put his arms around you and lifted you
To rest.
God's garden must be beautiful, he always
Takes the best.

He knew that you were in pain, he knew
That you would never get well on Earth
Again.
So he closed your weary eyelids and
Whispered: "Peace Be Thine".

He then took you up to heaven with hands
Gentle and so kind. It broke our hearts to
Lose you, but you did not go alone.
For part of us went with you, the day God
Called you home!!!

Poem by Shindonna Henderson

Don't Cry for Me

Here we are again
That old familiar place
Where the wind will blow
No one ever knows
The time or space

Don't cry for me
Don't shed a tear
The time I've shared with you
Will always be
And when I'm gone
Still carry on
Don't cry for me

No one is to blame
My death was meant to be
Don't carry guilt or shame
The reason why I came
Soon you'll see

Don't cry for me
When life is not the joy
It should be
With life comes pain
Soon time will end its course appointed
Then you will be rewarded
And all this world will see,
don't cry for me

Effective Point-of-Care Rapid Hiv Testing at Labor and Delivery

CORE Ctr, Chicago, IL and CDC, Atlanta, GA

Although all women should be screened for HIV during the antenatal period, an estimated 10%-15% of HIV-infected mothers do not access care before labor and delivery (L&D). Point-of-care rapid HIV testing in obstetric units could help L&D staff identify and offer prophylactic treatment to HIV-infected women in time to reduce perinatal HIV transmission.

Four (4) Chicago hospitals participating in the CDC multi-city Mother Infant Rapid Intervention at Delivery (MIRIAD) study implemented the rapid testing protocol. Trained obstetric staff performed rapid testing themselves on the L&D unit in 3 hospitals. In the 4th hospital, the rapid test was run in the laboratory. After determining eligibility and obtaining informed consent, blood was drawn for the Oraquick rapid HIV test and confirmatory standard testing. We also determined the median time from drawing of the participant's blood to informing her of her test results at each hospital.

Point-of-care rapid HIV testing by staff attending women in labor provides a more timely method to identify and treat women with HIV

From November 2001-July 2002, 6,262 women presented to the 4 Chicago obstetric units and 610 were eligible for rapid testing (>24 weeks pregnant and no documented HIV results available to L&D staff). Of these, 453 consented to participate and were tested with OraQuick. Three (3) previously undetected HIV-infected women were identified and started on antiretroviral prophylaxis. in the 3 hospitals where nurses, midwives, or physicians performed the rapid test at point-of-care), median turn around time was 45 minutes (range 20 mins to 3 hrs). At the hospital where the laboratory performed the rapid test, median turn around time was 3 hrs (range 90 mins to patient never informed of result.) Delays in delivering rapid test results were due to shift change in the laboratory, staff not calling for the result after the test was sent to the laboratory, patient sleeping, or patient having left the unit before test results were returned.

Point-of-Care rapid HIV testing by staff attending women in labor provides a more timely method to identify and treat women with HIV who had not been tested during their pregnancy than does conducting the rapid HIV tests in the hospital laboratory. L&D staff can be trained to perform onsite rapid testing and then offer peripartum anitretroviral prophylaxis that can further reduce perinatal HIV transmission in the U.S. ■

Mental Health at Women Alive

By, Renee Mosley & Adriana M. Pentz

Dedicated to providing free counseling services to individuals who are HIV infected and their immediate family, Women Alive's Mental Health Programs offer individuals a safe and non-judgemental environment to discuss issues that arise in their daily life. Many of our clients struggle with concerns around disclosure, initiating and maintaining relationships, isolation and decreased sense of self worth. Counseling services include individual, family, couples, and a woman's therapy group.

Based on a Needs Assessment survey conducted in the winter of 2002 by Rachel Pearson, MPH candidate, 82% of members at Women Alive feel that there second most important need to assistance in planning for a longer life, is "Emotional Support and Support Groups". In an effort to expand the accessibility of our Mental Health Services to our community in need, Women Alive is proud to announce our new hire, Mattie Davis, LCSW. Along with Renee Mosley and Elsa Garcia, Matti has dedicated her time to helping those individuals utilitizing our Mental Health services to improve their quality of life.

To enroll in services, contact Women Alive and notify a staff person of your interest in receiving counseling services. A counselor will contact you to schedule your initial session. Remember, support is available. ■

('New Vision' continued from page 2)

media bombards us with musical lyrics and videos that portray women as merely sexual objects - e.g. Sex Sells.

Dealing with this emerging assault against women and changing society's view of women rests within the power of women to create the vision of wholeness. We must come together and seize control of our lives and proclaim, "We are more than just a body. We are mind, body and spirit."

Further, we must work to improve the quality of life for HIV positive women and their families and prevent the spread of the disease; raise the visibility of women living with HIV/AIDS and make a dent in the headlines, which currently report very little on the impact of HIV/AIDS on women, and their families. n

KISS AND GEL

By, Stacie Stukin

Sara and Paul are like countless married couples in the developing world. While she raises children and looks after livestock on a farm in rural Zimbabwe, he works a subsistence-wage job in a distant town. They see each other, at best, once a month. The last time Paul came home, Sara noticed a vaginal discharge just days after he left. A local clinic confirmed her suspicion- Paul had given her a sexually transmitted infection. but when she tried to get him to wear a condom, she recieved a sever beating.

If 20 years of AIDS have taught us anything, it's that men, straight or gay, rich or poor, would sooner chuck a condom than slip it on. In sub-Saharan Afrcian countries, condom use falls as low as 7 percent. Nearly half of gay American men in their 20s report that they recently had unprotected anal sex. "I don't think it's hard to ask someone to wear a condom, but guys hate them," says Dyanne Stempel, a single white female living in Los Angeles. "They don't say anything and then they either can't perform or they get uncomfortable."

But what if Sara and Dyanne had a stealth method of protection? Something called, let's say, Coochie Cream or Booty Butter- an odorless gel, lotion, foam or suppository that could help protect them from STD's, but that would also ensure the seamless intimacy cherished in those passionate moments? "It would be a dream," Stempel says.

For 15 years, certain scientists, gravely underfunded and mostly dismissed by the AIDS research mainstream, have toiled to make this dream a reality. Now the fruit of their labor is ripening, just as the cause of women enters the vanguard of AIDS conciousness. Their inventions are called microbicides- and while the unfortunate name sounds like a fungus-eradication product, if all goes well, these woman controlled "chemical condoms" could reach the over-the-counter market in five years and become the biggest reproductive-health innovation since the birth-control pill.

> "These woman-controlled 'chemical condoms' could reach the over-the-counter market in five years and become the biggest reproductive-health innovation since the birth-control pill."

No longer the fantasy of womanist policy wonks and heated activists, microbicides have become a cause celebre, splashed onto the pages of publications like *Vogue* and *The Wall Street Journal.* Their credibility comes not only from the most promising candidates' recent clinical trial advances but also from the stepped-up efforts of billionaire philanthropists Bill and Melinda Gates, who have donated a total of $50 million to microbicide research. In February, they made their most recent contribution, $20 million to fund a Phase III trial- the final, FDA-required test of efficacy in humans- of a promising seaweed-based product called Carraguard.

The need for such a revolutionary product has become alarmingly clear: Worldwide, 17.6 million women have HIV. A single unprotected sex act is eight times more likely to infect a woman than a man. Accross Africa and Asia, women in ostensibly monogomous marriages are at great risk of contracting HIV and STD's. In Thailand, a study in with their husbands. the *Journal of Acquired Immune Deficiency Syndromes* reported, 76 HIV positive women said that their only sexual contact was with their husbands.

"The issue of women has come front and center in the AIDS epidemic," says Helene Gayle, MD, who championed women's prevention programs as a top official at the Centers for Disease Control and Prevention and now oversees the Gates Foundation's AIDS giving. "The reality is, we're still many years from having a vaccine, and that's made people realize we need to diversify research and development. We can't just focus on treatments and vaccines- we need to find intermediary technologies."

Carraguard is just one of nearly 60 microbicides in development in the United States, India, Brazil, Belgium and Britain. These products come in a wide variety of formulations. Some are contraceptive as well as antimicrobial. Others would allow for conception without nixing HIV. Because of the prevalence of anal sex, many researchers insist that microbicides must work rectally as well as vaginally. This has the added bonus of making them valuable to gay men as well as straight women. But each prototype aspires to a common goal: skin-to-skin contact, the ideal of intimacy accross all cultures.

David Phillips, PhD, a senior scientist at the Population Council, wishes that he could say he's the genius who discovered that a simple red, seaweed-based product called carrageenan prevents viral infections such as HIV. But in fact, carrageenan, a food thickener used in Campbell's soups, ice cream and baby food, has been known for its antiviral properties since the '60s. In the '80s, scientists began looking at carrageenan's potential for herpes prevention. That was when Phillips began the research that led to the formulation of Carraguard in the late

'90s. "We've shown that Carraguard is as effective against HIV in the test tube and against several sexually transmitted pathogens in animals," he says. "But there's still a lot we don't know about how HIV gets into the body. Now it's our job to prove it will work with people."

Carraguard is one of five microbicides set to enter advanced-stage clinical trials this year. With so much riding on the results of the research, scientists such as Zeda Rosenberg, the interim executive director of the International Partnership on microbicides at Family Health International, has a barrage of urgent questions to answer. Overseeing the Phase III tests of two other top contenders, PRO 2000 and BufferGel, Rosenberg is helping to design studies with upward of 8,000 women. As far as the sheer scale and ambition go, Rosenberg maintains an upbeat attitude. "Every challenge can be overcome with creative design and lots of resources," she says.

But the investigations are starting with a financial straitjacket. Carraguard, for instance, has only about $20 million in its research coffer, although conservative estimates put the cost of a trial closer to $50 million. Beyond the money, there are logistical and ethical problems. Scientists can't be in bed with participants when they actually use the gel, so they must rely on self-reporting rather than the data-gathering methods used in laboratory-controlled settings. Then there's the moral dilemma that arises when Western scientists give say, and African woman-whose chances of contracting HIV are 20 to 30 percent-a placebo gel rather than the real thing. It's true that the researchers will give all volunteers condoms and encourage the use of both latex and microbicide (or placebo gel). But even the best intentions could result in women being-or ultimately feeling-exploited when their risk of infection is frighteningly high. Rosenberg acknowledges the ethical implications but still defends the proceedings, arguing that the women will receive prevention and care at standards comparable to those in the U.S. "That means condom promotion and counseling and treatment of STDs." She says.

Rosenberg and her colleagues believe that a microbicide will have demonstrated efficacy if, over three years, there are at least 30 percent fewer infections among users than in the control group. That may sound far from ideal. But researchers at the London School of Hygiene and Topical Medicine estimate that a microbicide with 60 percent effectiveness could avert 2.5 million new HIV infections over three years worldwide. On top of the obvious human benefits, that translates into a $2.7 billion savings in health-care costs (not including HIV meds) and $1 billion in productivity for developing countries.

"This has been discussed by many experts in the field, and there is some consensus, at least for the first clinical study, that 30 percent could potentially lead to approval," says Debra Birnkrant, MD, director of the FDA's division of antiretroviral drugs, who has reviewed every microbicide that has entered trials. "This is being developed globally-not just for the U.S.-and if we could prevent 30 percent of infections in Africa, that would be tremendous." Still, she envisions the FDA recommending the products for the use with condoms. "The trials are being conducted with them, and the labels have to reflect that," she says.

Even with all the drum-rolling about the promise of the "fab five" microbicides, researchers have great cause for caution. Two years ago, four microbicide finalists had made it to Phase III trials, but all ultimately failed because they contained Nonoxynol-9. In studies, the spermicide was found to cause vaginal abrasions, making women even more susceptible to HIV.

The current crop works differently. Carraguard's carrageenan belongs to a family of compounds called sulfated polymers, which are believed to coat HIV and keep it from entering host cells. BufferGel, made of a foaming agent already used in many vaginal products, mixes with the vagina's natural acidity to create a pH level hostile to HIV. Then there are antiretroviral products like PMPA gel, which work like current AIDS therapies by blocking HIV replication. Since the '80s, hundreds of compounds have been screened in test tubes for their ability to prevent pregnancy and kill pathogens, says Henry L. Gabelnick, PhD, the director of a microbicide research consortium called CONRAD that in 2000 received $25 million from the Gates Foundation. After the devastating failure of Nonosxynol-9, he says, "people began looking for formulations that were less irritating and compounds that would bind the virus."

The finalists-mosts of which have passed the small Phase II tests for safety and initial indications of effectiveness-all offer promising approaches. The big problem now is money. The Rockefeller Foundation Microbicide Initiative, a working group of consultants, researchers and pharmaceutical analysts, estimates that total product-development costs for the first generation of microbicides will run more than $750 million (by contrast, the average drug, including HIV medications, costs $500 million to develop.) Sadly, the Initiative *

> "As a society, we talk a lot more about therapy than prevention," says Kevin Whaley, PhD, who helped develop BufferGel. "With microbicides, we're introducing a whole new category, and that's just stunning to some people."

projects only $230 million in public funding for microbicide development through the year 2005.

Once solution would be for deep-pocketed pharmaceutical giants to partner with the current loose network of academics, nonprofits and plucky, indie biotechs such as ReProtect, the Baltimore company that developed BufferGel. But prevention has never been Pharma's bread and butter. "As a society, we talk a lot more about therapy than prevention," says Kevin Whaley, PhD, who helped develop BufferGel. "With microbicides, were introducing a whole new category, and that's just stunning to some people." To make matters worse, the female condom and Today's Sponge, two products seen as business-case precursors to microbicides, were thought to enjoy strong market potential but turned out to be unmitigated flops. Annual worldwide sales of the female condom peaked at a miserable $6 million (in comparison, "male" condom sales have reached $295 million in the U.S. alone), and the sponge raked in a paltry $20 million-hardly the numbers to justify microbicides' non-insignificant development costs.

For the most part, pharmaceutical giants are watching microbicide testing from the sidelines and withholding their wallets. Janet Skidmore, a spokesperson for Merck, explains that her company's HIV prevention commitment lies, and will remain, firmly in vaccine territory. "Given our experience in the vaccine field, It's just the more effective approach for us," she says. She denies that this decision is based on economics or microbicides' early clinical stumbles. "We feel strongly that the best way to approach this pandemic is with a vaccine."

But if Merck and its brethren were in fact to consider the "return on investment" numbers compiled by the Rockefeller Foundation Microbicide Initiative, they'd likely flee in horror. While the group rates current microbicides are as "promising" and predicts that their global market size could reach $900 million by 2011, it places each candidate's statistical chances of clinical approval and market entry only at 25 percent. Even worse, projections show that any corporate backer of a first-generation microbicide is likely to incur financial losses in the tens of millions of dollars. For a microbicide to be effective in the developing world, it has to be cheap, as little as 35 cents per dose-obliterating profit margins.

Researchers and academics argue that as long as the clinical trials are publicly and philanthropically funded, a pharmaceutical company that owns or acquires a successful microbicide does stand a chance to make money. "It's not going to be a billion-dollar blockbuster," Gabelnick says. "But the market for spermicides now is only $40 to $50 million, and that hasn't kept personal-product companies from selling them." He also envisions a two-tier pricing system to balance out the cheapness of microbicides in poor countries. "People forget that a cycle of oral contraceptives sells for $30 in a pharmacy, but donor agencies probably get them for 30 cents or less," he says, adding that in many developing nations such as Brazil, India and China, there's a sizeable, growing middle class that can absorb a higher price point.

> Only 1 percent of the federal AIDS research budget--$35 million-- is currently allocated to microbicide research

That a viable, potentially lucrative microbicide market exists in developed coutries is something that UC/Berkeley epidemiologist Bethany Young Hold, PhD, is seeking to prove with a soon-to-be-published study of young American women. "Across the board, women are uncomfortable talking to their male partners about sex-whether they're rich, poor, white or black," she observes. Hold held focus groups to gauge women's interest in microbicides. Their responses were encouraging and even produced sexy packaging ideas, like a sleek gel (strawberry flavored preferred) contained in a lipstick-like case--the must-have purse item of the coming decade.

For now, all eyes are on the holy grail of FDA approval, which could take another five years. But the war chest for microbicide development remains disturbingly light, with money coming in piecemeal from the government, academic grants, private foundations and small biotech firms. According to the Washington, DC-based Global Campaign for Microbicides, an organization that raises public awareness and political and financial support, only 1 percent of the federal AIDS research budget, $35 million, is currently allocated to microbicide research.

For veteran activists such as Anna Forbes, the Global campaign's field organizer, this is a frustrating state-of-affairs. "When we treat microbicides like the ill-fated, red-haired stepchild, we're just cutting off our nose to spite our face," she says. "This could be revolutionary."

If microbidides are going to take hold, there needs to be a major public education push. According to the Kaiser Family Foundation, only 2 percent of Americans have even heard of microbicides.

A stronger show of political force will also be necessary, which is why people like policy officer Lara Stemple are working on campaigns like the California Microbicide Initiative (CaMi) in Los Angeles. CaMI and other groups have secured the sponsorship of eight senators and 38 house representatives for the Microbicide Development Act, which would appropriate money for a new microbicide program at the National Institutes of Health. Given the unpredictable AIDS climate under the Bush administration-with abstinence dominating the federal HIV education agenda and a paltry $200 million committed to the UN global AIDS fund--even Forbes concedes that the chance of passage is slim. But just introducing the act

will generate legislative awareness and serve as a starting point for creative funding strategies. "Global AIDS is a hot issue on Capital Hill," she says, "And if we can position microbicides as part of the issue, then it has a much better chance of making it."

> When a microbicide liberates women's --and gay men's-- sexuality from HIV, it could finally put the brakes on history's worst-ever public-health catastrophe.

With the profit sector playing possum until the proof comes in, what's urgently needed is funding from public and philanthropic sources. "We're looking for our Mrs. McCormick," Stemple says, invoking the wealthy widow who, with reproductive- rights activist Margeret Sanger, unsuccessfully lobbied the pharmaceutical industry to develop a safe, effective oral contraceptive. In 1951, Katherine Dexter McCormick put her International Harvester money where her mouth was, hiring the scientists to produce the research that ultimately led to the birth-control pill.

Before then, liberating women's sexuality from pregnancy might have seemed like speaking over wires, flying through the air or rocketing to the moon-once quixotic, even foolish, then suddenly, perhaps accidentally, attainable. When a microbicide liberates women's-and gay men's-sexuality from HIV, it could finally put the brakes on history's worst-ever public-health catastrophe. But in the absence of sufficient dollars and awareness, the revolution in the sheets will require what is sometimes equally hard to come by: movement in the streets. "It's clear microbicides are needed, and that they're imperative," Forbes says. "Since we're not able to attract corporate support, we have to make it happen ourselves." n

Senators Applauded for New Legislation Promoting HIV Prevention Technology for Women*

In Washington, DC, Bipartisan members of the U.S. Senate today introduced legislation to accelerate the development of HIV micorbicides, a technology aimed to put HIV prevention in the hands of millions of women around the world.

The Microbicide Development Act of 2003 was immediately hailed by international AIDS advocates, scientists, and public health organizers who endorse a comprehensive and accelerated global prevention trategy to defeat HIV/AIDS.

"Senators Jon Corzine (D-NJ), Olympia Snowe (R-ME), Gordon Smith (R-OR), and other Senate cosponsors have taken a powerful step forward to make a difference in the lives of millions of women at risk of HIV infection- from Sub-Saharan Africa to inner-city and rural communities in the United States," said Polly Harrison, Director of the Alliance for Microbicide Development.

Scientists are currently testing approximately 65 different microbicide compounds to determine whether they will help to protect against HIV and/or other infectious diseases. Six microbicides are currently being readied for U.S. Food and Drug Administration clinical trials that will assess their effectiveness in humans. It is estimated that development of a first-generation microbicide will require an investment of at least $500 million.

"Women currently comprise 50 percent of all new HIV infections globally," said Senator Jon Corzine (D-NJ), lead sponsor of the legislation. "The Federal government must move quickly to ensure that all women have the tools to protect themselves, their families, and communities from the devastation of HIV and AIDS."

Biologically, women are four times more vulnerable to HIV infection. That vulnerability is increased due to women's lack of economic and social power in many societies where they often cannot control sexual encounters or insist on protective measures such as abstinence or mutual monogamy. The typical woman who gets infected with HIV in such contexts has only one partner- her husband.

Recognizing the growing need for an HIV prevention tool that is controlled primarily by women, the *Microbicide Development Act of 2003* is intended to achieve better coordination and expanded resources for microbicide research and development activities at the U.S. National Institues of Health (NIH), Centers for Disease Control and Prevention (CDC), and U.S. Agency for International Development (USAID). A similiar measure is expected to be introduced in the House of Representatives. The legislation establishes a branch dedicated to microbicide research and development within the NIH's National Institute of Allergy and Infectious Diseases. Microbicide research at NIH is currently conducted with no single line of administrative accountability or specific funding coordination. In addition, the bill requires coordination between other Federal agencies supporting microbicide development, including CDC and USAID.

With 15,000 new HIV infections occurring globally each day, new prevention tools are urgently needed. According to a report from the Rockefeller Foundation, a microbicide could avert 2.5 million new HIV infections over three years using the most conservative estimates.

Lori Heise, director of the Global campaign for Microbicides stated, "Congress and the Administration must include microbicide development and research as an essential part of its omnibus global HIV/AIDS policy." n

(*This Press Release was recieved on April 10th, 2003)

Dear Debbie

Awareness Information Decisions Solutions

By, Debi Johnson

Here at Women Alive we understand that communication is important! And that you as an HIV-infected woman are important! And foremost, that your questions deserve an answer and not just any answer, but the one that you can understand and one in which you are satisfied. We are piloting a new concept in the HIV arena. A column that will provide you with a safe, confidential forum to ask questions that you feel are important and answers that you can understand.

The health-care provider-patient relationship is an important relationship for individuals infected with HIV. It is a place where communication should be open, non-threatening and respectful. Your appointment time should provide a supportive environment to ask questions, get answers and make decisions about your disease and its management. However, many times patients feel intimidated, fearful, judged and powerless, and leave their appointments unsatisfied with unanswered questions. Many healthcare providers, when faced with a patient's difficult diagnosis, such as HIV infection, close down their communications (not telling you everything about your disease or treatment choices or making decisions for you); thus closing off opportunities for shared decision-making. Appropriate professional attitudes and behaviors have come under increasing scrutiny in the United States, and current medical schools are revising their curricula to include encouragement in developing desireable attitudes.

Current literature supports that effective communication does have an impact on outcomes. Which means if you don't understand, for example, the omportance of taking your medications, you may miss a few doses and then your viarl load creeps up and pretty soon your medicine doesn't work anymore (this is a negative outcome). but perhaps if you felt comfortable asking the question, "what happens if I don't take my medication correctly?" and recieved an answer that you felt good about, you might never miss a dose and your viral load would stay undetectable (this is a positive outcome). So, through advocacy (asking the question) and education (understanding the answer) comes empowerment (becoming an active participant in your health care); and through empowerment you begin to take an active part in your medical plan. Sometimes that active part includes not doing what your medical professional thinks is best because you know it is not what is necessarily best for you. But, hey! You have made the decision that is right for you and understand what may or may not happen (the outcome).

Here at Women Alive, we understand the difficulty of getting your questions answered, of problem solving and what it takes to learn to be an advocate. We hope that the development of this column will serve as a starting place in feeling that someone is listening and will ehlp you to find the answers that you need to become empowered. Every questions is important and we will try to select the questions that appear to be the most important and beneficial for everyone. If we cannot answer your question in our column, we will try to send you referrals that may point you in the right direction or you can always talk to our Treatment Advocates or our Peer-to-Peer Counselors. n

> We hope that the development of this column will serve as a starting place in feeling that someone is listening and will help you to find the answers that you need to become empowered.

> Through advocacy (asking the question) and education (understanding the answer) comes empowerment (becoming an active participant in your health care)

(If you have a question or concern that you would like to share with Debbie, separate the following page, fill it out, and send it in to:

Dear Debbie
Women Alive Coalition
1566 S. Burnside Ave.
Los Angeles, CA 90019

Or check out Dear Debbie online at www.women-alive.org. Questions and concerns will be accepted electronically at DearDebbie@women-alive.org. Also, feel free to stop by the agency where you can put your questions in the drop box located in the common room area of Women Alive. We look forward to hearing from you, and remember, every question is important!)

*

Dear Debbie
Women Alive Coalition
1566 S. Burnside Ave.
Los Angeles, CA 90019

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 recieves 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 has many others.

Name:______________________________ CD4 count:______________________________

Address:______________________________ HIV RNA:______________________________

Age:______________________________ Medications:______________________________

You are important! Your questions desserve an answer! Through education, empowerment grows!

MEMBERSHIP INVITATION

Women Alive offers full membership to Women Living With HIV/AIDS and Honorary membership to those affected by AIDS. Women infected/affected by HIV are encouraged to join our team of volunteers.

- o Write articles in Spanish.
- o Typing and office needs.
- o Distribute/mail newsletters.
- o Join the editorial team.

Print your name_______________________

Address_______________________

City_____________ State__________ Zip ________

Signature_______________________

- o Please contact me at the numbers below
- o I have HIV/AIDS & want to become a member of Women Alive
- o I have a loved one with HIV/AIDS and want to be an honorary member of Women Alive.

Home Phone_______________________

Work Phone_______________________

I would like to help with: _______________________

____

7-02

I WANT TO BE AN ACTIVIST!

PLEASE ADD MY NAME TO THE AIDS ACTIVIST MAILING LIST.

I AM WILLING AND ABLE TO:

- ☐ Collect signatures on petitions
- ☐ Write letters
- ☐ Sign letters that are written
- ☐ Get arrested
- ☐ Participate in local demonstrations
- ☐ Do phone zaps
- ☐ Attend leadership trainings
- ☐ Do civil disobedience

Print your name ☐

Address ☐

City ☐

State/Zip Code ☐ ☐

Telephone number ☐

Comments? ☐

detach and mail today!

WOMEN ALIVE • KEEP YOUR NEWSLETTER COMING!

We are happy to provide Women Alive free of charge to people who cannot afford to make a donation; however we ask that anyone who can afford to donate, please do so • Donations in any amount are welcome & appreciated.

- o Enclosed is $15 for a one year. o Enclosed is $75 for a bulk order. Please send ____# of copies.
- o I am a Woman Living With AIDS/HIV: & o cannot afford to pay o can make a donation of $______.
- o Enclosed is an additional donation in the amount of $____ to help Women Alive (*Because, I know WA has no money*).
- o Please send back issues of Women Alive. o I live locally please put me on the EVENTS list o Send *Ecos Femeninos*

Name_______________________ Phone number (_____)_____-________

Address_______________________[_______________________

City _______________ State__________ Zip __________ *Signature*_______________________

Women Alive is a quarterly publication by and for women living with HIV/AIDS. The newsletter is mailed in an unmarked envelope. Names of supporters are strictly confidential. 7-02

1566 So. Burnside Ave. • Los Angeles • Ca • 90019 • OR • http://www.women-alive.org