

WORLD*

*Women Organized to Respond to Life-threatening Diseases

Number 12

A Northern California newsletter by, for and about women facing HIV disease

April 1992

- ▼ The next WORLD potluck for positive women will be Saturday, April 25, 11am-2pm. Mark your calendar now! (See p. 3.)
- ▼ We still have some spaces available for the WORLD retreat (June 5-7, 1992 in Nevada City, CA). For a registration packet, please call Gloria (510/832-5052).
- ▼ Are you interested in contributing to the Survival Guide for newly diagnosed women? If so, please call Barbara, 415/476-3644.
- ▼ The Women and Cancer Walk is coming up on May 9. It would be great to see AIDS activists & cancer activists working together. To get a pledge form or more info, call 415/985-7108.
- ▼ Judy Cagle, the first of many HIV+ women to write to us from Walker A women's prison, has been very ill. As we go to press, we have just heard that Judy is being released to be reunited with her family. Welcome home and best wishes to you, Judy!

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Fighting two diseases

by Chelsie

My name is Chelsie. I am a recovering addict.

During my years on the streets, AIDS was never an issue for me. I did what I needed to do in order to get what I needed to get. I never thought about AIDS one way or the other.

I was 28 when I cleaned up. That was four years ago. When I cleaned up, I got educated, and I got tested. I was negative. After that I never really thought about AIDS again until I was going to have surgery. I had to donate my own blood so I was tested. Again, I was negative.

During the time I stayed clean my life began to change. I started to acquire things—not just material things, but also self-respect, self-esteem, dignity, and a higher power in my life. I entered into a new relationship, started a new business, and bought a new car. Life was good to me.

Then one weekend I got the flu, and by Monday I was feeling more than a little sick. I went to the doctor and she thought it was hepatitis. But the test came out negative.

I started feeling better, so she figured it was just a virus. But after my

doctor questioned me some more about my high risk background, we decided to test for HIV again.

Going to Kaiser was a lot different than the clinic. The educator was a great guy who cared about me. He was concerned and knowledgeable. He asked a lot of questions about my lifestyle and my drug use. He really spent time getting to know me.

Well, I was so sure I had a negative test that I never went back for my results. So when he called me to come in, I guess I knew the test had come out positive. Still, I refused to believe it. (To this day we do not know why it took so long for me to test positive, because I had been having warning signs—yeast infections, shingles, etc.—for years.)

Thank God this man took the time to get to know me. The only thing I remember him saying was, "This is not an excuse to get loaded. And this is not a death sentence."

For a recovering addict, those words were the most important things I needed to hear, because the disease of my addiction could kill me faster than AIDS. As long as I stay clean and sober, I feel like I will be OK.

It has taken me a good year to adjust to the shock, and in that time I have been through many changes. The man I was seeing tested negative. He was unable to handle my status and he left. I have never felt so hurt and angry, but I found the strength to get through.

I confided in the wrong person, and pretty soon the whole Fellowship (Narcotics Anonymous) knew I was positive. But I guess that was God working in my life, because I've found comfort in being able to talk openly about my HIV status at meetings.

My T-cells have gone from 880 to under 300 in a year, and at the first of this year I got PCP (pneumocystis pneumonia) and received an AIDS diagnosis. Still, I have been able to get through.

Now am 32 years old and in spite of all the fear and devastation this diagnosis has brought, I have managed to

...I remember him saying, "This is not an excuse to get loaded..."

Fighting Two Diseases... (continued)

experience many wonderful things. It seems that all the "I should have"s, "I could have"s and "if only"s have been done or have gone away. I have been truly blessed with friendships I would never have known if I was "negative." I live a day at a time not only in recovery but in dealing with my pain, joy, laughter, sorrow and anger. AIDS keeps me focused on today and gives me a gift that so many people will know nothing about.

I have learned the real meaning of friendship, and how to let go of the past. Even though the man I was with has packed up and gone, I still find that men find me sexy and fun in spite of my status. I have learned to have compassion and have met the most extraordinary and courageous people who I would not have given a second look if not for AIDS. Above all, I have found strength in a "God" of my understanding, and more love for myself.

My family has been strengthened

and brought together by this disease. By coming to terms with my own life, I have found more patience and love for my child. As I watch with fascination as he grows into a young man, I am better able to understand his feelings and his shortcomings. Our relationship has grown into something I treasure with all my heart.

I have received the most precious gift of all: the unconditional love of a mother for her daughter. Every day I see a woman whose courage far outweighs mine, a woman who shares her hope and her faith and gives me tremendous strength. I have found in my mother a woman who—no matter what—has loved me and stood by me. Only AIDS has been able to give me the ability to look at this woman and realize how fortunate I am to have her for my mother and my friend.

My dog, Carrie Anne, was another gift sent to accompany me on my journey by a loving sister who sup-

ported me through a rough time, even though she didn't know I was positive. My illness pushed us to let go of our differences and become the Sisters We Never Were Before.

AIDS is something I would gladly give back in a heartbeat (especially when my lymphnodes are bulging and it's hard to walk). I know that along the way there will be days of depression and anger, moments of craziness and panic, bouts of nausea and dizziness, the AZT blues along with the sinus drips. This is just the way it will be.

But, AIDS has provided me a quick way of cutting through life's bullshit. (God has some sense of humor.) I have been able to turn a negative outlook into a positive one, and I have learned to use my energy wisely and productively. AIDS may take my body, but I refuse to give it my spirit. Life has not ended for me because of AIDS. No, no. Now I have even more reason to live it.



Pediatric Update By Vince Maloney

A Community Advisory Board (CAB) has been formed at Moffitt Hospital in San Francisco to focus on pediatric AIDS research. The board was organized by Dr. Diane Wara, chair of the Pediatric Core Committee of the AIDS Clinical Trials Group (ACTG). Areas where more pediatric research is needed include: **Perinatal transmission** to determine why some HIV+ women transmit to the fetus (30-50%), and some don't. About one-third of children perinatally-infected progress more rapidly than the others.

Oncology: At the December 1991 meeting of the ACTG, a pediatric researcher projected an increase in pediatric lymphomas of 350-1100 cases in the next five years.

Neurological disease: affects at least 60% of HIV-infected children.

Bacterial infections: more common in children than in adults (and can be life-threatening). Measles can be fatal.

Opportunistic infections of particular concern in pediatrics are MAI and TB. By contrast, CMV and KS, fairly common in adults, are rare in children.

Adolescents are included in ACTG trials as an "overlap" population, at the high end of the age spectrum in pediatric trials, or the low end of adult trials. According to an article on HIV/AIDS in adolescents with clotting disorders (*Pediatric Infectious Disease Journal*, April 1991), adolescents with AIDS progress more slowly than adults.

Socio-economic issues are more significant in pediatrics than adult AIDS, because more children with HIV are poor and do not have private physicians to advocate for them.

Pain management: Children with HIV suffer from "acute and chronic pain." But, according to Dr. Samuel Grubman (Summer 1991 *AmFAR Guide to Clinical Trials*), when children come from families with a history of substance abuse, clinicians are often afraid to prescribe narcotic pain medication.

Interested in joining the Pediatric Community Advisory Board?

Please call Vince Maloney at 415/922-5486 or Diane Wara at 415/476-2865.

Sunburst Camp for Positive Kids

Sunburst National AIDS Project provides a multi-disciplinary, therapeutic summer camp program in California for HIV/AIDS children and their families. Summer camp dates this year are July 3, 1992-July 10, 1992. Application packets can be obtained by calling 707/769-0169. All application information is confidential. Application deadline is June 3, 1992. Expenses are paid by Sunburst.

Party Reportback

The infected & affected straight folks' party (April 14) was a lot of fun. About 30 of us got together for food & conversation in a safe, comfortable environment. We hope to have another party in May. Everybody welcome. —Rachel R.

Special Events

- 1 ...CDC Demonstration:** The CDC's new definition of AIDS still does not include gynecological diseases that are common and often fatal to women with HIV, like cervical cancer and PID. Demonstrate at noon, U.N. Plaza (7th & Market) in San Francisco. Sponsored by ACTUP San Francisco & WHAM. For more info call 415/563-0724.
- 2 ...Wildflower Trip to Point Reyes for People with HIV:** Lighthouse, whale & seal watching, hike & tour of wildflowers. \$7 (schol. avail.), For info about this & other Shanti events, call 415/777-2273.
- 9 ...Los Angeles: Public Forum on Women & HIV:** 7-9pm, Midway Hospital, Pavilions Room, Los Angeles, CA 213/930-8820.
- 18..Alternative Approaches to the Treatment of AIDS Forum:** 1-4pm. Speakers will include an HIV+ woman who uses alternative treatments, an herbalist, a massage therapist, representatives from Healing Alternatives and the Community Consortium, and more. Sponsored by ACTUP/San Francisco Treatment Committee, WAN, and PHREDA. For info call 415/563-0724.
- 21 ..People of Color & HIV:** A Living with HIV Forum, AIDS Health Project, 1855 Folsom (@15th), San Francisco. 7-9pm, free. For info, call Carmen: 415/476-3902.
- 25 ..San Luis Obispo:** Conference on Women and HIV at California Polytechnic University. Spons. by San Luis Obispo County AIDS Support Network, 805/541-5752.

Monthly Events

- 1 ...Project Inform, AIDS 101,** 7:30PM, 150 Eureka, San Francisco, between 18th & 19th streets.
- 6 ...Dr. Conant's monthly patient meeting,** 6-7PM UCSF, Health Services West, room 301, San Francisco, (415) 923-1333.
- 7 ...Women's AIDS Network,** 9:30-11:30AM, at the CPC, 3180-18th St., 3rd floor, SF. 415/ 864-4376 x2007. Your participation in this meeting is important! WAN will be discussing the future and goals of the organization. Input from HIV+ women is crucial.
- 14..HIV+ Women's Support Group,** Oakland Kaiser, 510/596-6337.
- 15..WORLD submissions due.**
- 21..East Bay Women's AIDS Network,** 433 Jefferson, Oakland, 510/268-2559, 11:30AM.
- 25..WORLD Potluck & Planning Meeting for Positive Women:** Saturday 11am-2pm, Meet other

women living with HIV/AIDS, and help plan the future of WORLD. First-timers welcome! Women's Bldg, 3543-18th St., SF. HIV+ women only—Call 510/658-6930 for info. Confidential.

- 29..Project Inform Town Meeting,** 7:30PM, 150 Eureka, San Francisco, between 18th & 19th streets.

Weekly Events

Monday

- ▼ **Monday Night Live,** Aris Project, 7:30, 408/370-3272, San Jose, CA
- ▼ **AIDS in Focus,** 12:00, 91.7FM, KALW

Tuesday

- ▼ **ACTUP-GG,** 7:00PM, 539 Hayes St, SF

Wednesday

- ▼ **AIDS WEEK,** SF Examiner

Thursday

- ▼ **AIDS in Focus,** 7:15 AM, KPFA 94.1 FM
- ▼ **ACTUP-SF,** 7:30PM, Women's Bldg, SF

Mothers' Voices: a campaign to end AIDS

Join thousands of mothers, friends and family members by sending a Mother's Day card to President Bush and/or your congressional representative by May 4.

The Mothers' Voices Campaign's pre-printed cards say:

On this Mother's Day help us fight for what we care most about in our lives, the health and well being of our children. Demonstrate your leadership in this crisis by placing AIDS at the top of our country's domestic agenda. Please work to provide increased funding for research, effective education, and quality health care. It's time to find a cure!

You may obtain free cards (25 mini-mum) from Mothers' Voices, 245-8th Ave., #148, New York, NY 10011, Tel: 212/366-9217. Or send your own card (w/ copies to Mothers' Voices if possible).

Send cards to any (or all!) of the following:

President George Bush
The White House
1600 Pennsylvania Ave.
Washington, DC 20500

Hon. Representative _____*
U.S. House of Representatives
Washington, DC 20515

Hon. Senator _____*
U.S. Senate
Washington, DC 20510

*If you do not know who your representative or senator is, your local Women's League of Voters can tell you.

**It's important
that our voices be heard!**

**You
Are
Not
Alone!**

In the articles that follow, the words in bold appear in the glossary below

The ACTG 175 debate

Last month WORLD reported on a controversial new national drug trial (ACTG 175), a **randomized, double-blind** study with four treatment arms: a) AZT b) ddI c) AZT/ddC d) AZT/ddI. Participants must have T-4 cell counts between 200 and 500 and have had no AIDS diagnosis. Below, we present two arguments, one for and one against ACTG 175.

ACTG 175—Why?

by Linda Johnson and Donald Abrams, San Francisco General Hospital

ACTG 175 compares the effectiveness of single agent therapy vs. **combination therapy** in early HIV infection. To date, no compelling evidence exists to suggest which approach is preferable, nor when and how the treatment regimen should be instituted. Relevant studies which have been or are being conducted are either population specific (i.e. AIDS diagnosis) or still in progress.

A person participates in a clinical research study for a variety of reasons—not the least of which is to receive a therapy which may be helpful in the condition he/she is experiencing. Advantages include free or low cost access to a therapy which may or may not be available outside of a clinical trial setting, and laboratory information and follow-through in a health care delivery system. Participation in a clinical research study provides information will benefit a large number of people.

Most anti-viral studies no longer involve a **placebo** although many remain **randomized, blinded** studies. If a person prefers to know what medication(s) he/she is taking, a **blinded** study may not be the best choice. Unlike several other **antiviral** studies, ACTG 175 considers T-4 cell count decreases in addition to AIDS-defining events as endpoints for potential cross-over to other treatment arms. Anyone crossing-over will receive a **combination** regimen (i.e. AZT/ddC or AZT/ddI).

Nationally, ACTG 175 hopes to enroll 2500 participants, with the study being reflective of all persons experiencing HIV.

For more information about ACTG 175 at SF General, call Linda Johnson, RN at SFGH, 415/476-9296, ext. 84099.

ACTG 175—Why Not?

by Jesse C. Dobson, AIDS Treatment Activist

There has been a great deal of controversy surrounding the politics of this trial, but, as with any trial, there are several things you as a participant may want to consider before participating.

The main problem is that while this trial is designed to determine whether **combination therapy** is better than **monotherapy**, most scientists seem to think that combinations are better. This leaves you with a fifty-fifty chance of ending up on monotherapy, and you would be stuck on it for a long time (the trial lasts three years). If ddC is approved soon, as is hoped, you may have access to either a combination of AZT/ddI or AZT/ddC *now* instead of having to wait, which *may* have an impact on how quickly the disease progresses.

Even if you end up in a combination therapy arm of ACTG 175, participation in the trial, while paid for, is more of a hassle than taking the therapy outside of the trial. Frequent trips to get medication and to give blood samples would be required. This trial may have to be significantly changed or stopped if one of the ongoing trials show that one therapy is better than the other. This means all your effort may go to waste.

Another problem is that the politics of ACTG 175 are questionable. An enormous amount of resources is going to answer a question that could be already answered, draining resources from trials of possibly better drugs.

Glossary of Terms:

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Antiretroviral: a substance that stops or suppresses the activity of a retrovirus (i.e. AZT, ddI, ddC). HIV is a retrovirus.

Antiviral: a substance that stops or suppresses the activity of a virus (i.e. acyclovir, gancyclovir, foscarnet).

Blinding: process of preventing patients and/or their doctors from knowing whether the patient is taking active drug or placebo.

Combination therapy: Use of two or more types of treatments in combination (i.e. antiviral therapy with an immunomodulator).

Compassionate use: an FDA program that makes specific experimental drugs available to seriously ill people when no other treatment exists or when the patient cannot tolerate other treatments.

Double-blind: trial procedure in which neither experimental subjects nor doctors know which subjects are receiving the test drug and which are receiving a placebo or other therapy.

Expanded access ("parallel track"): a procedure established by the FDA which permits the use of investigational drugs by individual physicians. The purpose of this program is to make the

drug available to patients who need it, while collecting at least some limited data on efficacy and toxicity.

Open label ("non-masked" or "non-randomized") trial: a drug trial in which both doctors and subjects know what drug and dose a subject is taking.

Phase I clinical trials: toxicity and dose-finding clinical studies which evaluate the drug's actions in the body and its safe dosage range. Usually completed within a year, and involving a small number of research subjects.

Phase II clinical trials: efficacy studies which often include several hundred human volunteers. Designed to assess the drug's effectiveness precisely and to detect major adverse reactions (side effects).

Phase III clinical trials: involve up to several thousand human subjects to confirm earlier findings of effectiveness and to detect side effects that occur only rarely or after a long period of treatment. Phase III trials may last several years.

Think it over!

Every person asked to be in a research study has these rights:

- To be told what the study is trying to find out, what the possible benefits and risks are, and what alternatives are available.
- To ask any questions before and during the study, and to be free of pressure when considering whether to join or remain in a study.
- To receive a copy of the signed and dated consent form.

Questions to ask yourself:

Is helping to find better treatments for HIV important to me?

Can I accept the changes a trial may make in my daily life?

Am I committed enough to:

- take the drug as often as I should?
- go to the clinic as needed?
- stick with a trial as long as it lasts?

Am I willing to follow all of a trial's policies?

Are the pro's of taking part greater than the con's?

Will I have the support of my family and friends?

Questions to ask the doctor:

Facts about the study:

What is the purpose of the study?
Who is running the study?
Who is paying for the study?
What treatment(s) may I receive?
Does the study use a **placebo**?
Why do doctors believe that this treatment may work?

Risks and benefits:

Is this a **Phase I, II or III** trial?
How may I be helped by the treatment?
What are the risks? Does the treatment have any known **side effects**? What will happen if I experience side effects? What will happen if I get sicker?
What are my other options?

What treatment will involve:

How long will the trial last?
How often will I need to come to the clinic? How much time will I have to spend at each visit?
How many times a day will I need to take a drug?
What other things will I need to do?
How is the drug given—as a pill, in a shot, or in another way?
What dosage of the drug will I get?
What kinds of tests and measurements will be done?
Will I be able to see all my test results?
Who will treat me in the study? Will I see

the same doctor or nurse each time?
Can I keep seeing my private doctor, if I have one?
Will a social worker (or other trained staff) provide support and help me deal with problems?
What type of long-term follow up does the study have? If the drug helps me, can I keep taking it after the study is over?
Is there a built-in reasonable end point where I will be offered the treatment (if on **placebo**) or the other alternative (if on the treatment)?
What other medications may I use while participating in this trial?

If you are or may become pregnant while on the trial:

Can I participate if I am pregnant?
What will happen if I become pregnant while participating in the trial?
What information (if any) is known about the effect of the drug on pregnant women or on the fetus?
What information (if any) is known about the effect of this drug on **vertical transmission** of the virus?

Costs:

What costs will be covered by the trial?
What other costs can I expect?
What other help with costs is available?

Placebo: an inactive substance ("sugar pill") against which test drugs (or "real" drugs) are compared. In placebo-controlled trials the control group takes a placebo, while the test group takes an experimental drug. Many such studies are double-blinded so that neither the patients nor their doctors know which substance the patients are receiving.

Prophylaxis: treatment to prevent people from getting a disease.

Protocol: detailed plan which states a clinical trial's rationale, goal, the drugs involved, dosage levels, methods of administration and treatment, as well as who may participate.

Randomized trial: trial which assigns participants by chance to receive one of the treatments being studied.

Side effects: an unintended effect of a drug. Side effects which are unwanted, harmful or poisonous are called "adverse reactions."

Toxicity: the degree to which a medicine is poisonous. Clinical trials determine how much of a drug can be taken safely without having a toxic effect.

Resources

AIDS Clinical Trials Information Service (1-800-Trials-A): Provides current information (English & Spanish) on federally and privately sponsored clinical trials for people with HIV/AIDS. Mon-Fri, 9am-7pm Eastern time.

CDC National AIDS Information Clearinghouse: Offers a wide variety of HIV/AIDS information, resources and publications, incl. "*AIDS Clinical Trials: Talking it Over*" a booklet to help people understand clinical trials. 1-800/458-5231.

AIDS Treatment Directory: \$44/year. Write to: AMFAR, 6020 N. Lindbergh Blvd., St. Louis, MO 63042.

Bay Area Directory of HIV Clinical Trials: Updated 3 times/year, this directory has been re-written to be more readable. Avail. free from the Community Consortium, 415/476-9554.

Trials Search: Provides HIV+ individuals with a personalized computer printout of all ongoing Bay Area drug trials for which they are eligible. Fee is \$0-7 sliding scale. For more info. call Jay Seward, Davies Medical Ctr, 415/565-6368. ♦

Statewide Budget Crisis:

What's the Problem?

The California legislature is in the process of putting together a budget for 1992-93. Governor Wilson wants to maintain funding for AIDS services at last year's level. The AIDS epidemic is growing and there will be more new AIDS cases this year than any previous year. Furthermore, the change in the AIDS definition will double or triple the current AIDS case load. Thus, maintaining current levels of funding will actually result in a *decrease* in service dollars per-person in the state of California at a time when the need for services is rising dramatically.

The San Francisco Health Commission recently approved a city health budget cutting hundreds of thousands of dollars from AIDS programs. Dementia care services that were scheduled to begin this year will not start and substance abuse training for health care workers at San Francisco General Hospital's AIDS clinics is being discontinued. Although the local Office of AIDS will be seeking Federal funding for some of these services, there is no guarantee they will ever get it.

Recent federal cuts completely eliminated funds for Home Health Care services, which allow persons living with AIDS to receive in-home care versus lengthy hospital stays. Federal funds to the State of California which were intended for other AIDS programs were subsequently transferred to refinance Home Health Care programs.

On a federal level, Ryan White C.A.R.E. money was supposed to provide *new* money for direct AIDS services and treatment. Instead, state AIDS programs that were already in existence had their funding cut and were told to fund those programs with C.A.R.E. dollars. Federal funding for the State's AIDS Drug Program was cut by \$600,000 and Home Health Care suffered an \$800,000 cut. In other words, what was supposed to be *new* money turned out to be an umbrella of *old* money, and rather than an *increase*, we have seen a *decrease* in Federal AIDS

dollars. Furthermore, the federal government has never fully appropriated C.A.R.E. money and the National Institutes of Health (NIH) cannot get the money it needs to adequately fund AIDS research for new drugs.

The situation looks bad and it's getting worse every day. It is extremely important that Local, State and Federal officials never stop hearing about the need for increased AIDS funding and services. If that means calling them every day, **CALL THEM EVERY DAY!!** Local Supervisors, State Senators and Assembly persons, Federal Representatives and Congresspersons need to hear from people with AIDS and their advocates constantly!

AIDS funding for research, prevention and care is the most important issue to deal with right now. Without dollars for research, federally sponsored AIDS research into new and better AIDS drugs will be stalled. Without dollars for prevention and education efforts, the infection rate will continue to rise. Without dollars for care, persons who cannot afford to pay for health care and treatments will lack access to the services they need.

What are activists doing??

In January, ACT UP/Golden Gate put together a State AIDS Budget Augmentation Proposal. This is a proposal to add an additional 15.1 million dollars to the state AIDS budget to increase treatment, early intervention, home health care and prevention education efforts in the State of California. The money to augment the AIDS budget would potentially come from the Department of Tourism's proposed 85 million dollar off-highway vehicle park and from money saved by streamlining the Medi-Cal processing procedure.

How can you help??

CALL your local Senator and Assembly person and tell them to support an increase in the AIDS budget, with an emphasis on the need for services and treatment. Let your local representa-

tives know that if they don't oppose AFDC and social program cuts, and if they don't support increased AIDS spending, they will not get your vote! Call your friends and family members and have them do the same. Remember, there's a general election this year!

ORGANIZE a group of people to pay your local officials a visit to speak in person with them about the need for increased AIDS spending. (Do this before April 9th with your Senator!)

WRITE your Senators, Assembly persons and the Governor and tell them to increase AIDS spending and to oppose cuts in health and social service funding!! Did you know?... Every handwritten letter a public official receives is counted as the voice of 1,000 concerned citizens??

What else can you do?

Alameda County will soon be receiving a large sum of Federal dollars (Title I C.A.R.E.) because the county has recently been declared a "disaster" city for AIDS. Unless people with AIDS and their advocates are a part of the process which determines how those funds are spent, there is no guarantee they will be spent in a way that best serves the needs of the women with HIV/AIDS in the community.

The Title I planning committee will be meeting on April 7th and 8th, from noon to 2pm, at 160 Franklin St., 3rd floor in Oakland. Show up and **GIVE YOUR INPUT!** (There will be a public comment period.)

Currently there is no ACT UP in the East Bay and there is very little community input into the funding process. **It is critical that people get involved now, in whatever way they can, to make sure that AIDS is a priority to every politician!!**

*If that means calling
them every day,
Call Them Every Day!!*

We welcome your input!
Letters and submissions to
WORLD are due by the 15th
of every month. We do not
print names unless
authorized to do so.

Dear WORLD:

I cannot express how helpful and comforting your newsletter is to me. I have been HIV+ (infected through heterosexual sex) for approximately a year and a half. I was diagnosed last April 1991, so this is all fairly new for me. I really gain a lot of strength from your newsletter and the women I read about.

I share your newsletter with so many other women like myself. I am interested in getting the October 1991 issue since it dealt with sex and relationships; an area I feel I've lost forever. I would really like to know more about how single women such as myself cope. Thank you for everything! God bless you all.

—Member, PWA Coalition support group "Sister-to-Sister," New York

Dear WORLD:

I am a Black HIV-positive lesbian in a correctional institute for women. Recently a friend with whom I've been corresponding (pen pals) for the past 3 years, an "out" Jewish lesbian living with Environmental Illness sent me an article about lesbians living with HIV and about WORLD. If anyone would be interested in pen pal correspondence, I would love to hear from you. I am always interested in networking with other HIV+ women. Thank you.

—North Carolina

Dear WORLD:

In April of 1991 I was diagnosed with AIDS. I am 69 years old, a widow and heterosexual. It is believed I contracted the virus from my husband who during his illness (leukemia) received many blood transfusions. It is wonderful what you are doing. It is so difficult to find groups or news on women with AIDS.

—Santa Ana, CA

Dear WORLD:

I was pleased to read your article on PID, but I wanted to add some information on prevention and treatment. The vast majority of cases of PID are caused by sexually transmitted diseases, primarily gonorrhea and chlamydia. Prevention, therefore, means **safe sex** in non-monogamous relationships, the same safe sex that protects you and your partner from exchanging HIV and syphilis.

PID occurs when gonorrhea and/or chlamydia travel up into the womb and tubes and ovaries. The article described severe abdominal pain, but the infection is often painless. However, it can be detected by pelvic exam because clinicians routinely test for both organisms in women who are sexually active, whether they complain of pain or not.

Both infections are curable with antibiotics and do not usually require hospitalization. It is **very** important to complete the medication and to return to your clinician for follow-up exams to ensure that the infection is gone. The sooner detection and treatment occur, the less likely PID is to occur.

—Jennifer Burroughs, NP

Dear WORLD:

I am taking care of a brother who is a young man dealing with AIDS. It has been a hard four years but I have grown...My sister is also HIV+, but we rarely communicate. Maybe through your newsletter we might begin...

I know that sensitivity and empathy can help, but I believe networking, be it with HIV+ people or others, is most important. Thank you for having the courage and love to start this network.

—San Francisco

Dear San Francisco:

You may be interested in Kairos House (114 Douglass, San Francisco, CA 94114, Tel: 415/861-0877), a support center for caregivers (family, friends, lovers, healthcare providers, etc.) of people with AIDS. They have support groups and a caregivers' resource book, "Together We Care."

Dear WORLD:

First of all I would like to introduce myself to whoever is reading my "letra." My name is "Lupe." I have read your WORLD newsletter every time.

I'm doing time in C.I.W. for narcotics. I live in Walker A with all the girls that are HIV+. This is my first time in prison. I was sentenced to three years and I have eight more months to do.

When I got here I volunteered to have an AIDS test and it came back "positive." After you cry, you learn to accept it and then you learn to live with it. Yes, I was scared and angry at first but after that I learned to be strong and have faith in God. Our lives are in his hands, so I leave it up to him.

I know that I have to educate myself about this virus if I want to be a survivor. And as for me, I do want to survive as long as I can. I'm a realistic person. I wouldn't want to hide in the darkness just because I have this virus.

We have to be responsible for our own acts and be prepared for the consequences. When I was using drugs I really didn't stop and think it could happen to me. But it did. Now that I'm sober and clean it's not too late for me to start a life without drugs.

I have two boys. One is 14 years old and the youngest is 9 years old. In order for me to be with them and get a chance to see these two beautiful and healthy kids grow up, I have to be willing to live clean and sober. That's why I'm ready to be a fighter in order to be a survivor.

I love my kids very much. They don't know about my virus. I know there is going to be a day when I have to tell them about it, but right now it's not the right time. For now, I thank the Lord for waking me up every morning. Remember: Be a fighter so you can become a survivor. God Bless You.

—Love your new friend, Lupe
P.S. I'm 29 and Mexican all the way!

Would you like to correspond with someone who has printed a letter or article in WORLD? We do not give out anyone's address without prior consent. However, we would be happy to forward your letters on.

New Support Groups

April 1992

Group	Time	Place	Contact	Intake?	Childcare	Fee
HIV+ Young Women (new gp) co-spons: Bay+ & WIMH	Thursdays 5-7pm	333 Valencia Street #222 San Francisco, CA	Julie, 415/386-4615 Carmen, 864-2364	call 1st	Yes	Free
Heterosexual women & men with HIV or AIDS	Tuesdays 7pm	Mission Distr. (call for address) San Francisco, CA	David Silven/AHP 415/476-3902	Yes call 1st	No	\$0-40 sliding
Women Embracing Life (W.E.L.) HIV+ asympt, 6 wk closed	Mondays 7-8:30pm	Women's Bldg, 3543 18th St. San Francisco, CA	Michele Carstens 415/647-5866	Yes call 1st	may be arranged	\$0-5 sliding
HIV+ people (men & women) (+ and their family & friends)	Mondays 7-8:30pm	680 W. Tennyson Rd., Rm 12 Project Eden, Hayward, CA	Sherrol Gray 510/887-0566	drop- in	No	Free
HIV+ people (men & women)	Thursdays 7-8:30pm	680 W. Tennyson Rd., Rm 13-D Project Eden, Hayward, CA	Ken Athey 510/887-0566	drop- in	No	Free
Theater Classes for People with AIDS/ARC/HIV & Loved Ones	Wednesdays 1:30-3:30pm	Rest Stop Support Center 134 Church St., San Francisco	Jamie, Erik, or Paul 415/621-1701	call 1st		

The classified ads:

- ▼ **HIV+ Oakland woman in desperate need of filing cabinet.** Please contact Sharen c/o WORLD (510/658-6930) if you can help.
- ▼ **HIV+ asymptomatic WM looking for HIV+ WF.** I'm 34 years old. I've been alone for a long time and am ready to have an ongoing friendship. My hobbies are birds, bonsai, art and classical music. Respond to: Eric, P.O. Box 4491, Salinas, CA 93912.
- ▼ **HIV+ SWM, Healthy 50, seeks HIV+ or HIV- woman** with adventurous spirit for relationship. I am a longtime HIV volunteer, activist, speaker and author. Strongly committed to wellness and living a passionate life. Diverse interests, creative mind, compassionate heart. Hap, 415/388-6561 in Mill Valley, CA.

WORLD is now accepting personals ads.

(When space permits.) Free (donations appreciated). Please be brief (50 words max.) The appearance of an ad in WORLD does not constitute an endorsement by WORLD.

Thanks for your support!

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Rebecca Denison, editor
Daniel Johnston, layout and production

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How did you hear about WORLD? _____

- ☐ Please add my name to your mailing list. (I understand it will be kept confidential.)
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Enclosed is my contribution to WORLD. (May we thank you in our next issue? _____)
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- ☐ I'd like to help. I have the following skills: _____

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