

CHOICES

JUNE, 2007

THE HAWAII ISLAND HIV/AIDS NEWSLETTER



SPEAKER 'S BUREAU

HIHAF has received an increase in calls recently from the community requesting that we provide an HIV+ guest speaker to come to their agency, classroom, or group and provide a more personal touch to the education of the community around HIV/AIDS issues.

Research suggests that providing personal stories in addition to general education around HIV/AIDS can greatly enhance the experience one has in a presentation and has a greater lasting influence on the choices people make regarding their own sexual health. Also, a more personal face to HIV can be the most effective reducer of stigma and prejudice.

In response to this community need, HIHAF is looking for volunteers on both sides of the island who are HIV+ , or close to someone who is + , and willing to go out into the community and “talk story” regarding your own experiences around living with HIV and the reality of HIV/AIDS. Volunteers will team up with HIHAF staff to do presentations. Volunteers may choose to only address the public agencies like police, doctors, fire, etc. and/or address school classrooms, community based organizations, and other larger community groups.

The ideal volunteer would be comfortable in front of groups, be able to drive to and from meetings, and able to relate effectively to the public. Stipends may be available for those regularly participating in the speaker 's bureau.

If you are interested or know of someone who might be a good candidate, give us a call.

Contact Daron at 982-8800.

A message from your Treatment Advocate

Skin Photosensitivity with Bactrim DS

Bactrim DS is a combination of two antibiotics (sulfamethoxazole with trimethoprim) used to treat a wide variety of bacterial infections. It is also used to prevent or treat pneumocystis carinii pneumonia (a.k.a. PCP) and toxoplasmosis.

Patients with AIDS may be more sensitive to the side effects of the drug, especially skin reactions and fever. This medication may make you more sensitive to the sun. Since we all live in Hawaii, where it is usually sunny, we must be cautious. Please avoid prolonged sun exposure as much as possible and use a sunscreen or wear protective clothing when outdoors. A reddish skin rash may occur throughout the body with excessive sun exposure while taking Bactrim DS. If you start to notice this skin rash, blisters, itching, or swelling, please call your physician.

The most frequent side effects from taking Bactrim DS are nausea, vomiting, diarrhea, loss of appetite, fatigue, or headaches. Use of this medication for a long period of time or for repeated periods may result in oral thrush.

Try to remember that your doctor has prescribed this medication because the benefit to you is greater than the risk of side effects.

NOTE *Before taking this medication, tell your doctor if you are allergic to sulfa medications or trimethoprim and if you are taking dofetilide or methenamine.

HIV TESTING IN HAWAII – UNCERTAIN TIMES

For all of us who have benefited by publicly funded HIV testing and counseling programs in Hawaii over the past decade, it may be of great concern to know the future of these programs are very uncertain. Many have enjoyed the ease at which they find testing available close to home via outreach workers who come to them. For some, the fact that testing is free and needle free has made all the difference. Most of us appreciate knowing that testing is still anonymous and confidential and find comfort in that.

Due to several factors directly affecting the way agencies such as HIHAF do HIV testing, our testing programs will be going through changes over the course of this year. The extent of these changes is still unknown. However, we'd like to share with you what we do know for certain up to this point.

Until further notice, HIHAF will no longer be able to offer HIV testing. The oral test called Orasure that we and other agencies in Hawaii use for HIV testing is no longer available to us. This is due to the unavailability of a chemical reagent which is used at the state laboratory for processing Orasure tests. We have been informed, that this chemical reagent will no longer be manufactured and made available in the U.S. Our state Department of Health has told us that an alternative chemical reagent has been identified for use with the Orasure test. Until this alternative reagent has been tested and approved for use in by state lab, or until another solution is found, Orasure will not be available in Hawaii.

We are currently working together with the Department of Health and other state agencies to find new methods, in addition to preserving some of the old methods, for offering HIV testing to the public. Authorities in Hawaii are working diligently on making changes to administrative rules that would allow us to use rapid testing here in Hawaii.

For now, free, confidential, and anonymous testing will still be available on the Big Island through the Department of Health phlebotomists. This is needle blood draw based testing that is sent to the state lab in Honolulu for processing. One can expect the usual two to three week turn around for results. For information on the Department of Health workers' schedules and locations, please call 974-4247 (East Hawaii), 322-1920 (West Hawaii).

Testing for HIV and other sexually transmitted diseases is also usually available through your doctor or local clinic. For more information, call your doctor or call us at HIHAF and we'll try to help you find an appropriate place to go. Please note that testing at doctors' offices and clinics usually have a fee involved and is not considered anonymous testing.

HIHAF and other agencies have received numerous calls from concerned citizens wondering if it is true that we no longer offer anonymous HIV testing. This is due to some recent articles and news coverage around new laws and requirements for HIV testing at the federal level. Hawaii has remained up to this point one of the last states in the union to still offer anonymous testing. However, due to these new federal laws and requirements added to public funding for HIV testing, the anonymity of programs such as ours in this state may disappear sometime in 2008. For now, HIV testing with the Department of Health is anonymous.

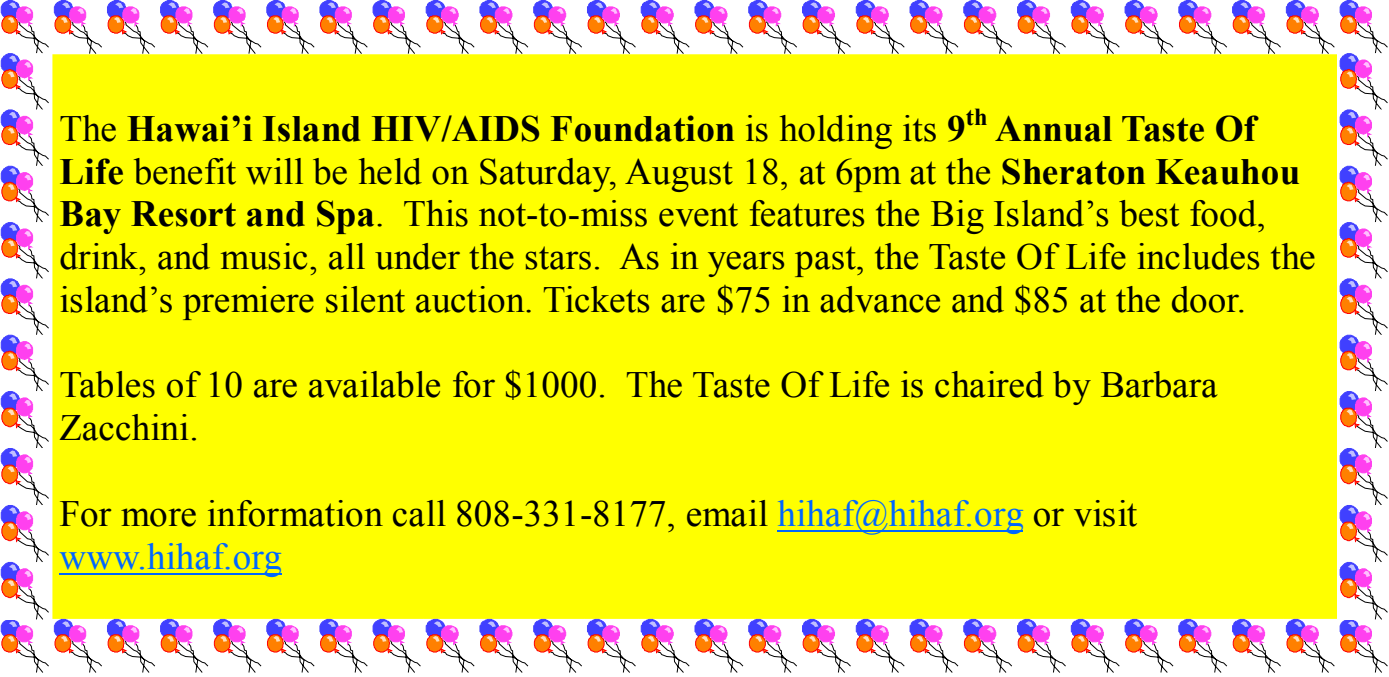
SUCCESSFUL SALE IN KONA

**The Kona-side rummage sale went well and grossed over \$1,300.00
The net proceeds will go to purchasing items for the Pantries.**

Mahalo to all donors.

**And
Mahalo**

**John □ Rob □ Winic □ Kipapa
Yvonne □ Lisa □ Karen □ David
Victor □ Wing □ Georgie □ Melissa
and Shani**



The **Hawai'i Island HIV/AIDS Foundation** is holding its **9th Annual Taste Of Life** benefit will be held on Saturday, August 18, at 6pm at the **Sheraton Keauhou Bay Resort and Spa**. This not-to-miss event features the Big Island's best food, drink, and music, all under the stars. As in years past, the Taste Of Life includes the island's premiere silent auction. Tickets are \$75 in advance and \$85 at the door.

Tables of 10 are available for \$1000. The Taste Of Life is chaired by Barbara Zacchini.

For more information call 808-331-8177, email hihaf@hihaf.org or visit www.hihaf.org

GREAT FOOD, AN OPEN BAR, GREAT PEOPLE. A BEAUTIFUL SUNSET OVER THE PACIFIC
AND MUCH MAHALO IS GUANANTEED.

THIS IS ONE EVENT YOU DON'T WANT TO MISS.
SEE YOU THERE!



WELCOME CAMERON

Please join in welcoming a new member to our staff, Cameron Baily-Bram. Cameron joins us as the coordinator for this year's "Taste of Life" event scheduled for August 18th. She has a great deal of experience coordinating fundraising events and we are truly fortunate to have her working with us. Cameron's email address is cameron@hihaf.org.

Please add her to your contact lists. She can be reached on extension 131 here in the Kona office.

Welcome to our group Cameron!

(CNN) -- Chimpanzee tests of an anti-AIDS vaccine show preventive results that are sufficiently promising to allow human trials and even show improvement in animals infected before inoculation, scientists said Wednesday.

In a separate study, AIDS researchers said a power three-drug "cocktail" was found to stop HIV from reproducing and infecting new cells. As a result, HIV levels in the bloodstream plummeted about 99 percent within two weeks.

AIDS VACCINE?

A vaccine, developed by a team from the University of Pennsylvania working with the Coulston Foundation of Alamogordo, New Mexico, and Apollon Inc. of Malvern, Pennsylvania, is already being used on selected human subjects, including those who are HIV-negative and those who are HIV-positive.

Foundation chief executive Frederick Coulston said the chimpanzee results don't necessarily mean future human trials will show similar success, but he was optimistic.

"We have a vaccine now that looks like it's the answer," Coulston said.

Researchers cautioned, however, that a commercially available AIDS vaccine was still several years away, considering that four phases of human trials lie ahead.

The vaccine uses no living HIV, so it cannot cause infection, he said. An account of the testing was published Wednesday in the British science journal Nature.

AIDS CURE?

In the other AIDS study, the three-drug "cocktail" was shown to devastate HIV in the tonsils and lymph nodes, where the virus is produced and stored.

Dr. Ashley Haase of the University of Minnesota and other scientists sampled the tonsils of 10 people during treatment.

Their research, reported in the journal Science, found that within six months, the drug therapy eliminated more than 99 percent of cells actively producing HIV.

AIDS-Related Quackery and Fraud

Stephen Barrett, M.D.

Acquired immune deficiency syndrome (AIDS) is a fatal disease caused by the human immunodeficiency virus (HIV). This organism can remain in a person's body for years before symptoms appear and the individual is considered to have AIDS. The virus disrupts the functioning of the body's immune system, rendering the infected individual progressively unable to resist organisms that would normally be harmless.

Most people infected with HIV are adults in their twenties, thirties, and forties, but the disease can occur at any age. The initial stage of the disease is a brief illness that typically includes fever, sore throat, skin rash, swollen lymph glands, headache, and malaise. This phase, termed acute HIV syndrome, usually lasts one to two weeks and is followed by a period in which the virus keeps multiplying but causes no symptoms. The median length of the symptom-free period in untreated individuals is about ten years, but the disease progresses much faster in some people and may remain quiescent indefinitely in a small percentage of others. Thus, at any given time, most individuals who carry the AIDS virus exhibit no signs of illness. However, regardless of the stage of the disease, an infected person can transmit the virus to others.

Once clinical symptoms appear, the course of the disease can vary considerably, depending in part on the extent of immune damage and the treatment received by the patient. Eventually most people with AIDS become thin, easily fatigued, and prone to diarrhea, swollen lymph glands, and multiple infections. *Pneumocystis carinii* pneumonia, other opportunistic infections, and a skin cancer called Kaposi's

sarcoma are life-threatening complications. In addition, some patients suffer from dementia. Opportunistic infections are caused by organisms that normally are harmless but can thrive when immunity is impaired.

Finding a cure for AIDS has been very difficult because HIV infects several types of cells and inserts a copy of itself into their genetic material (DNA). This "tricks" the cells into treating the virus's genes as their own. The virus is then safe from attack by the body's immune system and is reproduced each time the host cells reproduce.

Although no cure for AIDS has been found, significant progress has been made. Early treatment of HIV-infected individuals can delay the onset of AIDS and increase survival time. Progress has also been made in preventing or fighting *Pneumocystis carinii* pneumonia and several other AIDS-related infections.

Quackery and Fraud

The fact that AIDS causes great suffering and is deadly has encouraged the marketing of hundreds of unproven remedies to People with AIDS. In addition, many companies in the "health food" industry have produced vitamin concoctions claimed to "strengthen the immune system" of healthy persons. John Renner, M.D., president of the Consumer Health Information Research Institute, who attended meetings of groups promoting unorthodox methods, has commented that "many of the expert quacks in arthritis, cancer, and heart disease have now shifted into AIDS" and that "every quack remedy seems to have been converted into an AIDS treatment."

The "cures" he observed have included processed blue-green algae (pond scum), BHT (an antioxidant used as a food preservative), pills derived from mice given the AIDS virus, herbal capsules, bottles of "T cells," and thumping on the thymus gland . Some firms have offered to freeze and store bone marrow, claiming that it could be used to restore in People living with AIDS marrow when AIDS began to deplete the body's supply of bone marrow, which manufactures the body's blood cells. Autohemotherapy -- a worthless procedure in which a sample of the patient's blood is withdrawn, exposed to hydrogen peroxide and then replaced -- has also been recommended.

Many Mexican cancer clinics offer their unproven treatments to People living with AIDS, and a black market has developed in drugs that have shown promise but lack FDA approval because the agency is not convinced they are safe and effective. Several drugs available without a prescription in Mexico are being smuggled into the United States. Drugs are also imported through "buyers' clubs," which obtain the drugs from other countries where they are legally prescribed or used in clinical trials. "Legitimate" buyers' clubs require a prescription written by an American physician who supervises the patient's care. However, some buyers' clubs obtain drugs for people who are not under medical care. Some also supply drugs to victims of cancer, Alzheimer's disease, chronic fatigue syndrome, and other diseases. The FDA appears willing to permit buyers' clubs to operate, even though technically illegal, provided: (a) patrons are purchasing drugs for their own use under medical supervision; (b) the club does not commercialize or promote its products; and (c) the products do not present "unreasonable" safety risks .

Some entrepreneurs have attempted to exploit public fear of acquiring AIDS. Covers for public toilets and telephone receivers have been marketed with claims that they will prevent transmission of the HIV virus. Such products are worthless because HIV is not transmitted in this manner. Nor can it be transmitted by means of a mosquito bite. Rubber dental dams to prevent direct contact during oral-genital sex have been marketed despite the minuscule likelihood of HIV transmission by this route.

A few people have marketed shares of companies falsely claimed to have developed an effective method of diagnosing or treating HIV infections. Several individuals and groups have claimed that the U.S. Army, the Central Intelligence Agency, the World Health Organization, and Russian agents have conspired in various ways to eliminate blacks or gays by introducing HIV into vaccines for smallpox, polio, and/or hepatitis . A few skeptics have even claimed that HIV is not the cause of AIDS , even though the evidence that it does is overwhelming.

Several studies have shown that a significant percentage of people with AIDS use unproven treatment:

- A study of patients hospitalized in Illinois found that 18 out of 50 with AIDS and two of 30 patients with cancer had used "alternative" treatments. Acupuncture was used by 15 of the AIDS patients, mental imagery by 12 of them, massage therapy by 11, megavitamins by 10, acupuncture by 8, unapproved medications by 7, and a high-cereal diet by 1 patient

- A study of 79 patients attending the St. Louis AIDS Clinical Trials Unit found that 44 (56%) had tried an "alternative" remedy. The most commonly used were vitamins (46% of patients), herbal therapy (16%), imagery or meditation (14%), and nonapproved drugs (14%). Most patients using these methods thought they had improved their general well-being but readily admitted that the benefit was largely psychologic. The average yearly cost was \$356, but 14 of the patients spent between \$500 and \$2,700, and two patients spent more than \$9,000 each [9].
- Interviews with 114 patients attending the AIDS Clinic of the University of California San Francisco Medical Center indicated that 25 (22%) had taken one or more herbal products during the 3 months before the survey. The study's authors expressed concern that herbal extracts can produce diarrhea, liver toxicity, and other symptoms common in AIDS itself.
- Dutch sociologists who interviewed people who used alternative treatments reported that 46% assumed that the treatment was effective, 66% thought it would strengthen their resistance, and 34% said they felt better because they had the feeling of being actively involved in their treatment.

Many health-food retailers claim to carry products that can help HIV-infected patients by boosting their immune system. This claim is false.

In 1989, volunteers of the Consumer Health Education Council telephoned 41 Houston-area health-food stores and asked to speak with the person who provided nutritional advice. The callers explained that they had a brother with AIDS who was seeking an effective alternative treatment for HIV. The callers also explained that the brother's wife was still having sex with her husband and was seeking products that would reduce her risk of being infected, or make it impossible. All 41 retailers offered products they said could benefit the brother's immune system, improve the woman's immunity, and protect her against harm from HIV. The recommended products included vitamins (41 stores), vitamin C (38 stores), "immune boosters" (38 stores), coenzyme Q10 (26 stores), germanium (26 stores), lecithin (19 stores), ornithine and/or arginine (9 stores), gamma-linolenic acid (7 stores), "raw glandulars" (7 stores), hydrogen peroxide (5 stores), homeopathic cell salts (5 stores), Bach flower remedies (4 stores), blue-green algae (4 stores), cysteine (3 stores), and herbal baths (2 stores). Thirty retailers said they carried products that would cure AIDS. Not one recommended abstinence or use of a condom [12]. More recently, researchers at the University of Alabama (Birmingham) asked employees of 20 local health-food stores in Birmingham what they recommend for people with AIDS. Again, a wide variety of herbs and other products were recommended.

Hawai'i Island HIV/AIDS Foundation

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Mission Statement

The Hawaii Island HIV/AIDS Foundation is a non-profit organization dedicated to assisting those affected by HIV/AIDS to maximize their quality of life, and to ending the spread of HIV. We also utilize the lessons learned in the HIV epidemic to care and advocate for others in the fight against related diseases.

Vision

To build a healthier, stronger, and more sustainable community that supports all its members with a focus on HIV issues.

Core Values

Responsiveness: To people with HIV/AIDS and their families and to the prevention education needs of the community.

Accountability: To our consumers, funding sources, and the community at large.

Integrity: To provide services to the entire community in a humane, loving, non-judgmental manner.

Diversity: To embrace the philosophy of "inclusiveness".

Collaboration: To establish and maintain partnerships within the community that maximizes resources and decreases duplication of services.

Leadership: To set the highest standards for responsibility to our mission, vision and values, and be recognized as a positive, inspirational role model in our community.

Advocacy: A collective public voice to speak on behalf of those affected by HIV/AIDS.

Editorial Policy

The articles contained in this publication are meant to inform and entertain only. They do not constitute an endorsement. The publication of any name or image does not necessarily imply anything about that persons condition, health or sexual orientation. The opinions expressed are those of individual authors and do not necessarily represent official positions of HIHAF or any other organization mentioned herein.

Contributions of articles and other materials for publication are encouraged and welcomed.