The STEP Ezine

LIFELONG AIDS Alliance

STEP

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The Seattle Treatment Education Project's (STEP) EZINE is an electronic treatment resource newsletter distributed monthly to case managers, front-line workers, people affected by HIV/AIDS, physicians, other public health and allied health professionals and people living with HIV/AIDS.

STEP's contact information is: STEP at Lifelong AIDS Alliance, 1002 E. Seneca Street, Seattle, WA 98122
(206) 329-4857 o (206) 957-1659. We also have a toll free number 1-888-399- (STEP) 7837 Anywhere in the US

Stigma of AIDS is Helping to Spread Epidemic

By Vincent J. Lynch, Ph.D.

Acquired Immune Deficiency Syndrome. I first heard those words more than 20 years ago. But it wasn't until six years later, while I listened to a man dying of AIDS tell the story of what he was going through, that the reality of what it meant really hit me. By that time more than 100,000 Americans had contracted HIV, and over 60,000 had died of AIDS. The disease had become real for me and for my colleagues in virtually every corner of the country.

So much about HIV/AIDS and the epidemic has changed since then. Yet one thing has not changed nearly enough - HIV is now, as it was in 1989, the most stigmatized disease in American society. In 1989, the stigma attached to HIV, while undeserved, was at least a little more understandable. We knew very little about the disease then. Fears of being infected from kissing, holding hands or sharing a cup with someone with HIV were still common.

Doctors and patients were scrambling to stir up scientific research programs that in many ways had been slow to respond. Despite a rapidly expanding caseload, there was very little reliable medical or scientific information about the virus, how it was transmitted, or what could be done to treat it.

In fact, effective HIV treatments were virtually non-existent at that time. The few medicines that were being used were no match for the virus, which quickly became resistant. The treatment regimens often involved so many pills and such severe side effects that many people felt that taking their medicines every day was as difficult as the disease itself.

Too often, being HIV positive meant having to cope on your own. It wasn't uncommon for doctors and other healthcare workers to refuse to see patients who they knew were HIV positive. Social workers around the country responded at that time, and services for many people began, gradually, to improve.

The situation today is very different. We know how HIV is transmitted, and we know how to prevent infection. Scientists have learned how HIV attacks the body's immune system, what its weaknesses are and how to exploit them. They've even mapped out the virus's genetic structure.

HIV treatments have also improved dramatically in recent years. With the introduction of powerful new drugs in the mid-1990s, HIV/AIDS death rates began to drop for the first time since the start of the epidemic. More recently, treatments that require fewer pills and cause fewer side effects have begun to help people with HIV/AIDS lead longer, healthier lives. Thanks to these advances in care, HIV is on its way to becoming a chronic medical condition.

Support services for people with HIV have also improved. In practically every city across the country you will find community organizations and groups dedicated to helping ensure that HIV positive individuals get the care and support they need and deserve.

Yet, despite all this progress, the terrible stigma associated with HIV and AIDS still has not lifted. Isolation, fear and shame continue to cloud this diagnosis for many.

What's worse is that the stigma surrounding HIV actually helps to perpetuate the epidemic. Half of the 1,000,000 Americans estimated to be infected with HIV don't even know they have the virus. The cause is not ignorance as much as it is fear. Each year, tens of thousands of people who have contracted HIV do not get tested out of fear that an HIV positive diagnosis will mean a life of isolation and discrimination.

Misinformation accelerates the spread of HIV in communities across the country, particularly among minority and poorer populations that already suffer more than their share of prejudice and discrimination. Despite progress in other areas, HIV infection rates among African Americans, Hispanics and women have increased dramatically in recent years.

We can't afford to let another 20 years go by before we separate the myths surrounding HIV and AIDS from the reality. It's time we started seeing the disease for what it is: a serious communicable disease that is both avoidable and treatable. We need more open and frank education and more community leadership to address this epidemic. We must also target resources to address the changing demographics of the disease, so that information and education programs can be tailored to the audiences that need them most.

Finally, people living with HIV/AIDS must have access to the medical care and prevention and treatment information they need. Research advances have meant that more and more people with HIV are living full, normal lives. It's time that the human progress in how we handle HIV/AIDS in our community begins to match the advances being made in the research lab.

Vincent J. Lynch, Ph.D., is Director of Continuing Education at Boston College Graduate School of Social Work, and founder and organizer of the Annual National Conference on Social Work and HIV/AIDS.

Gilead’s Truvada is Approved by the FDA

The Food and Drug Administration approved Gilead’s Truvada, a one-tablet, once- a- day dosed co-formulation of Viread and Emtriva. This medication combines 200 mg of emtricibicine and 300 mg of tenofovir fumarate.

This once- a-day new combination may make it easier for doctors when prescribing new regimens. Truvada must be taken in combination with other anti-HIV medications to achieve maximum viral suppression.

The company is planning to sell Truvada to the developing world at a not-profit price through Gilead’s Access Program. The developing world counts for more than 70% of all infections. For more information on Truvada, go to Gilead.com, talk to your doctor or call the STEP Program at 1-888-399-7837

The FDA Approves Use of Sculptra (New Fill) for Treatment of Lipoatrophy or Facial Fat Loss

On August 4, 2004, The US Food and Drug Administration or FDA approved Dermik laboratories's Sculptra also know as *NewFill* for the treatment of facial fat loss (lipoatrophy) in individuals living with HIV/AIDS. Sunken cheeks are one of the most noticeable effects of lipoatrophy. A large percentage people living with HIV/AIDS experience some kind of fat loss in the face or arms and legs.

The loss of facial fat has further stigmatized people living with the disease and the approval of Sculptra may help to correct that problem in some. Treatments with Sculptra aren't cheap and they do not have a permanent effect. There is anecdotal evidence of patients needing injections every 12 to 15 months. The injectable poly-L-lactic acid is a polymer synthetically derived from natural components that is injected under the skin to improve facial contours. There are some visible delayed side effects like bumps under the skin and redness. Bruising and swelling are also common on the area being treated.

For more information, go to the product's web site: www.Sculptra.com /US

The Men's Program at *Lifelong AIDS Alliance* is looking for you!

LIFELONG
AIDS Alliance

EDUCATION

OUTREACH SPECIALIST MEN'S PROGRAM

Job Description

LIFELONG AIDS Alliance is a non-profit agency that is committed to preventing the spread of HIV, and to providing practical support services and advocating for those whose lives are affected by HIV and AIDS.

DEFINITION:
The Outreach Specialist is responsible for developing and implementing outreach programs, events and activities aimed at providing information regarding HIV/AIDS to the gay and bisexual population in Seattle/King County. This position reports to the Education Manager.

PRIMARY RESPONSIBILITIES:

1. Develop and implement outreach programs, events and activities targeted toward gay and bisexual men who have sex with men addressing HIV transmission and prevention.
2. Recruit, train and supervise volunteers who will perform one-to-one and group outreach activities in bars, bathhouses, sex clubs and other social venues.
3. Identify and/or develop and distribute information and materials promoting risk reduction and commitment to sexual safety.
4. Assist in program budgeting process
5. Develop and manage distribution plan for condoms and other safer sex materials to targeted community venues and activities.
6. Complete monthly and quarterly reports as required

7. Serve as liaison between the Agency and agencies, organizations and businesses serving gay, lesbian and bisexual populations.

SECONDARY RESPONSIBILITIES:

1. Monitor and participate in evaluation of program efficacy and success.
2. Remain active in the recruitment, retention and appreciation of volunteers.
3. Perform other duties as assigned.

QUALIFICATIONS:

- Bachelor's Degree in Health Education, Sexuality Education, Communications or equivalent experience.
- Two years work experience in health education, social services or communication field.
- Experience with project planning, implementation and evaluation.
- Experience and comfort in working with persons of diverse sexual orientations, socio-economic backgrounds, ethnicities and cultures.
- Excellent verbal, written and interpersonal communication skills.
- Knowledge of HIV/AIDS related issues.
- Current Washington State drivers license and/or regular access to transportation.
- Ability to work a flexible schedule.
- Able to lift at least 25 pounds

Katherine Kizer
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Lifelong AIDS Alliance
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ACTU New Clinical Trials

Study # 1

Purpose of This Trial:

To evaluate the safety and effectiveness of three different dose levels of SCH 417690 (an investigational medication to treat (HIV-1), in HIV-infected individuals who are failing their current antiretroviral regimen (current regimen must contain ritonavir).

Requirements to Enter Study:
·CD4 cell count of at least 50 cells/mm3
·Viral load of at least 5000 copies/ml
·Current antiretroviral regimen must contain ritonavir for at least 8 weeks
·Failure of at least one other antiretroviral regimen containing at least 3 drugs
·No history of Hepatitis B or C
·No history of seizures or recent trauma to the head with loss of consciousness

Medications While on Study:
Subjects will be randomized (like flipping a coin) to receive one of three SCH 417690 doses (5 mg, 10 mg, or 15 mg), or a look-alike placebo (does not contain any real medicine).

For the first 14 days, subjects will stay on their current failing regimen with the SCH 417690 or placebo added on.

After 14 days, can change background medications to an optimized regimen, which must contain ritonavir (not provided).

(SCH 417690 is an investigational medication)

Length of Study: 48 weeks.

Visits involve a physical exam, questionnaires, EKG (screen, day 14, weeks 8, 24 and 48), peripheral neuropathy assessment (entry, weeks 24 and 48), and blood drawn from a vein in the arm.

Reimbursement: Exams, study medication (SCH 417690), and lab tests given at no cost. $20 for each on-study visit starting at entry.

Contact: Alyssa Spingola or Lori Cray at (206) 731-3184 spingola@u.washington.edu or lcray@u.washington.edu

Study #2:

Combination Therapy with Fish Oil and Fenofibrate for High Triglyceride Levels in Patients Receiving Highly Active Antiretroviral Therapy (HAART)

Purpose: To see whether the combination of fish oil and fenofibrate will lower the level of triglycerides (a fatty substance in the blood) in patients whose triglyceride levels are not responding to one of these agents alone.

Treatment Phase 1 [Patients are randomized (like flipping a coin) to receive either]:
Arm A: Fish oil supplement 3 gm twice a day
Arm B: Fenofibrate 160 mg once a day

Phase 2
At week 10, patients whose triglyceride levels are still higher than 200 mg/dL while only using one agent will begin a combination therapy with both the fish oil and fenofibrate.

STUDY TREATMENT
Fish oil supplement and fenofibrate are supplied. Antiretrovirals are NOT provided.

ELIGIBILITY (requirements to enter study)
- HIV positive men and women age 18 or older
- Fasting triglycerides at least 400 mg/dL
- LDL (low-density lipoprotein) 160 mg/dL or lower
- HIV viral load 10,000 or lower
- Receiving HAART for at least 3 months before study entry
- On a lipid-lowering (low fat) diet and exercise program for at least 28 days before screening appointment (Self report is acceptable)
- Not pregnant/breast-feeding
- No History of coronary heart disease, congestive heart failure, peripheral vascular disease, stroke, diabetes or uncontrolled high blood pressure.

COMPENSATION
Exams and study medications provided at no cost. $20.00 for each on-study visit starting at entry. For more information, please contact the ACTU at (206) 731-3184

Swedish Medical Center HIV Research Studies

Research Study for HIV Positive Persons Failing Their Current Regimen

48 week study of an experimental NNRTI in combination with other antiretroviral drugs in people who have resistance to protease inhibitors and NNRTI's.
To qualify you must have:

- HIV Viral Load > 1,000 copies/mL
- Documented resistance testing showing resistance to PI's and NNRTI's
-

For more information please call Heather at (206)-386-2820

HIV Study for Multiply Treated People Who are Failing their Current Regimen
Study Drug:
An investigational protease inhibitor with a combination of other drugs.
Length: 96 weeks
Study related lab tests, including genotyping and physical exams are free. The investigational drug is provided at no cost.
Reimbursement for childcare and transportation are possible. Will work around your schedule (evenings, weekends, etc.)

For more information please call Janice at (206)-386-2523

Tipranavir Early Access Program

A limited number of spaces in the Tipranavir early access program are available to persons with private providers and through the Madison Clinic. Patients must have a CD4 count ≤ 100 copies/mm^3.

For more information please call Heather at (206)-386-2820

Protease Inhibitor Switch Study

Swedish Medical Center is looking for HIV+ people to participate in a research study that will replace Kaletra® with a currently marked protease inhibitor to see if it will improve cholesterol levels. To take part in this study, your current viral load must be <50 copies/mL. This is a 48-week trial that includes:

- Laboratory testing
- Physical Exams
- Some Medications
- Reimbursement for travel and child care.
-

For more information please call Heather (206)-386-2820

HIV Study for People Who Have Never Been Treated for HIV
Study Drug: Kaletra vs. Amprenavir/ritonavir with abacavir and 3TC
Length: 48 weeks
Study related lab tests, physical exams and study medications are free.Reimbursement for childcare and transportation are possible. Will work around your schedule (evenings, weekends, etc..)

For more information please call Janice at: (206)-386-2523

HIV Study for People Who Have Taken an HIV Medication Called a Non-Nucleoside Reverse Inhibitor.
This is a study to test multiple doses of a potential new investigational drug when it is given over 7 days.

For more information please call Janice at: (206)-386-2523

Lifelong's STEP Program is inviting you to a Town Hall Meeting

Reyataz® (atazanavir sulfate)
Town Hall Meeting

Speaker: **Peter Shalit, MD**
Private Practice, Internal Medicine
Clinical Asst. Profesor of Medicine, University of Washington
Medical Director, HIV Research Program, Swedish Medical Center

When: **Thursday, September 16th, 2004**
6:00 pm – 8:00 pm
Dinner and Refreshments provided

Where: **Lifelong AIDS Alliance – Conference Room**
1002 East Seneca Street
Seattle, WA 98122
Conference room through the double glass door at the end of the main parking lot

Please RSVP: **Roberto Gonzalez**
***STEP* Program**
206-957-1659 or 1-888-399-7837 (outside Seattle)
Call by September 13th, 2004 (space is limited)

You have been cordially invited by Rubén Gamundi
Patient and Community Affairs Manager
Bristol-Myers Squibb

(In accordance with the PhRMA Code on Interactions with Healthcare Professionals, attendance at this program is limited to people living with HIV, their caregivers, and healthcare professionals who are involved with HIV and AIDS.

Do you know that Seattle Treatment Education Program gets over 50,000 hits a month on their Web site link to ***thebody.com***?
Curious?
Visit us online at www.thebody.com/step/steppage.html

ACKNOWLEDGEMENTS

- Please note that this is not a complete list of all HIV-related treatment information. STEP strives to provide the very latest in HIV/AIDS treatment information, research and drug development information. The most current research directions and antiretroviral drug data are provided throughout the Ezine publications. You will find highlight reports as well as extensive follow-up reports from many of the AIDS research and science conferences on the Ezine. In addition, all STEP quarterly treatment journals are available on our Web site at http://www.thebody.com/step/steppage.html or by calling our National Talkline at 1-888-399-STEP (7837). STEP works hard to give unbiased treatment information to all interested parties. If you have comments, questions, suggestions or grievances, please contact step@lifelongaidsalliance.org.

The Ezine producer is Roberto Gonzalez

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Jon Hubert, D.D.S., Janice Price, R.N., M.Ed.

- **Disclaimer:** STEP reviews a wide spectrum of HIV treatment options, but does not endorse any particular product, treatment, company, or individual. Participation in the preparation of the materials included in the STEP Ezine does not imply endorsement by any of the individuals who have contributed to the production.

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