

# Client Newsletter Winter 09'

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## SENATE TO INCREASE HIV PREVENTION MEASURES

Jan. 28, 2009

Washington, DC – Yesterday, the Senate Appropriations Committee approved its portion of the American Recovery and Reinvestment Act. Included in the economic stimulus package is \$400 million for domestic HIV and STD testing and prevention programs as part of a \$5.8 billion Prevention and Wellness Fund to prevent diseases and to reduce future healthcare costs.

"The AIDS Institute praises the Senate Appropriations Committee for including increased funding for HIV prevention at the CDC," commented Carl Schmid, Director of Federal Affairs. "Preventing disease, such as HIV/AIDS, will dramatically reduce future healthcare costs." The CDC estimates that the 56,300 new infections each year in the U.S. may result in \$56 billion in medical care and lost productivity.

The House version of the bill includes \$335 million in increased funding for CDC's Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention. The AIDS Institute will be encouraging the Congress to support the highest possible funding level when the bill goes to conference and that some of the money will be used for Hepatitis prevention.

Funding for HIV prevention at the CDC was cut by \$3.5 million in FY08 and although a final FY09 appropriation bill has not been released yet, both the House and Senate were proposing no increases for FY09. The AIDS Institute has been urging the Congress and the Obama-Biden Transition Team to dramatically increase HIV prevention spending particularly in light of CDC's announcement last summer that the number of new infections in the

U.S. has been 40 percent higher than previous estimates. The CDC has estimated it needs an additional \$877 million over the next five years to significantly reduce the number of new infections.

There are other elements in the bill that will benefit people with HIV/AIDS. Under the bill passed by the Committee, spending at the National Institutes of Health would increase by \$3.5 billion. This amount is substantially higher than the House version of the bill which calls for increased NIH spending of \$2 billion. "We are extremely pleased with the Senate's focus on biomedical research. We anticipate a portion of this funding will be dedicated to HIV/AIDS research, including the development of new drugs, biomedical prevention methods such as vaccines and microbicides, and behavioral research," commented Michael Ruppel, Interim Executive Director of The AIDS Institute.

The AIDS Institute also strongly supports the \$87 billion in Medicaid aid to the states to temporarily increase the share of Medicaid costs the federal government reimburses states. This funding was included in the Senate Finance Committee's portion of the economic stimulus bill. Medicaid is the largest provider of HIV/AIDS care and treatment in the U.S. and due to the economic crisis, states are burdened with increased healthcare costs, particularly as people lose their jobs and health insurance. Without these Medicaid increases, low-income people with HIV/AIDS would have to turn to the already overburdened and under funded Ryan White HIV Program.

The AIDS Institute urges the Senate to keep these provisions in the bill as the economic stimulus package moves through the Senate and that when the bill is conferred with the House, the highest level of funding will be adopted.

One program that was not included to receive funding in the bill was the AIDS Drug Assistance Program (ADAP), which provides lifesaving medications to low-income people with HIV/AIDS. The AIDS Institute supported the request of the Congressional Black Caucus Health Braintrust that called for \$300 million to help states during this economic crisis so that people will be able to access medications.

Source: Outinamerica.com

### INSIDE THIS ISSUE:

New Staff Bios	2
A Farewell!	2
Fighting Fatigue	3
Holiday Party Wrap Up	3
Do you have a story?	4
Counseling, Testing...	4
A Good Doctor	5
Oregon Aids Hotline	6
Capacity Building	7
RN Services	8
New Treatments	9

## Reminders and Announcements

### The next Friends and Family Group will be held on March

10<sup>th</sup>. Please contact Casandra or Angela for additional info.

**Don't forget:** Care Packages are available the second Friday of every month. Come by for household cleaning products on March 13th and personal hygiene items on April 10th.

**Due to budget constraints** bus tokens for non-medical trips have been temporarily suspended. We understand how important access to public transportation is and are committed to finding additional funding to help you meet this important need.

**Please remember** the office is closed on Fridays and Case Manager's are available on a limited basis by appointment only.

## New Staff Bios

### The new C's and A's of HIV Alliance

**C**asandra comes to us from Bellingham, WA where she was working for an agency doing Energy Assistance and Conservation Education. She has done HIV counseling and testing in the past and graduated with a Health degree from Western Washington University in 2006. She is very excited to be working at the Alliance and has really enjoyed everyone she has met and worked with.

She spends her free time mostly cooking, reading, spending time with friends and family, crafting and walking the dog.

**C**arlos is the newest Bilingual Case Manager to come to HIV Alliance. His ethnic heritage and colorful background will help fill a much needed vacancy. Carlos' long term dedication to social services makes him a dedicated and talented addition to the HIV Alliance team.

Thanks for joining the team Carlos!

**A**ngela, "After a couple of years in prevention, I decided to see what all the hype was about in client services and I'm lovin it already! My name is Angela and I'm excited to meet you all and re-meet some of you too. (Some of you from Wednesday nights may remember me by my ferocious dog barking and whimpering behind the partition) I'm a crafting fanatic, love astro turf, dogs, cooking, tasty food, cheese (though I'm apparently lactose intolerant), corny movies, playing cards, hugs, friends, and a bizarre sense of humor. I am incredibly passionate about this work, and committed to making a space where you feel comfortable chatting with me about what your needs and concerns are, as well as and learning a little bit about who you are and what's important to you in your life. My email is [clientsvs5@hivalliance.org](mailto:clientsvs5@hivalliance.org) and my ext. is 138 (both of which were Amber's so I've got some big shoes to fill!)"

### A Farewell to one of HIV Alliance's Best and Brightest

**A**fter seven years with the HIV Alliance I have decided to move to Portland and have accepted a position with CAREAssist. I can't tell you how much I have learned from each of you over the years. Thank you for sharing your stories, making me laugh and helping me see just how strong people can be. Anytime I faced a challenge in my personal life, I thought of all of you and how each of you bravely overcome tremendous obstacles everyday. You

are truly some of the strongest individuals I have ever met in my life and you have my respect.

I know there have been a lot of changes to Client Services in the last year and I am excited that we now have such a strong team of Case Managers. I'm also pleased to announce that Deb McLaughlin will be the new Client Services Program Manager and know that she will do an outstanding job in the position. While dealing with these transitions, please remember that we have an

open case load in order to let you find a Case Manager you work well with. If you are unsure who your Case Manager is, don't hesitate to call us for an appointment.

I hope to return for the Annual Summer Picnic and until then I will miss you all. Take good care of yourselves and each other!

With love,  
Jonathan

# Goodbye Jonathan!

"Jonathon, you have been an amazing mentor and friend. Your capacity for love seems immeasurable and your advocacy and hard work over the years has

"You're the best Jonathon!"  
- Client

"Jonathon, I have always appreciated your compassion & understanding. You have been a great advocate for our clients & a supportive co-worker." - **Renee Yandel, Program Director**

"Jonathon, I know only one small bit of you and have only had a few moments to work with you and see you in "action". But, from what little I have seen, I have been greatly impressed by your zeal to help forward the cause!" -**Greg Krupa, Capacity Building Intern**

"Thank you Jonathan for all your hard work, your sense of humor and your kindness. I appreciated your kindness and consideration of my time and the way you did whatever you could to support me in doing my own job. You were such a joy to work with, I miss you already!" - **Melissa Edwards, Finance Director**

## Fighting Fatigue

Fatigue is tiredness that does not go away when you rest. It can be physical or psychological. Fatigue is one of two main ways the body warns you about a problem. The other warning is pain. Most of us pay attention to pain, and stop whatever causes us pain. We don't pay as much attention to fatigue. One reason might be that fatigue sneaks up on us. It usually gets worse so slowly that we don't even notice. People with HIV

and fatigue tend to get sicker faster than people without fatigue. Also, ongoing fatigue can weaken the immune system.



People with HIV should find out what is causing their fatigue and **treat it**. There are many reasons for fatigue including anemia, active HIV infections, other active infections, poor nutrition, low hormone levels, depression and lifestyle issues such as lack of sleep. Work with your health care provider to find the cause of your fatigue and the best way to treat it.

### “Why am I so tired?”

The bottom line is that fatigue is a very common condition for people with HIV. Untreated fatigue can make HIV progress faster. It can be very diffi-

*“Untreated fatigue can make HIV progress faster”*

cult to figure out the cause of fatigue. Several different factors can cause the same symptoms. Blood tests can identify some

causes but not others. The more information you can give your health care provider, the easier it will be to determine what is causing your fatigue and how to treat it.

## Holiday Party Wrap Up

### This Years Holiday Party was a Great Success!

Thanks to the generosity of countless supporters and businesses in and around the Eugene area, the party helped give 200 gifts to clients and their families, brought over 100 attendants together to share holiday sentiment and joy, and helped fuse a more supportive and familial group of clients and staffers alike.

HIV Alliance and it's clients wants to sincerely thank First Baptist Church for it's efforts. Without their support this event never would have taken place, and we all would have starved without the great meal you provided for us!

Thanks  
HIV Alliance

### Special Note

HIV Alliance would also like to extend a warm and sincere thank you to Janet Bott. Because of Janet's tireless efforts to help facilitate the gift giving process from businesses and donors, The Client Holiday party was able to provide more than enough gifts and holiday cheer to all.

**Do you have a story to tell?** Want to help our community learn more about the personal side of HIV? For over ten years, HIV Alliance has provided the Speakers in the Schools program to our community, and we'd like you to consider joining our team of volunteer speakers. This is an opportunity for you to share what your life is like, mostly with middle and high school students. You will be trained on presentation skills, basics of HIV transmission, and how to craft your story in a way that continues to have a great impact in the lives of everyone to whom we speak. As Bo, one of our veteran speakers, says "Facts and figures don't resonate with the students...the emotional connection does." When a student hears a Speaker's story, that student can relate the story to their own life. As one high school teacher succinctly put it "My students are always moved by the presentation – without exception." If you would like to be a part of this program, please contact Amy at x. 116 or [volunteer@hivalliance.org](mailto:volunteer@hivalliance.org)

### Purpose of the program

- To put a face and personal story to the HIV/AIDS epidemic
- To enhance HIV/AIDS education by addressing the biology of HIV and the risks associated
- To provide youth and our community at large hope and increased understanding







## Counseling, Testing, and Referral Services

Our testing counselors and prevention staff are available to answer questions about HIV and assist individuals in understanding their own risk for acquiring/transmitting HIV.

**NOT ALL INDIVIDUALS ARE ELIGIBLE FOR A FREE HIV TEST. A TESTING COUNSELOR CAN HELP DETERMINE IF INDIVIDUALS ARE ELIGIBLE.**

The following populations are at highest risk in Lane County and are encouraged to seek counseling, testing and referrals services at the HIV Alliance:

Testing is also available for the populations below:

Populations at Highest Risk		Testing Times and Locations		
	Gay, bisexual and other men who have sex with men (MSM)*	Mondays 5-7 PM		Tuesdays 5-7 PM
		HIV Alliance, 1966 Garden Ave		
People who inject drugs*		Wed 6-7:30 PM	Thurs 6-7:30 PM	Fridays 3-5 PM
		NEX Van, End of Blair**	NEX Van, Glenwood**	NEX, 1966 Garden Ave
	Sexual partners of people living with HIV/AIDS	Mondays 5-7 PM		Tuesdays 5-7 PM
		HIV Alliance, 1966 Garden Ave		
Homeless and Runaway Youth (Ages 16-21)		Thursdays 5:30-6:30		
		New Roads Drop-In Center, 941 W 7th Ave		
	Transgender People	Mondays 5-7 PM		Tuesdays 5-7 PM
		HIV Alliance, 1966 Garden Ave		
Sex Workers		All testing times and location excluding New Roads Drop-In center where individual must be under 21.		

## **In Search of a Good Doctor**

Generally, membership in the national professional society of a specialty — often referred to as being a “fellow” in the organization, as in Fellow of the American College of Surgeons, or F.A.C.S. — requires board certification and a certain degree of clinical experience. Many physicians will denote their specific society affiliation after the M.D. in their name; for example, if the doctor is a fellow of the American College of Physicians, the national professional society of doctors specializing in internal medicine, his name might appear as “Joseph Smith, M.D., F.A.C.P.”

The advice of close friends and colleagues can further help to distinguish among doctors. “I suggest that people first identify the hospital where they wish to be admitted,” said Dr. Jeffrey P. Harris, president of the American College of Physicians. “Ask the hospital for a list of board-certified internists with admitting privileges. Then ask trusted friends, neighbors and colleagues whom they see and feel comfortable with.”

The last — and most critical — part of deciding on any physician is the first appointment. Most of the doctors I contacted unequivocally stated that patients should know what to expect and arm themselves with the right questions. And, as Dr. Rubinstein said, bedside manner is only one of many concerns. “While excellent quality health care integrates caring with doing the right thing medically,” she said, “a caring attitude can mask poor quality medicine.”

Dr. Richard L. Schilsky, president of the American Society for Clinical Oncology, recommends that [cancer](#) patients meeting an oncologist for the first time ask about board certification in the specialty needed, length of time in practice, experience with the patient’s specific problem, membership in professional organizations and participation in clinical trials.

If the patient is meeting a surgical oncologist for the first time, Dr. Schilsky recommends also asking the surgeon about the number of times annually she or he performs the specific operation needed, as well as the hospitals in which those operations are performed. While it is difficult to specify a standard number patients can keep in mind, [research has shown](#) that [hospital mortality rates are lower](#) when those operations are performed frequently.

Some individuals may feel uncomfortable questioning their prospective doctors, but becoming more active and knowledgeable can only improve your care. There is even a nonprofit group, the Foundation for Informed Medical Decision Making, devoted to educating patients to become more involved in their health care decisions (see below).

### Researching Your Condition

All the doctors I spoke with urged patients to exercise caution when going through information from commercial or industry Web sites.

“The Web can be a good place but also a dangerous place,” Dr. Epperly said. “It’s important to find sites that aren’t biased and that provide evidence-based information.”

Many of the doctors suggested going to sites supported by patient advocacy groups or nonprofit groups that are focused on certain diseases. Such sites often offer not only information but also active online communities.

Almost all of the national professional societies now have part of their official Web sites devoted to patients. These sites and links are excellent sources of information on the illnesses treated by that specialty and, in the case of surgical or anesthesia professional organizations, the procedures performed.

“Our specialty site, [familydoctor.org](#),” Dr. Epperly said, “aims to help meet patient needs on common afflictions in this country. The content is written by experts and presented in a way that people without medical training can understand.”

**Resource Database Launches Website**  
**<http://www.oregonaidshotline.com/>**

*Oregon Aids Hotline launches its new website, providing a much needed online HIV/AIDS database for Oregonians. The site streamlines all the information a person living with HIV will need to combat their illness. Support services from alcohol and drug, legal advocacy, disability services, child care, energy needs, culturally specific services, education, training, prevention services, other hotlines and websites, counseling & therapy, care giver support, financial aid, spiritual aid, case management, dental care, and even pet services! The website is easy to use and offers online chat help and an 800 number for assistance. HIV Alliance is working with the website, guaranteeing that all services regarding HIV care and support services in Lane, Coos, Curry, and Josephine Counties are properly listed.*

*We hope and encourage the use of this site. Persons who use the sight can help add to its database by giving information on organizations that may not be listed. The Oregon Aids Hotline helps unite all the services and organizations associated with preventing and supporting those with the disease, further enhancing the viability of all of the organizations listed. Please help us enhance the efficacy of this hotline by actively using it, and also submitting resources where they are lacking.*

**Oregon AIDS / STD Hotline**

Don't forget! This is your newsletter. Please call or email us to help contribute your compelling stories or information that you would like to share. Ask for Renee or Greg.

Phone: 342-5088

Email: [admin@hivalliance.org](mailto:admin@hivalliance.org)

Some of you may know that in August of 2008 HIV Alliance was awarded a Capacity Building Grant from Department of Human Services HIV Care and Treatment. The purpose of this grant is to prepare for a pilot project that will begin July 2009. For this project HIV Alliance will become a Care Coordination Center. We will serve 4 Oregon counties with case management and support services.

*The pilot project will include Lane, Coos, Josephine, and Curry counties.* Below are some frequently asked questions regarding this project.

### ***Why does HIV Alliance need to provide services to counties like Josephine?***

In recent years some of the Public Health Departments who were providing Ryan White Case Management have experienced serious budget issues. Three of these counties, Coos, Josephine and Curry, decided not to provide Ryan White Services any longer. Therefore, Department of Human Services needed to find another partner. HIV Alliance is committed to the health of all people living with HIV, and applied for this grant with the goal of improving services for people in those counties.

### ***What kind of work is being done now during the capacity building to prepare for the pilot project?***

The capacity building involves several aspects. First we want to be sure that we have the technological capability to serve additional clients, and improve the service to current clients. We have upgraded the computer system, and are implementing new software and hardware that will allow consistent access to the state server and improve communication. We have upgraded the phone system. The new system answers every call. Our goal is for every client to be able to easily reach a case manager or a voice mail. Second, we need to be able to provide effective referrals to the clients in other counties. We are currently training all staff to become certified information and referral specialists. Our goal is to effectively carry out all the tasks needed to connect clients to the services they need. In this effort we have partnered with Cascade AIDS Project (CAP). CAP was awarded a grant to develop a statewide database of services for people living with HIV/AIDS. Our team will be responsible for entering and maintaining the services for our service area. Finally, we need to update our website. The information there is frequently out of date, and the text is not reader friendly. Our goal is to have a website that can easily be updated, will be more interactive and will be a place for our clients to gather information. In addition, HIV Alliance staff is participating on the DHS Work Group for the pilot project. This group is planning services that will be offered under the pilot project.

Our hope is to continue to provide case managers who will assist you with support services, accessing benefits, advocacy and obtaining insurance. In addition, HIV Alliance will have nursing available to Lane and Coos clients. See the article below for details. Josephine and Curry county clients will be able to access RN services in their own community.

## RN Services

### **RN SERVICES- How we can help you?**

Many clients have become familiar with the case managers at HIV Alliance. We have an RN Case manager, Cindy and several Psychosocial case managers, Grace, Elyn, Cassandra, Angela and Carlos. If you need help with financial assistance, medical transportation, housing, careassist or insurance, call your Psychosocial case manager. *But when should you contact your RN Case Manager?*

Our RN Case Manager has experience with HIV/AIDS and attends annual training updates. Here are some ways she can assist you.

**INFORMATION:** The RN is a wonderful resource for questions related to HIV, as well as other health issues. If you are newly diagnosed, or need an update, she can assist with current information. The RN can provide you with websites or books that are considered safe sources of information. Sometimes after an doctors visit we find that we did not understand all that the doctor said. The RN can help you to understand the information your doctor gives you or the instructions he gives.

**MEDICATION:** Adherence to HIV Medication is very important, so this is a major focus of Ryan White RN Case managers. Whether you have just started medications, are switching medications or have been taking them for a long time, if you are struggling with your medications, or the side effects, the RN is a resource you can use. The RN may be able to assist you in figuring out ways to limit side effects, and strategies for taking your medications. For those with serious adherence issues, the RN will work closely with you to monitor your medication.

**NUTRITION:** We all hear a lot about how important nutrition is to our health. But what do you need to do to improve your nutrition? Talk with our RN about ways to improve your nutrition. The RN case manager can give you practical strategies to improve your diet. Good nutrition can help make you feel better in so many ways. From depression to medication management, good nutrition has a role to play!

**MULTIPLE DIAGNOSIS:** Many of our clients face more that HIV/AIDS. You may be diagnosed with other serious conditions, such as high blood pressure, diabetes, Hepatitis C or cancer. If you find managing multiple diagnosis a challenge, our RN may be able to assist you. Because other conditions can complicate HIV treatment and care, Ryan White RNs focus on helping clients to manage medication regimens, understand diagnoses, and develop strategies to improve quality of life.

These are just some of the ways that the RN at HIV Alliance can assist you. The RN is available by ap-

**Isentress (Raltegravir): The first integrase inhibitor**

*Written by Marie Dorsey, Pharm.D., February 26, 2009*

Isentress (raltegravir) is one of the newest and most unique drugs for the treatment of Human Immunodeficiency Virus (HIV)-1, and is used in combination with antiretroviral drugs for clients resistant to other antiretroviral medications. The U.S. Food and Drug Administration (FDA) reviewed the new drug on priority status and approved it in October 2007.

As the very first drug in the new class of the integrase inhibitors, Isentress is unlike other HIV therapies in that it prevents the combination of viral DNA with human DNA. This genetic integration is a crucial step in the process of viral replication (carried out by the integrase enzyme). When integration is prevented, there is less production of virus and therefore, lower levels of virus in the blood. It is possible that Isentress may also increase the number of CD4 white blood cells, and improve the immune system by allowing a stronger attack on other infections.

Isentress is supplied as a 400mg tablet that is taken twice a day without regard to food, but must be taken in combination with other HIV medications. Studies have not been performed on pregnant women or children below 16 years of age. Isentress is less likely to interact with other drugs, and the most common side effects are, diarrhea, nausea, and headache. Isentress is NOT a medication that cures HIV and does not prevent the transmission of HIV through sexual intercourse, sharing needles, or coming into contact with an infected person's blood. Clients taking Isentress may still become ill with infections.

The cost of Isentress is around \$1,000 per month. The drug company that produces Isentress, Merck, offers a patient assistance program for obtaining free medication for those who qualify. Call Merck at 800-850-3430 for more information on the assistance program. If you think you may be a candidate for taking Isentress, contact your doctor for additional medical advice.

*Information obtained from Pharmacist's letter, 2008 and Isentress package insert, 2007.*

