POSITIVE VOICES-SEPTEMBER 2009

Your Newsletter by Positive People for Positive People

HIV and You: Managing Drug Resistance (Part 2 of 3)

What Factors Contribute to Resistance During Treatment?

The "golden rule" of antiretroviral therapy is: the lower your viral load while on treatment, the less likely it is that the virus will continue reproducing and mutating. An effective HIV regimen should keep the level of virus low—preferably "undetectable."

Unfortunately, there are a number of factors that can prevent an HIV drug regimen from being as effective as it can be. These include:

- Poor treatment adherence: In order for HIV drugs to work correctly, they must be taken exactly as prescribed. Skipping doses or not taking your medication correctly can cause the amount of an HIV drug to decrease in the bloodstream. If the drug level becomes too low, HIV can reproduce more freely and accumulate mutations. There are a number of reasons why someone might struggle with treatment adherence, including side effects, a hectic schedule or forgetfulness. If you've been having difficulty adhering to your drug regimen, it's nothing to be embarrassed about—be sure to tell your doctor (or the STAP Medical Advocate!) so that you can come up with solutions, which might include simplifying your treatment.
- Poor absorption: Not only must HIV drugs be taken on schedule, they also need to be absorbed effectively into the bloodstream. A drug, or combination of drugs, that is not absorbed properly can result in levels in the bloodstream that are too low and, ultimately, allow HIV reproduction and the accumulation of drug-resistance mutations. Certain drugs have dietary requirements, which can affect absorption. People with HIV can also experience diarrhea and vomiting, which can cause HIV drugs to be expelled from the gut too quickly and affect absorption.
- Varying drug interactions: Interactions between drugs—including common HIV medications—can be a major problem. For example, if Viread (tenofovir) is combined with Reyataz (atazanavir), blood levels of Reyataz can fall to dangerously low levels. This is why the protease Norvir (ritonavir), which boosts Reyataz levels in the bloodstream, must be used if Viread is also prescribed. There are many drug interactions like this. Be sure that your doctor knows all of the medications you are taking, including prescription drugs, over-the-counter remedies and nutritional supplements.

Do I Have Drug Resistance?

The viral load test is one of the best tools available to determine if your HIV treatment is working. An undetectable viral load is an excellent sign that treatment is working correctly. Viral load can also show when treatment *isn't working properly*:

- Your viral load fails to go undetectable within the first several months of starting a new HIV drug regimen.
- Your viral load goes from being undetectable to detectable (note: A one-time "blip" in viral load is not usually a sign that a drug regimen is no longer working).
- Your detectable viral load continues increasing, even though you are still taking your prescribed HIV drug regimen.

While viral load can help you determine if your drug regimen isn't working effectively, it cannot explain why this is happening.

This is where drug-resistance testing comes in. These tests can help you and your doctor determine if your virus has become resistant to the medications you're taking—or, if you haven't started treatment yet, help figure out if you were infected with a drug-resistant strain of HIV that might affect your selection of medications.

In Part 3, next month, learn more about drug resistance tests and how you can avoid resistance issues...Stay tuned!

2009-2010 Local Foods Guide Now Available!!!

The new, FREE, 32-page "2009-2010 Guide to Foods Produced in the Southern Tier and Finger Lakes" is now available in hard copy at the Tompkins County Cornell Cooperative Extension Education Center at 615 Willow Avenue in Ithaca.

The Guide lists producers of dairy, meat, poultry, eggs, honey, maple, specialty products, U-Pick farms, farmers' markets, CSA farms and roadside stands throughout our multi-county region. It also is available online at ccetompkins.org. Sorry, but we are not able to provide hard copies by mail!

For more information, call Cornell Cooperative Extension of Tompkins County at 607.272.2292.

Produced by the Cornell Cooperative Extension Agriculture Program in Tompkins, Tioga, Chemung, Cortland & Schuyler Counties.

HOPE DISPENSARY OF THE SOUTHERN TIER

The Hope Dispensary Of The Southern Tier, a service provided by Lourdes Hospital, is a new program designed to provide medications to those that are uninsured or underinsured and have a limited income. Here is how you qualify:

- 1. You must have no prescription coverage
- 2. Have a photo ID or Social Security Card
- 3. Bring one of any of the following as proof of income: Pay Stubs or Bank Statement, SSI/SSD paperwork or Unemployment or Pink Slip form from employer.
- 4. Bring proof of residency one piece of mail with your name and address, such as a phone bill, NYSEG bill or cable bill.
- 5. Bring the prescription with you

If you need assistance with providing this information to determine eligibity, they have an onsite Social Worker who can help you with the process. There is a monthly income level that you cannot exceed. The information is listed on the next page.

Family Size and Monthly Income

1	=	\$1,805	2 =	\$2,428
3	=	\$3,052	4 =	\$3,675
5	=	\$4,298	6 =	\$4,922
7	=	\$5,545	8 =	\$6,168

The Hope Dispensary will verify your information onsite and the Social Worker that is present each day they are open will also provide screenings for financial assistance to access 50% discounted up to possibly free healthcare in the Lourdes network. This is great information!!!

Hope Dispensary does not carry all medications. They do cover HIV medication as well as antidepressants. <u>They do not carry any controlled substances or birth control.</u> If they do not have the medication that you need, they have programs developed so that you might qualify for free medication directly from the pharmaceutical corporations. They use medication samples and generic medications. They are located at 477 State Street in Binghamton and their number is 607-584-9376. They are open Monday through Friday from 10AM – 6PM.

New LGBT Information Site Launched

www.asaging.org/larc

The American Society on Aging has created a Lesbian, Gay, Bisexual, and Transgender (LGBT) Aging Resources Clearinghouse that holds information related to and resources for people aged 50 and older. The site's searchable resources span several categories: education and training; health and mental health; housing and support services; populations and communities; and public policy, advocacy, and legal issues. Also available are annotated listings for service providers, community and professional organizations, information sites, reports and articles, and links for ordering DVDs, books, and other useful products.

FREE CELL PHONES

There is a government sponsored program available that can provide you with a free cell phone and 68 free minutes per month. Eligibility is based on your participation in one of several State or government programs like PUBLIC HOUSING, FOOD STAMPS, MEDICAID and more. There is also a limit to the amount of income you receive each month. This program is called LifeLine Assistance and you can find out about it through safelink.com or calling 1-800-378-1684. If you help with the application process, please call your STAP case manager for assistance.

<u>DIAGNOSIS SURVIVORSHIP A – Z WEBSITE</u>

This is a great resource for all clients dealing with HIV/AIDS, Cancer and other life altering diagnosis. It is full of terrific information on dozens of topics that most of us forget to think about or ask our family, friends and healthcare providers.

Here is the website: http://www.survivorshipatoz.org/hiv/ This site is definitely answer-oriented and user friendly. Below you will find out more about the organization.

Who We Are

Survivorship A to Z is an independent not-for-profit corporation consisting of a small but dedicated staff, volunteer experts, volunteers living after a diagnosis of HIV disease, patient advocates and caregivers.

Survivorship A to Z was founded by David S. Landay after his partner died of HIV and both parents died of cancer.

Why We Exist

Our site exists because the best chance for surviving and thriving beyond an AIDS/Cancer diagnosis is to be an educated consumer. We learned the hard way that there is no single place which has unbiased information covering the financial, legal and practical aspects of living through all stages of life after a diagnosis - starting with summaries and much less on an individualized basis. Our goal is to help you take control by providing in one place:

- All the practical, financial and legal information needed to thrive in the "new normal" that
 exists after a life-changing diagnosis starting with diagnosis, going through a hopefully
 long life, and including end-of-life that as human beings we will all face one day.
- Information on a personalized basis so you don't have to read about stuff that doesn't apply to you - and so you'll know about all that does, including subjects most people wouldn't ordinarily think about.
- Tools to help you keep track of information you need and to make complicated decisions more simple. For example, how to choose the best treatment for you and your lifestyle or how to choose among health insurance policies from the point of view of a person with your health condition. (Yes, you still can buy health insurance - life insurance too!)
- Information in different levels so you can learn what you need to know when you need to know it. For instance, you can read a summary if that is all you need. At the other extreme, our information digs down to form letters and how to complete forms such as the Social Security Disability Insurance application.

We encourage you and all other users to share what you learn so other people don't have to waste precious time reinventing the wheel or going up blind alleys.

Where Our Information Comes From

Information comes from independent experts, nationally recognized law firms, research, government documents, caregivers, patient advocates and patients.

A CLIENT'S FEELING OF GRATITUDE

My name is Bill H. and I too feel like a survivor. I thank God for every day that He gives me and the comfort that I feel from that. There are a lot of people who pray for me daily and my faith in God keeps me going.

One of the greatest gifts I've received so far is that now I have a partner in my life. His name is Eddie. I met him this year in April, he is not positive and it doesn't matter to him that I am. We love each and I am grateful there is someone I care for that shows me affection, caring and support. Also, I thank God for my special extended family of Rick and his mom Linda, who have taken me into their home and treated me as one of their own.

Friday, August 21, I was on my way to work my regular schedule as a long time volunteer of STAP and one block away, my car was hit by a dump truck, which did extensive damage to my car and shook me up like crazy. After dealing with the driver and the police, I drove to STAP as it started to rain. My passenger door and window had been crushed. Jackie came out and put plastic covering over the broken window and door. Jackie, I really want to thank you for that gesture that meant so much to me because of my frame of mind.

I love volunteering at STAP doing front desk tasks and answering the telephones. That contact and involvement and the friendships I developed there keep me going and make my life better. It allows me to give back to the people that helped me when I needed them and still them the most.

My special thanks to all my good friends at STAP: Nancy, John, Nicole, Ann, Candace, Gayle, Robin, Todd, Joe B, Larry, Greta, Ed, Jennifer, Julie, Mary, Steve, Kristina, Teresa, Jackie, Michelle. Wendy and Jessica. You are all very special to me. To Stacy, I miss you a lot. I love all my friends that I have met in my HIV Support Group and Friends Dinner. I am one grateful positive man.

ONEONTA RALLY FOR RECOVERY 2009

Hello All Friends of Recovery!!! The 2009 Rally for Recovery including Walk and Family Day, will be held in Neahwa Park, in the Large Pavilion in Oneonta on Sept 20, 12 - 5 PM.

The first 50 registrants will receive a free Event T-Shirt. The Walk Registration begins at 12PM and the Two Mile Walk begins at 1PM. There will be an optional One Mile Walk also. There is a \$3.00 donation and food will be served from 1:30PM onwards. Live music runs from 1:30PM – 4PM. There will be lots of games and family activities for all.

For more information, you can email this address: <u>brig.seaver@gmail.com</u> or call the Turning Point at 607-267-4435. This is from the Friends of Recovery Delaware and Otsego Counties.

AIDS RIDE VOLUNTEERS NEEDED

Hi All. I am passing on this information in the hopes that you and yours are looking for a fun adventure. There are other options but the one's listed are needy. Pass it on sign up anything you can do to help will be appreciated. If you have not registered to volunteer for The Aids RIDE For LIFE, because you're wondering what you want to do...I would like to offer a great opportunity for you and a few friends.

The following are Pit Stops that really need people. This is such a fun thing to do. The Riders come in and you get to show how appreciative you are by serving lunch, or offering a snack, water, etc...

Seneca Falls: Pit stop #4 - Lunch Stop. Time= 9am to 12noon &12pm -3pm (you can stay all day)

Thee Amish Market: Pit Stop # 5 - Time=10:15am - 1pm & 1pm - 3:30pm (or you can stay the entire time)

Bellwether: Pit Stop #6 last stop before Cass Park -Time= 11:30am - 2:00pm & 2pm - 4:30pm (again you can sign up for the whole shift)

To register go to <u>www.aidsrideforlife</u> and look under registration and click on volunteer. Then complete the information and <u>be sure to say under the comment section</u> that you want one of the pit stops mentioned. This is a great opportunity to help in a different way, help is really needed. get a group and go!!! Thanks a million x 10 in advance

Candace Phelan/Volunteer Coordinator/Southern Tier AIDS Program Phone: 607.798.1706 ext. 225 or www.stapinc.org.

HIV POSITIVE WOMEN'S CONFERENCE LINE STARTING

I wanted to take a moment and tell you of an exciting program that is taking place for HIV Positive persons living in New York State. In April on 2009 the NYS DOH has allowed People Living with HIV in New York State to start a secure dialogue via conference calls. The CNY HIV Care Network facilitates these calls through the Rural Connect initiative. The first group, started in April for HIV Poz Gay Men, conducts calls once a week and is being facilitated by an HIV Poz Gay Man.

Rural Connect recently secured additional phone lines to support a weekly call specific to HIV Positive Women living in NY. Women's calls will be facilitated by an HIV Positive Woman beginning mid-September. Conference calls currently include topics such as disclosure, adherence, access to services, living skills, and barriers to services or any topic that the callers want to bring up! As a person living with HIV, I have found these calls to be helpful in ending isolation particularly to those living in rural areas with little to no transportation. Should you have any questions or suggestions about "Rural Connect" conference calls please contact me either by phone or e-mail. I wish you all a safe and healthy remainder of the summer.

Paul Carr/Program Assistant/CNY HIV Care Network/315 472-8099/pcarr@cnyhsa.com

SPIRIT OF THE OLD WEST TRAIN RIDE

STAP is hosting a Spirit of the Old West Train Ride on Saturday, October 10, 2009. Clients from the Delaware/Otsego region have requested this exciting event and STAP has listened! This event is open to all STAP clients and their immediate family. Participants will enjoy a train ride through Charlotte Valley Railroad during the height of New York's beautiful foliage season. A boxed lunch will be provided to participants. Transportation to/from the Railroad is not provided. If you are interested in attending this event please call STAP today at 1-800-333-0892 and reserve your space. Space is limited. Here is some history about the event.

Built in 1869, the Cooperstown & Charlotte Valley Railroad gives visitors to our area the chance to experience what was once the primary form of transportation throughout the country - riding the rails. In an area rich with railroad history the Cooperstown & Charlotte Valley Railroad takes visitors back in time with vintage rail cars and locomotives through the scenic wilderness of the upper Susquehanna River Valley. The Railroad crosses the river twice over two steel-truss bridges, and travels through a variety of landscapes, including forests, wetlands and agricultural land. In the beautifully restored Milford Depot in Milford, NY, also built in 1869, visitors can view a variety of exhibits and displays.

FREE CONCERT IN SIDNEY

Every Other Friday Night (6:30pm-6pm)Sidney, New York (July 10 - October 30)
1st Annual Friday River Fest/Whitaker's Lot next to Main St. Bridge, Sidney, NY
Free Concerts, multiple performers each event / Visit www.fridayriverfest.com for list of performers

ON-GOING MEETINGS AND COMMUNITY SERVICES

JOIN CONSUMER ADVISORY COMMITTEE [CAC] MEETINGS

The STAP <u>Consumer Advisory Committee</u> is a committee facilitated by and made up of consumers (STAP clients) who welcome other consumers and their significant others, caretakers and family members to join them on the second Tuesday of each month. This collaborative effort provides a confidential space for clients to make recommendations regarding STAP client services and other programs in a non-judgmental environment. The meetings are held following the Friends Dinner at 6:15 at Trinity Memorial Church (on the corner of Main & Oak Streets) in downtown Binghamton.

Call 1-800-333-0892 for directions or more details. If you cannot attend these meetings, mail your opinions or suggestions to STAP, 122 Baldwin Street, Johnson City, 13790, Attention CAC. CAC is encouraging consumers in other counties to organize monthly meetings in their area. Contact your case manager to discuss developing CAC in your community.

THE DRAGON SLAYERS

Hepatitis C and Co-Infection Support Group. Meetings at 6:00 – 7:00PM on alternate Tuesdays at Trinity M, 44 Main Street, Oak Street Entrance in Binghamton. For information, call (607) 798-1706.

FRIENDS DINNER

Friends meet every Tuesday evening for a time of fellowship and good food. Join us at Trinity Memorial Church (on the corner of Main & Oak Streets) in downtown Binghamton. Doors open at 5PM and dinner is served between 5:30 & 5:45. No charge, just come with a smile and a friendly attitude – ready to meet and greet friends and have a hearty meal.

Parking is available on Oak Street behind the Church Annex. Use the Oak Street entrance for the cafeteria. Free bus passes are available for STAP clients! Call your case manager for details. Bus passes available for transportation to/from the Friends Dinner only. For more information call Bill at 607-724-0103.

FREE ANONYMOUS RAPID HIV TESTING

Walk-in Anonymous testing every Monday from 1:00 – 4:30PM and Thursday from 1:00 – 3:00PM at STAP's office, 122 Baldwin Street, Johnson City, NY. For information and other testing times available through the month, please call (607) 798-1706. Confidential Rapid Testing is also available Friday 9AM- Noon & by Appointment.

<u>ONEONTA_SOCIAL_GROUP</u>

Oneonta Social Group every Saturday at the First Methodist Church, 66 Chestnut Street in the Dolly Room from 12:30PM-1:30PM.HIV/AIDS and affected welcome – Brunch is between 11:30-1PM. This is not an official STAP Group.

<u>ASK THE MEDICAL ADVOCATE</u>

Have general questions or concerns regarding HIV?
Want to better manage side effects of your HIV medications?
Concerned about interactions between your HIV meds and other meds that you take?
Want to better understand the results of your blood work or other lab tests?
Concerned about HIV exposure risks to your negative partner?
Interested in alternative or complementary therapies for HIV?

STAP's Medical Advocate, James Elrod, is available to answer your questions—by phone, email, or in person—you choose! It's a great way to get a direct, individualized answer to your questions. Contact James at (607) 426-9445, or by email: jelrod@stapinc.org

Ask the Medical Advocate!