

POSITIVE VOICES – AUGUST 2009

Your Newsletter by Positive People for Positive People

A Survivor - How One Stopped Merely Existing and Resumed Living

Part 3: Riding The Wave

This, the 3rd of 3 articles, relates a survivor's evolvement from living to merely existing, then coming full circle when he (me) resumes living. In Part 2, I wrote about identifying my issues and setting priorities. Now I will share with you how I made the transition, identify some resources and give you some examples of my rediscovered living.

First I needed to stop being an CSW kind of person – no, not a Clinical Social Worker – but a **Coulda, Shoulda, Woulda** guy. I can't change the past, so I had to stop beating myself up. What I can do, is learn from the past and go forward. My new definition of CSW is **CAN-SHALL-WILL**. I don't set goals with time frames that are unrealistic though. Go slow but steady. I don't set myself up for failure.

Resuming my HAART regimen and sticking to it is less of a challenge now that I use blister packs. Some pharmacies will dispense your Rx's this way. Others use pill boards. A great resource for do it yourself dispensing materials is <http://www.forgettingthepill.com/>. They have a wide selection of boards, alarms, reminders, etc. I use their blister pack kit. We all know the importance of adhering to the HAART regimen. But if for some reason you can't or won't comply, tell your health care provider. You may get a lecture, but at least he or she has the facts. When dealing with your provider, keep these two concepts in mind:

- He or she can't read minds. **SPEAK** your concerns
- Don't lie – he or she deserves the truth

These concepts also apply to your case manager at STAP, who may be your single greatest resource. She or he and the rest of the STAP team are amazing. Don't squander it.

Riding the wave off life has been fantastic. I'm doing fun things, some for the very first time. The best example? At nearly age 60, I was a kid again for one magical night. I went to the circus compliments of STAP!!!! I'll keep riding the wave until it wanes away. But that won't mean the end of living – not by a long shot – because there will be another new wave right behind it. And I'll ride that one too.

I hope you have enjoyed reading this series as much as I have writing it. If I have inspired even one victim to be a survivor, then I will have validated my new purpose in life. I'll submit more articles from time to time. But for now, I will enjoy the summer. You do the same. Come ride the wave- be a **SURVIVOR!**

Email your comments: iamasurvivor@frontier.com. See you soon. – Bill

KYDS Family Days in the Park

Keeping Youth Drug-Free and Safe

Come join us on the following Thursdays from 5:30-7:30pm for FREE family and community fun including.....

Games, Snacks, Giveaways, Entertainment, Appearances by Local Mascots, and Information for Families on Substance Abuse Prevention.

August 6, 2009 at Northside Park (Oak Hill Ave., Endicott)

August 13, 2009 at Recreation Park (Beethoven Street, Binghamton)

August 20, 2009 at Highland Park (Hooper Road, Endwell)

August 27, 2009 at Otsiningo Park (1 Otsiningo Park, Binghamton)

For more information contact Melinda Kmetz at 607-778-1146 or mkmetz@co.broome.ny.us or visit www.kydscoalition.org

The KYDS Coalition is a grant program coordinated through the Broome County Mental Health Department funded by a federal grant, the Drug Free Communities Support Program. KYDS Coalition Mission Statement: "The Broome County Youth Prevention Partnership is Keeping Youth Drug-free and Safe (KYDS Coalition) is committed to reducing substance abuse among youth of our area".

An Update From The Director of Client Services

August is an always a busy month for STAP, especially in the client services department at the Southern Tier AIDS Program. The staff has been hosting a bunch of community service projects to thank our community for all the support we have received over the last 25 years STAP has been in existence. Among these include three collaborative events with the Mobile Food Pantry- the last one scheduled for August 21st in Ithaca. We are also hosting an event at the zoo later this month (check out this issue for more information on the "Day at the Ross Park Zoo" Event.) I have received several requests regarding things people would like to do as a group-thank you for your input. I am happy to be a part of an agency that continues to incorporate client, staff and community feedback in all the plans they make. We are trying to do what we can with your suggestions in this sad economy and I apologize that we cannot do it all.

If you get a chance and are interested, "Rent" is playing at the Hangar Theater in Ithaca August 7-22. You might even see a client in the production! A group of us are planning on going to support Hangar as they raise awareness about HIV in our community. We also hope to provide a Spirit of the Old West Train Ride in October, so keep looking for more information about that in upcoming issues. For now, all is quiet in Clients Services, but as you know that won't last for long....

Until next month!!

Gayle

MOBILE FOOD PANTRY

The Southern Tier AIDS Program's Client Services department is hosting a mobile food giveaway in the month of August, as part of their twenty-fifth year anniversary year celebrations and community services initiatives. This is the third event of its kind the Client Services staff is hosting, with previous successful Mobile Food Pantries held in Broome and Tioga counties during May and June. The August event will be staffed by STAP staff and volunteers, and hosted in coordination with the Food Bank of the Southern Tier and the Ithaca Housing Authority. The Tompkins county event is scheduled for Friday, August 21 from 10-11:30 at The Northside Public Housing Development Community Center parking lot, 625 Hancock Street, Ithaca. If you are interested in volunteering to work at this event please call Gayle Pado at 1-800-333-0892.

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.

FREE CONCERTS

Every Wednesday (6:30pm-8pm) Sidney, New York (July 8 - Aug 26)
Don Clayton Trailside Concert Series
Keith Clark Park, River St., Sidney, NY
Free Outdoor Concert, different bands each week

Every Thursday (6:30pm-8pm) Unadilla, New York (June 25 - August 13)
Unadilla Concert Series
Community House Lawn, Main St., Unadilla, NY
Free Outdoor Concert, different bands each week

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

FROM A CLIENTS VOICE: JOURNEYS SPIRITUAL RETREAT

I have gone to the spiritual retreat since 1996. I come home with new inspiration and full of love and compassion for others living with HIV/AIDS. I get to know others not just from the outside, but from the inside as well.

We do and experience many activities such as tie-dye t-shirts, haircuts, massages, energy work, painting, drawing, nature walks in the woods around the lake, camp fires, but most of all it gives us a chance to really get to know others and what they go through in their lives living with HIV/AIDS.

Our joys and our sadness are shared with all and how each one of us cope with our every day struggles. We laugh, cry, hug, and thank GOD for our time at such a wonderful place. But most of all it would not be possible if it was not for the SOUTHERN TIER AIDS PROGRAM that has so graciously given us the opportunity to be able to have such a wonderful spiritual retreat. It shows the commitment that they have in serving their clients.

Every day, we have different clergy from all faiths that come up and just hang out with us to talk with us one on one, or sometimes they just share part of their everyday life with us. Sometimes they just listen to us talk about our struggles, rejections, and how we sometimes think we are all alone in life because of HIV/AIDS. Most of all they give us the confidence that we are all GODS children and He loves each and every one of us and that He is there to listen to us and guide us if we are just ready to put our trust in Him.

The food is good and the staff at Sky Lake are friendly and courteous to us. But the staff from STAP are so kind (sometime you don't look at them as staff, you think they are part of us and I think they get as much from our retreat as most of us do).

But most of all when it is time to leave, none of us really want to go but we know we must. And when we leave it makes us leave knowing that each one of us need to give our love and respect to everyone that was part of the retreat. I do know that we all leave with peace and love in our heart and cannot wait until next year. May GOD bless each and every one of you that was part of 2009 JOURNEYS SPIRITUAL RETREAT. Are you ready to start your spiritual journey with us next year? - Wayne

FROM THE MEDICAL ADVOCATE

HIV and You: Managing Drug Resistance (Part 1 of 3)

The availability of antiretroviral therapy has made the fight against HIV a lot easier. But the medications can't do it alone. They need you! Working closely with your doctor, you'll need to choose and monitor your treatment carefully. One of the most important issues to be aware of is HIV drug resistance. Fortunately, we now know a lot about how to reduce the risk of drug resistance and treat drug-resistant virus. We also have technologies that test for drug-resistant virus and help us make important treatment decisions. These drug-resistance tests have become a routine part of HIV care.

So, What Is HIV Drug Resistance?

In simple terms, drug resistance refers to the ability of disease-causing viruses—such as HIV—to continue multiplying despite the presence of drugs that usually kill them. With HIV, drug resistance is caused by changes, or mutations, in the virus's genetic structure. These mutations can lead to changes in certain proteins that help HIV reproduce itself. Mutations are very common in HIV. This is because HIV reproduces at an extremely rapid rate and is not equipped to correct the mistakes it makes during reproduction. Mutations occur randomly, on a daily basis, but many are harmless. In fact, most mutations actually put HIV at a disadvantage—they reduce the virus's "fitness" and slow its ability to infect CD4 cells in the body. However, a number of mutations can actually give HIV a survival advantage when HIV medications are used, because these mutations can block drugs from working against HIV. These are the mutations we are concerned about when we talk about drug resistance. For people infected with HIV, drug resistance can render drugs less effective or even completely ineffective, significantly reducing treatment options.

How Does Resistance Occur?

HIV drug-resistance mutations can occur both before and during HIV treatment. Here's how this happens:

Transmission of drug-resistant HIV. Many HIV-positive people now take HIV drugs. If someone has developed resistance to one or more of these HIV drugs and has unprotected sex or shares needles with someone who is not infected with the virus, it is possible that they can infect their partner with a drug-resistant variant—a strain of HIV containing mutations that can cause resistance. In the United States and other countries where HIV treatment is widely used, between 5 percent and 20 percent of new HIV cases involve strains of the virus that are resistant to at least one HIV medication.

During treatment. Even if someone is infected with HIV that doesn't contain drug-resistance mutations, genetic changes still occur over time, even before treatment is started. This ends up creating a large mixture of virus in the body. Some HIV cells in the mixture contain mutations that can resist an antiretroviral drug—which explains why one-drug treatment (monotherapy) should never be used to treat HIV.

Soon after combination HIV drug treatment is started, the amount of virus is dramatically reduced. However, if the amount of virus isn't pushed down and kept at very low levels, HIV can continue reproducing, acquiring additional mutations. And once the virus has accumulated enough mutations, a high level of resistance to the drugs being used can occur, causing viral load to increase and CD4 cells to drop.

A major concern with these mutations is that they can result in cross-resistance. This means that HIV resistance to one drug can automatically become resistant to other drugs in the same class. For example, if you're on a drug regimen that contains Sustiva and your virus becomes resistant to it, chances are that your virus is also resistant to the other drugs in that class, Viramune and Rescriptor, even though you haven't taken these drugs. Stay tuned for Part 2, *What You Can Do About Drug Resistance?* Next month!

FROM THE CAC COMMITTEE

During our last meeting on July 14, we discussed how to expand the newsletter and looked for new ways to have clients who read Positive Voices send in their articles, suggestions or thoughts to us for publication. Can any of you help us figure out how it would be easier or more convenient for readers to connect with us?? We need your help on this! You can send your submissions/information/etc. for the Positive Voices to wiedersf@aol.com or call Brian at 607-724-1272. **SAVE THE DATE!!!!** On August 11, we are presenting a workshop about receiving enhanced benefits for Medicare through a program called EVERCARE. A local representative from the company will present this information at the Friends Dinner on Tuesday, August 11. Dinner and presentation start at 5:30PM. Look for the section on the Friends Dinner in this newsletter for directions.

MORE SAVE THE DATES

Binghamton Mets Stadium
Mets N' Pets Night
Thursday, August 27th

Go to www.bmets.com and upload a photo of your pet supporting the Binghamton Mets - photos will be displayed and voted on - winner will receive a prize.

Advance tickets to the game on 8/27 are available for \$5.00 each - you must submit the money to Mary Kaminsky prior to Monday, August 24th. There will be fireworks after the game.

A Day at the Zoo

Friday, August 28th, 11AM - 2PM

Ross Park Zoo

Lunch & Zoo Admission provided by STAP and & the HIV Care Network

FREE!!!! Just call 1-800-333-0892 by August 25 and let us know you are coming so we have enough food!

AIDS Ride for Life - September 12, 2009

Interested in volunteering? Sign-up right on line through STAP's website!

Doggone Fun on the Run - October 3, 2009

ON-GOING MEETINGS AND COMMUNITY SERVICES

JOIN CONSUMER ADVISORY COMMITTEE [CAC] MEETINGS

The STAP Consumer Advisory Committee 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.

POSITIVE CONNECTIONS IN DELAWARE/OTSEGO COUNTIES

A Social Support Group for people infected and affected by HIV/AIDS in Delaware and Otsego counties. The group meets every Saturday at the United Methodist Church located at 66 Chestnut Street (Use the side entrance next to the Dollar General, then first door on the left). A bread lunch is provided to the public starting at 11:00 AM, with the Support Group following from 12:30 – 1:30 PM. Sorry, no transportation is available. Call John for more information at 434-0511. THIS IS NOT A STAP SPONSORED EVENT.

ONEONTA SOCIAL GROUP

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.

ASK THE MEDICAL ADVOCATE

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!

SOUTHERN TIER GENDER ALLIANCE

For information, contact Ethan at (607) 651-9175 or elewis3@binghamton.edu

PFLAG

(For Parents, Families, Friends and Allies of Lesbians and Gays). Meets monthly. Contact Dee Davis at (607) 727-6935 for more information.

ALL COUNTIES COUNCIL OF THE ARTS

There is a great website for the Council of The Arts that has a lot of listings, including special events, concerts, etc. going on around Chenango, Broome, Otsego, Madison and other counties

The link is www.chenangoarts.org. Check it out because you will be impressed with all the low cost activities. If anyone wants to attend you can contact Candace about the event you are interested in and she will try to get tickets for you. Advance notice is greatly appreciated.

Candace Phelan
Volunteer Coordinator
Phone: 607.798.1706 ext. 225

NOTE: Information about your counties local Food Pantries and Community Meals are available by calling your local STAP office and asking to speak to a case manager for listings near you!