

## **POSITIVE VOICES - MARCH 2012**

*Your Newsletter by Positive People for Positive People*

### **A Client's Story**

Hello everyone. My name is Cranny, I am a gay man and I have AIDS. The journey started in January in 2009. Driving myself to the ER with a 105 fever, where I was diagnosed with pneumonia. After spending some time in ICU and quarantined, I was released and then drove myself home. I had a very understanding boss, but was not allowed to return to work until they found out what was exactly wrong with me. The doctor, already knowing that I was a gay man had scheduled a re-check in March. My friend ,who was going to take me to my appointment stopped by the house the day before. She remembered the day but could not remember the time. When I let her in, she took a look at me and said "Get your shoes and socks on, you are going to hospital now." I tried to tell her that I was OK but did not fly by her. I did go to the hospital where I was admitted. During my stay, I went through extreme swelling of my legs, my testicles and every lymph node in my body. I was checked for leukemia, lymphoma and finally HIV. The day that they came in and told me that I was HIV pos. I thought my whole world had dropped out from underneath me. It has been a journey that I will never ever forget. My friend and another gay man have stood by me for this entire time. It was through Catholic Charities where everything started going uphill for me. It was through them I got my SSI and eventually my SSD and all of the other benefits that I have received. During my association with this organization, I found out about STAP. This organization was another stepping stone for me. Through this team, I was able to get more

benefits, like a dentist who works with HIV pos people and the marvelous support group that they have. My partner, who is also positive, and I have made many trips to Binghamton to attend the group meetings and the wonderful dinner that is prepared for us through some of the local churches in the area. There are all kinds of support, camaraderie and information out there that is available and besides, the retreat that is there for us and let us not forget the marvelous Thanksgiving dinner that is prepared for us. If it were not for the staff and the volunteers that give us their time, we would not have this time together. I just wished that we could spend more time with this occasion to get to know more of our community. Let us give a great big YAHOO to them for their devotion to us. Don't forget who you are and any other problems that we have being associated with this disease. Don't be ashamed of being positive. Our friends and family are not going to become infected by our disease just by coming in contact with us. Whether it be shaking someone's hand, drinking out of the same glass or sitting on the same toilet. It has taken me quite a long time to get over this stigma, but with some education, I got over it. Be yourself and get out. There are tremendous amounts of support groups available for us. Find them and go to some meetings. If you are not comfortable with them, then find another one. What you find will surprise you. We are still people, human beings and deserve the same rights as everyone else. "Thank you" to everyone and hopefully, I have helped someone out there in "our" community. Bless you!

\*\*\*My Story (part 2) will be in next month's newsletter\*\*\*

## The Plan “B” Question: Is the HIV community prepared for when the Affordable Care Act fails?

By Sue Saltmarsh, Positivelyaware.com

On World AIDS Day, there were 6,595 people on ADAP waiting lists in 12 states. Four states are currently considering starting waiting lists, and 17 have instituted “other cost containment measures,” including reduced formularies, medical criteria requirements, expenditure caps, lower financial eligibility, and client cost sharing. Six states have disenrolled 445 people due to changes in financial eligibility requirements. In Florida, they not only have the longest waiting list (3,213), but they have also reduced their formulary and are considering lowering financial eligibility requirements.

President Obama, in his World AIDS Day remarks, said he was committing “an additional \$15 million for the Ryan White Program that supports care provided by HIV medical clinics across the country. We want to keep those doors open so they can keep saving lives. We’re committing an additional \$35 million for state AIDS-drug assistance programs.” But as we’ve learned the hard way, no matter how good his intentions are, without the cooperation of Congress, those commitments will not be fulfilled. In addition to HIV/AIDS-specific programs, there are also the well-known threats to Medicare and Medicaid, which many HIV-positive people rely on, and the uncertainty of how much, if anything else, of the Affordable Care Act (ACA) will actually become a reality.

According to the press release entitled “The Beginning of the End of AIDS” issued on World AIDS Day, the ACA “seeks to expand Medicaid for the lowest income people; it strengthens and improves Medicare, and makes private insurance work better for all Americans, including people with HIV.” The operative word there is “seeks” (when Medicare and Medicaid are attacked almost daily by those who want to see them entirely destroyed) and does anyone really believe that private insurance will ever “work better for all Americans”?

At the U.S. Conference on AIDS in Chicago in November, there were several sessions devoted to the issues of access to treatment, sustaining ADAP, preparing for the implementation of the ACA, and how the 2012 elections could affect the HIV community.

As someone attending her first HIV conference, a reporter for *Positively Aware*, a political junkie, and a single-payer activist, I found myself in four of those sessions repeatedly asking the same question of speakers who seemed to take it for granted that the ACA would roll out in 2014 as promised in the legislation signed in 2010. The question was: If the ACA either doesn't get implemented as planned or fails, does the HIV community have a Plan B?

It seems curious that a community which has been so successful in its activism in the past, that has never allowed itself to accept a too-good-to-be-true scheme, and that is certainly not naïve in the ways of politicians would be so completely taken in by the rosy promises of the ACA's expansion of Medicaid to "cover everybody."

In a session entitled "The Ryan White Program and the 2012 Election, 2013 Reauthorization and 2014 Health Care Expansion: What Next?" Anne Donnelly of Project Inform answered that single-payer was originally Plan A, and AIDS advocates had fought hard for it, but, obviously, it didn't even make it to the table. She went on to say that the ACA is now "the law of the land," implying that it would indeed be implemented, but both she and Ernest Hopkins, Director of Federal Affairs at the San Francisco AIDS Foundation, admitted that perhaps some more thought should go into devising a Plan B.

The next morning, attending the "Sustaining ADAP Until 2014" session, led by the AIDS Institute's Carl Schmidt and featuring PA's Jeff Berry, I expanded on the question by adding the proposal that the HIV community start reaching out to other "disease groups" in order to form an unified voice in demanding single-payer health care. Mr. Schmidt assured me that some of that outreach was taking place.

Between sessions, TPAN volunteer Jimmy Simpson and fellow staffer Tom Holler joined me in the hallway outside a session called “Progress Not Repeal” about the implementation of the ACA. We held signs urging support for single-payer and handed out fact sheets on the benefits to HIV-positive people—until hotel security people told us such activity was “against policy” and then stood there to make sure we weren’t being “raucous” or disruptive. I guess they’d heard about the “Occupy Gilead” protest that took place in the Exhibition Hall—kudos to whoever organized that well-designed, obviously well-rehearsed, articulately raucous protest of Gilead’s high price for Atripla and CEO Jim Martin’s \$42 million salary.

Perhaps it’s not just about the ACA or the state of the health care system at any given time. Perhaps we should also be questioning the goals of the National HIV/AIDS Strategy—not for their value, but for their viability. Everyone agrees that the goal of testing more people and linking them to care is not only sound public health care policy, but it will save money in the long run. But once again, if we can’t even guarantee treatment for the people we know are positive now, how can we expect those who would be newly diagnosed to willingly be tested?

New York City’s Health Department has now recommended providing HIV drugs to every person who’s diagnosed, as soon as they’re diagnosed. According to an AP story, “City health officials said they anticipated that the cost for expanding the use of AIDS drugs would be covered by private insurance or by the AIDS Drug Assistance Program, a \$270 million program for the uninsured or underinsured that is partially funded through federal dollars. The health officials said they expect the benefits over the long term would far outweigh the initial costs because there would be fewer hospitalizations and new HIV cases.” But what if people are uninsured or can’t afford the co-pays? What if New York’s ADAP, like many others across the country, can’t handle the influx of new enrollees and institutes a waiting list?

No one can predict how this will turn out. Skepticism is sometimes the healthiest approach, and in this case, it certainly seems to be. I hope

there are HIV/AIDS advocates out there who *are* thinking about Plan B, who *are* talking to cancer survivors and cardiac patients and diabetics. I hope the HIV community will lead when the ACA inevitably fails and the battle lines are drawn in the fight for single-payer health care. But to do so, we have to be prepared for the fight.

Lots of people at USCA told me I was preaching to the choir with my single-payer message. I say the choir needs to rehearse so when the time comes, the song will be huge and undeniable and triumphant.

## **ON GOING MEETINGS AND COMMUNITY SERVICES**

### **Join/ Attend: 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 @ 5:45 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.

## Emergency Pet Fund

Our “Bottle Drive” is continuing to raise funds for the Emergency Pet Fund to assist clients with medical expenses to save their dear pet or to help provide for humane end of life expenses.

Bottles and cans can be dropped off at the “Friend’s Dinner” or at STAP offices. Please make sure that the bags ONLY have bottles or cans - we have also gotten some household garbage be accident. We also accept gift or financial donations for this cause, just be sure to make note that they are for “The Emergency Pet Fund”.

We would like to thank everyone who has helped out with this special cause.

## Friends Who Care Support Groups

**Broome County:** “Friends Who Care” meets every Tuesday at 3 pm - 4:30 pm at Trinity Memorial Church located at 44 Main St. in Binghamton... come join us for Binghamton’s HIV/AIDS Support Group **\*\***(open to clients only). Also stay for a good (free) meal afterwards at the “Friends Dinner”.

**Chemung County:** Men Living with HIV Support Group; 2<sup>nd</sup> Monday of each month; 6-7:30pm; Ivy Clinic, 600 Ivy St., Suite 206, Elmira. For more information people can contact me via phone or email. Lynn Bassler, LMSW Treatment Adherence Counselor, Ivy Clinic, 737-8188.

**Tompkins County:** The IVY Clinic is pleased to let all HIV+ men in the Ithaca and surrounding area know there is a support group that is held the third Tuesday of every month at the Ithaca STAP office. Time for the group is 6-7:30 pm and topics vary from month to month. If you are interested in attending please e-mail Shannon Sprague at [ssprague@aomc.org](mailto:ssprague@aomc.org) for further information.

**Tompkins County:** A NEW support group open to ALL HIV+ clients of STAP is starting in Ithaca. The first group meeting will be on December 1<sup>st</sup> from 1:00-2:00PM at the Ithaca office, and the 1<sup>st</sup> Thursday of the every month thereafter. Please call Autumn Cook, STAP Medical Advocate at 607-426-9445 for more information.

**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 Alisa at (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 @ 5:30. 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. Call your case manager for details. Free Bus passes available for transportation to/from the Friends Dinner only. (STAP clients only) For more information about the “Friends Dinner, call STAP in Johnson City and they will get you in touch with Bill.

### **Free Anonymous Rapid HIV Testing**

Walk-in *Anonymous* testing is available in our STAP Johnson City office every Monday from 1:00-4:30PM and Thursdays from 1:00-3:00PM. *Confidential* testing is available in our STAP Johnson City office Thursdays from 9:00AM - 12:00PM. STAP's office is located at 122 Baldwin Street Johnson City, NY 13790. Walk-in *Anonymous* Testing is also available at STAP's Ithaca office located at 501 S. Meadow Street, Ithaca, NY 14850 on Tuesdays from 9:00AM-11:30AM, and *Confidential* testing can be scheduled Thursdays, 9:00AM-11:30AM. For more information and other testing opportunities available, please call (607)798-1706.



## **Free EDUCATIONAL Lunch/Dinner**

Our next “EDUCATIONAL LUNCH” (Monday, April 23<sup>rd</sup>, 2012) will be held again at Grande’s on Upper Front Street at 12 noon. Keep in mind that you need to R.S.V.P. with Martha (607) 238-8350 to save a seat for you and a guest; if you have any questions, she will be happy to help you. Seating is limited to the first 30 people and she needs to know who will attend at least a week in advance. \* You must provide your own transportation to and from this event.

## **Tax Season Is Here:**

In the next few weeks you will be receiving any number of documents related to your specific tax situation - this can become confusing. The “Good News” is that Cynthia Knight will be available to help us out with our taxes again this year. She has been a volunteer for STAP for several years and has helped so many with all our “special needs” when it comes to doing our taxes correctly. With that being said, she has asked me to remind all seeking assistance to **PLEASE contact her as early as possible.**

You can contact Candace @ STAP or by email at : [cphelan@stapinc.org](mailto:cphelan@stapinc.org)

You can contact Cyndi by email at: [cknight1957@gmail.com](mailto:cknight1957@gmail.com) or ask Candace to get you in contact with her by phone. Keep in mind she provides this service at “no charge” to clients.

## Ask the Medical Advocates

C.H.O.I.C.E.S. is a self-paced educational series designed specifically for YOU to learn and understand HIV and your body. Whether you take one quick course or decide to go through the entire program and take charge of YOUR HIV, ask a Medical Advocate about C.H.O.I.C.E.S. today...

This program can help you by:

- Answering general questions or concerns regarding HIV
- Help you better manage side effects of your HIV medications
- Alleviate concerns about interactions between your HIV meds and other meds that you take
- Help you better understand the results of your blood work or other lab tests
- Learn how to reduce HIV exposure risks for your negative partners

*Contact: Stacy at #798-1706 Ext. 210 or Autumn at #280-8322*

\* Every 3<sup>rd</sup> Tuesday of the month at 5 pm - just before the Friends Dinner come join us for our monthly C.H.O.I.C.E.S. module. (open to all) We have found that we get more out of the program when we learn the modules as a group. Informative questions and discussions are raised.

\* Next Program will be March 20th at 5 pm with Autumn in the dining room at Trinity Church. Followed with a free dinner prepared by one of the local churches that supports our “Friend’s Dinner”.

## From the Editor:

I would like to Thank our “Friends” for sharing their stories with us and hope that the stories will continue to come into the newsletter. Again, I want to remind everybody that this newsletter is for us & from us - that being said...

Please take a few minutes to send in some comments / concerns / questions for the Medical Advocate. If you don't feel like sharing your story, tell us about something that has worked for you in dealing with all that we must due to our diagnosis. Keep in mind, for some of us this is their only form of support while dealing with this disease.

Just because you may feel your input may not be helpful enough, someone else may find it just what they needed to hear to help them overcome a current barrier they may be dealing with.

# **Nutrition Education Workshop**

**(Exclusively for STAP clients)**

**Date: March 13<sup>th</sup> 2012**

**Where: Trinity Memorial Church**

**Time: 4:00 PM to 5:30 PM**

**RSVP by March 9<sup>th</sup> to**

**Stacy Nickerson, Medical Advocate @**

**607-798-1706 (Ext. 210)**

**Learn how to prepare healthy and delicious meals on a limited budget with a registered dietician from Cornell Cooperative Extension.**

**Take home all the ingredients you will need to prepare the meal again on your own!**

**Limited to 20 people!**