

POSITIVE VOICES - February 2013

Your Newsletter by Positive People for Positive People

“You were given this life because you are strong enough to live it” -Unknown

I'm one of those people who never looks forward to the end of the year, we tend to reflect on that past year. The thought of all those who will not be joining us in this New Year, and that can bring a tear. And this approach to the New Year was worse than any of recent memory. I was already on shaky ground to start off with, I had a deep personal loss when a close friend suddenly died this summer. That in itself was like being blown apart by a cannonball and I was still looking for all my “pieces”.

Then, the Newtown 26. I think my heart stopped beating, I had no feelings - my emotions shut off - a pain overload. Sure I cried - it hurt! Now I can see I was in shock, tears to the point where I could not watch the TV coverage. What was this world coming to? Why do humans continue to do horrible things to each other? You could drive yourself crazy asking yourself “Why?”

During this time of many tears, I noticed that my companion animals were turning up their “antics” and wanting “extra” cuddle time. It was like they were working for a smile from me. They picked up on my sadness and wanted to comfort me, show me that things will get better again. The dog played in the snow as if it was his first time seeing it, at that moment “playing in the snow” was the most important thing he could be doing. There it was again - right in front of my face : The joy of living in the moment. We all did it when we were kids, wake up to find No School because of a “Snow Day” and it was the start of a new adventure just outside your door. My world was making no sense to me and then my dog showed me how to find a way back to myself. Other pieces of the puzzle were still to be discovered and the pets would come to remind me of other “lessons” I have learned along the way. I found a way to get back to a peaceful place with the assistance of one of the horses, a snow covered field, beautiful blue sky with a few wispy clouds - I was able to have that talk with the “soul” and ask for peace.

Pets Are Wonderful Support - damn right!

When I could not find answers out there to explain what I thought was the world's problems, I looked inside my circle to help me find a path forward. They would stay by my side when I needed that comfort from contact, other times they would find ways to entertain me or just make me smile, and they would lead me to an answer when I could recognize the question. I can't really explain the whole thing, but I feel like my pets helped me find my way through the very hard times I was experiencing as 2012 was coming to an end. They have always brought joy to my life and I have many happy times with them - maybe that was all they really needed to show me.

January 11, 2013 (POZ.com)

We Can Change This - by Jeremiah Johnson

The former Peace Corps volunteer who helped change its discriminatory HIV policy reflects on five years of living with the virus.

January 11 marks five years since I was diagnosed with HIV. Since then, I have undergone a transformative journey filled with highs and lows, peaks and valleys. Yet through it all—through every single challenge I have faced as a gay man living with HIV—I have had tremendous support. I had a father who was brave enough to stand by me even when he didn't understand me. I had friends who loved me when the negativity from others and from within myself felt like it would crush me. I had a loving and caring doctor who patiently listened to all my questions (even the ones I was afraid to ask) and helped me get on life saving treatment.

It is thanks to them that a situation which could have broken me has instead empowered me. I am stronger and more capable than ever before to fight for my rights and the rights of other people like me.

But, for me, it was very dark before the dawn. Before I could step into the light, I felt alone in the shadows, trying to find my way by myself. When I was diagnosed with HIV, I was halfway across the world; far away from my family and friends and serving as a Peace Corps volunteer in Ukraine. After serving for 16 months with 11 months to go, I was offered an HIV test as part of my mid-service medical exam. I took the test, not expecting that it would come back positive, and not knowing how much it would change my life.

That was how, thousands of miles from home, I found out that I had HIV. The virus that was at the center of so much worldwide discussion was inside of me - just under the surface of my skin. I knew the facts: I knew that I could live a normal life so long as I had medication, but still I felt despair in my heart. Every negative thing I had ever heard or thought about the virus or those who carry it seemed to suddenly flourish in me, and I internalized it. The shame, the fear, the despair all grew in and around me. I needed help, and I desperately needed support. But, even more than that, I needed empowerment. I needed to finish the last year of my Peace Corps service and prove to myself that my diagnosis would not define me. I decided, even in the dark haze of my diagnosis, that I would not retreat and not back down. I needed more than ever to feel valuable, to feel loved, and to feel powerful.

But instead of finding what I needed, I found opposition, isolation, stigma, and discrimination. Shortly after my diagnosis, I was contacted by Peace Corps administration and told that I would have to leave Ukraine - that the laws there would not allow me to complete my service. When I later asked them if I could finish

my service in another country with less oppressive laws, I was told that I could not continue as a volunteer. According to them, being HIV positive meant that I could not fulfill my duties as a volunteer and that they would be unable to take care of my medical needs in a developing nation. It did not matter to them that I was physically just as strong as ever, or that all I needed was regular blood work and possibly treatment to keep me strong. It seemed that Peace Corps saw me only as a burden - as a liability that needed to be returned home immediately.

The loss I felt was tremendous and the obstacles ahead of me felt insurmountable. Instead of support, I was surrounded by people who seemed ready to get rid of me. Instead of empowerment I had been shown just how little worth I had. Instead of love, I felt despair—deep and profound and all encompassing. Behind me I saw only loss: The loss of the work I was completing in Ukraine, loss of the hopes I had for the projects started in the small town where I had been stationed, the loss of the friends I had made and the students to whom I had taught English, and finally, the loss of my perfect health. In front of me, I saw fear - the fear of being forced to tell friends and family why I had returned home, the fear of unexpectedly having to find a job and a place to live, the fear of finding a doctor and confronting my new diagnosis.

It took a friend—an amazing person in my life—to remind me that I was not powerless and that I was just as valuable as ever. In my darkest moment, my friend lifted me up so that I could see the path forward- so that I could see my way back from the brink of destruction. It is because of that support that I felt strong enough to contact a lawyer about my dismissal from Peace Corps. That lawyer then connected me with the American Civil Liberties Union, who took my case and helped me challenge the legality of what Peace Corps had done. From there the support around me grew - as I felt more empowered, more friends and family rallied to my side and gave me the love I needed to fight the negativity that was invading my life. I found a job where I could be out about my HIV status. I found a doctor who treated me as a peer and gave me confidence in managing my own health. Things still felt dark, but the warmth around me let me know that night was almost over - that I was headed back to a better place.

Just six months after being kicked out, the dawn came. The Peace Corps stopped defending their policy and announced that volunteers with HIV would be able to continue their service uninterrupted. It was a victory not only for the rights of volunteers living with HIV, but also for me, personally. It showed me that no matter what others said about me, I could stand up to anything so long as I had support. With the help of my friends, my family, and my doctor I would not only survive—I would thrive.

It hasn't been all smooth sailing since that time. It is never easy to be part of such a highly stigmatized group of people - but with every bump and every fall, I have had a network of people to help catch me- to help me find my way back to where I belong.

The support that helped me fight back against discrimination is the kind of support that every single person living with HIV should receive. Every. Single. One. I don't care how they got HIV, where they live, who they love, what ethnicity they are, how much money they have, or what gender they are. We all deserve to be loved, embraced, and empowered. We should all have the right to access the best medications that don't produce side effects. We should be protected by our governments, not prosecuted by them. We should all have healthcare from nonjudgmental doctors who treat us as equals. We should have friends and family who stand by us and help us continue to reach for our dreams. We should all be treated as amazing, beautiful, sexy, and very capable individuals. We should all be treated as more than a virus.

But right now for the **34 million people living with HIV** there is no guarantee for support, no guarantee for love, no guarantee for safety, and no guarantee for medical care. Right now there is so much work that must still be done to protect the rights, dignity, and dreams of HIV positive individuals. And we can't wait because right now millions of people still need life-saving treatment. Right now, **45 countries** still have laws that undermine the rights and well-being of people living with HIV. Right now millions of people, human beings just like you and me, are dying every year because medications are too expensive, too inaccessible, too far away. Right now the dreams of millions of people living with HIV must take a backseat to fear: fear of violence, fear of financial insecurity, fear for their health, fear of being rejected, fear of being alone.

We can change this. You and me. We and our friends. We can raise awareness through social media. We can write our legislators. We can learn what efforts are being made to stop injustice and support them. We can empower people living with HIV with our words and never make them feel limited - never clip their wings. We can demand that governments, international organizations, pharmaceutical companies, medical doctors, AIDS service organizations, and HIV prevention organizations place the wellbeing and quality of life for people living with HIV above ALL other priorities.

Support and justice is obtainable for all those with HIV, but we must all work together to demand for change. It will not be given freely. We cannot keep the status quo; we must look at existing systems, organizations, and policies with new eyes and learn to question what can be better. We will have to think outside of the box and ponder what makes people living with HIV feel like victims, feel helpless, feel stupid, and feel abandoned. We will also have to consider our own role in the stigmatization

of people living with HIV. How do we speak about HIV when we think no one around us is infected? How do we deal with the possibility that a sexual partner might be living with HIV? How do we truly and honestly feel about people who are HIV positive?

How do we change ourselves? How do we change the world to be a safer, more empowering place for people living with HIV? How do we stop stigma and discrimination?

Today, five years after my diagnosis, I am thankful that I feel safe, strong, and healthy. I dream of a day when all people living with HIV can feel the same way.

Jeremiah is currently a 2nd year MPH student in the sociomedical sciences department at the Mailman School of Public Health. Diagnosed with HIV in 2008, Jeremiah has firsthand knowledge of the impact that stigma and discrimination have on people living with HIV. Since his success in changing Peace Corps' discriminatory policy on HIV, Jeremiah has continued to raise awareness for the detrimental impact that stigma has on the spread of HIV and the lives of those living with the virus. Most recently, he spent two years in northern Colorado working as a case manager and prevention specialist at the Northern Colorado AIDS Project. There, he learned that there is still much work to be done to improve the quality of life for people living with HIV.

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 any Tuesday night at the Friends Dinner;(where we hold court so-to-speak). The floor is always open so that any concerns can be addressed as soon as possible. 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 during the Friends Dinner at Trinity Memorial Church, downtown Binghamton. Call 1-800-333-0892 for directions or more details. If you cannot attend these meetings, mail or e-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.

Do you have something you would like to share / a question / a topic and you want to get it in the newsletter?

A) You could relay it via your case worker - who would be happy to help you,

B) Stacy or Michelle can help get it to where it needs to be... try.

I can't believe people would have nothing to say, this disease has tested every fiber of my existence, taught me lessons I did not want to learn and showed me just how strong you can be when you are willing to look inside yourself for the strength.

*Currently we are working on a time and place where we will be able to have a showing (or more than one) of the documentary "How to Survive a Plague" (Google it). STAP has offered the Johnson City office as a possible venue that can be used after-hours for this purpose. STAP would also like to make available a showing for staff who would also be interested in seeing the film. At this time we are only able to have showings in the Binghamton area, if interest & turnout will warrant it, we will do everything possible to have showings in other areas. This time of the year travel can be difficult, so it is being considered while planning this event. Seating will be limited so once we have the date(s) Candace will have a sign up sheet to attend. *(No Charge).

Friends Who Care Support Groups

Broome County: “Friends Who Care” meets every Tuesday at 3 pm - 4:30/5:00 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”.

This group of “Friends” started up 4 years ago when we were unhappy with the “canned” therapy we were getting at our local mental health. Trinity came to our rescue and allowed us to hold our meetings prior to the Friends Dinners on Tuesdays. The bonds we have formed over time have us calling each other “family” - this is truly a “support group”. We consider ourselves “Lucky” to be part of something so special. New members are welcome. - **Take a chance.**

Chemung County: Men Living with HIV Support Group; 2nd Monday of each month; 6-7:30pm; Ivy Clinic, 600 Ivy St., Suite 206, Elmira. For more information people can contact: **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. If you are interested in attending please e-mail Shannon Sprague at ssprague@aomc.org for further information.

Friends Dinner

“Friends” meet every Tuesday for a time of fellowship and food. Join us at Trinity Memorial Church (corner of Main & Oak St. - across from the High School) in 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 friends and have a hearty meal. Parking is on Oak St. behind the Church Annex & use the Oak St. entrance for the cafeteria. Call your case manager for info. Free bus passes available for transportation to/from the dinner (STAP clients only). For more info about the “Friends Dinner”, call STAP and they will get you in touch with Bill.

Free Anonymous Rapid HIV Testing

Walk-in *Anonymous* testing is available in the STAP Johnson City office Mon from 1PM-4:30PM and Thurs from 1PM-3PM. *Confidential* testing is available in the Johnson City office Thurs from 9AM-12PM at 122 Baldwin Street, Johnson City. Walk-in *Anonymous* testing is also available Tues from 9:00AM-11:30AM, and *Confidential* testing is Thursdays, 9:00AM-11:30AM at STAP's Ithaca office located at 501 S. Meadow St, Ithaca. For more info and other testing opportunities call (607)798-1706.

Free EDUCATIONAL Lunch: February & March 2013

Tuesday: February 12th at 12 noon will be our first “lunch” of the year.

Monday: March 18th at 12 noon will be the second “lunch” of the year.

***See Flyer enclosed. * Both dates will have a guest speaker.**

From this point on, all these “lunches” will be held at Grandes’ on Vestal Ave. If anyone is unsure where this is - Martha will help with that....

* As usual seating is limited (you & a guest only) and must be reserved with Martha at least a week before the event. *R.S.V.P. - Martha # 607-644-7586.*

These are “learning events” - please respect everyone’s right to learn.

** Please turn off your cell phones / important calls ? Vibrate !

Leave the room if you take the call.

Ask the Medical Advocate

** DO YOU Know What the C.H.O.I.C.E.S. Program Is?

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...

Medical Advocacy Coordinator: Stacy # (607) 798-1706 Ext. 210

Medical Advocate: Autumn # (607) 426-9445

* Every 3rd Tuesday of the month at 4:30 pm - just before the Friends Dinner. Come join us for our monthly educational session (open to everyone). We have found that we get more out of the program when we learn the information as a group. Informative questions and discussions are raised.