

POSITIVE VOICES-JULY 2011

Your Newsletter by Positive People for Positive People

Sky Lake Client Retreat: 2011

On June 14th over fifty clients and staff of the Southern Tier AIDS Program set out on a life changing adventure: The Annual Journey: A Client Wellness Retreat. For some, the retreat was a new experience, and for others it was a familiar haven they look forward to annually. Participants enjoyed three days and two nights at the beautiful Sky Lake Retreat Center in Windsor, NY. During the get-away folks enjoyed massages, crafts, games, campfires, fishing, a karaoke party and a healing service just to name a few activities. The agenda was packed with education and plenty of opportunities to make new friends and lasting memories. This year participants even had the chance to learn about safer sex techniques and get one-on-one education with STAP Prevention Educators. Thanks to the generosity of the Gesso Foundation, several providers throughout the Southern Tier, and the help of STAP's Development team, STAP is dedicated to ensuring this retreat continues year after year because there is magic happens at the Lake that can not be described in words, but must be felt with the heart...Here is one client's experience:

A Client's Reflections on Sky Lake

This was my third year at the Sky Lake Retreat, two years ago was my first and I was only diagnosed 4 months earlier. Maybe it was all the familiar faces when we arrived but I got a feeling that this visit was going to be different this time. Since my first visit to camp I have come to terms with my diagnosis and learned how to take control and started to live life again. Now I look back at the first year and see how much of a sponge I was, absorbing all the information I could to help me understand what life was going to be like with this disease - at that time I was unaware of just how much I had learned.

The second year seemed to be the emotional one, I had a good time, but I was able to open up more and deal with the demons that we all carry around with us. That year I spoke at the Rose Pedal Ceremony, something that was very powerful for me even with the tears.

This year seemed to bring some strange calm about me from the minute I arrived, it just felt so good to be among friends who understand the importance/ joy of life. To be around so many smiles and free spirits who left their troubles

behind as I had done. To be able to sit and talk with people who have become true friends, who unfortunately I don't get to see often enough. To laugh, and it seems there was so much laughter this year - at least that's what I kept seeing. I went home that last day feeling refreshed and renewed - looking forward to seeing my friends again next summer and sharing stories of the life we have lived in the past year. Sometimes just the simple things in life have such a big meaning. I'm sure in the weeks to come I will still be basking in the "heart light" I experienced this year at camp.

-Will

UPDATE: A Survivor - How One Stopped Merely Existing and Resumed Living

Where has the time gone? It's been two years since I wrote the *I Am A Survivor* articles. It seems like it was just yesterday. Why the delay in writing the promised update? A combination of things: lazy, didn't think I had anything to report, did I mention lazy? But here I am now ready to give you an update on what's been happening. My plate is still full - new helpings of the same old stuff.

I now use voice recognition software almost exclusively for notes like this. My fingers just aren't good enough. If you read my Facebook posts and comments, you can easily tell if I'm using the software or typing by hand.

Healthcare is now all received at Albany Medical Center. Care there is excellent. I changed primarily because of the retirement of Dr. Chaffee and more recently the departure of Dr Zhao. It's just as far to Albany as it was the Binghamton.

I now have a pacemaker. Was having low heart rate. Only problem with it - it sets off metal detectors.

Viral load is still undetectable. CD4 is a paltry 119. Don't think they are never going to get very much higher even though my HAART compliance rate is 99%. Those cells appear to be permanently damaged.

My pet cat Brownie, died on New Year's Eve 2010. He was 18 years old. I saw Brownie be born and I saw him die. I have not replaced him yet because there is no replacing. Perhaps I'll adopt a kitty soon. I'll know when the time is right.

I'm proofing this as I write. My style of writing has changed. H-E double hockey sticks - I'VE CHANGED.

That brings me to the best news. I am still 'street' drug free. It's not easy, but I'm doing it - one day at a time I DON'T WANT THAT JUNK ANYMORE!!

My higher power still is my strength. Living in the boonies and no transportation makes attending Sunday Mass difficult. I chose to rekindle my Roman Catholic upbringing. Where I live Mass is televised on cable VERY early in the morning.

The solution for me comes via the Internet. As early as Saturday afternoon, the current Sunday's Mass is taped (in advance) and placed online at: <http://thesundaymass.org/>

I urge you to find some way of connecting with your higher power - whomever - or whatever that may be. I guarantee that you will gain the strength you need to manage YOUR plate.

I expect to be around for a long time and my cause of death, when it happens, will be from something other than complications from AIDS. Remember, I am a not a victim- I AM A SURVIVOR.

Join me in not just existing - but LIVING again. If I can do it so can you. Re-read the earlier articles for some tips. Life is what you make of it. Come on LIVE it!

By the way someone asked me about the 'Picture it" phrase in Part I. I borrowed that from Sophia Petrillo (played by the late Estelle Getty) on The Golden Girls.

Hope to 'see' you out there- online or on the street.

You can join me on Facebook: <https://www.facebook.com/Smithwb1049>

Have a GREAT summer!

- Bill

Have questions about end of life issues?

Thanks to one of our dedicated and knowledgeable STAP volunteers, Sarah Lewis, individual appointments and group information sessions are available to STAP clients to assist you with any questions you may have about living will declarations and memorial planning. Please contact Kelly Conroy, Medical Advocacy Coordinator, at 607-206-3418 if you are interested in meeting with Sarah.

Making Medical Advocacy Work for You...

Are you looking to improve or maintain overall good health? Medical Advocacy is much more than tracking Cd4 counts and viral loads. We can help you get the information you need to make important decisions that impact your health. We have a wealth of resources to share with you about many topics. We understand that many people experience medical issues other than HIV, such as heart disease and diabetes. We can partner with you and help you reach your goals regarding your overall health. Maybe you have questions about nutrition, the latest treatment guidelines, new HIV medications, alternative therapies, exercise, mental health, managing side effects, family planning, or immunizations. Contact a medical advocate today with your specific questions and we will work with you to keep you in charge of your health. Please contact one of our Medical Advocates for more information on making medical advocacy work for you!

Wixie Skellett 607-206-0331

Kelly Conroy 607-206-3418

SAVE THE DATE!

STAP and Gilead Sciences cordially invites you to dinner and a presentation at Grande's
Bella Cucina Restaurant
(1171 Vestal Avenue, Binghamton)

Thursday, July 7th
HIV and Inflammation
Presented by Samara Gabree, NP
Albany Medical Center
Division of HIV Medicine

Thursday, August 4th
Treatment Initiation & New Treatment Guidelines
Presenter TBA

Both events are FREE!
Hope to see you there!!

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 or Brian Wieder at 607-724-1272 to discuss developing CAC in your community.

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 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 throughout the month, please call (607)798-1706.

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 ADVOCATES

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?

Kelly Conroy/Medical Advocacy Coordinator/.607-206-3418.

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:

You must have no prescription coverage

Have a photo ID or Social Security Card

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.

Bring proof of residency - one piece of mail with your name and address, such as a phone bill, NYSEG bill or cable bill.

Bring the prescription with you

If you need assistance with providing this information to determine eligibility, 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. They do not carry any controlled substances or birth control. 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 need help with the application process, please call your STAP case manager for assistance.

Community Art Class at The Cube

STAP is offering a Community Art Class at The Cube located at 208 State Street, Binghamton, NY. The class is open to all groups: HIV positive, HIV negative, LGBTQ community, gay or straight. The classes include drawing, collage, watercolor, painting and more. No experience is necessary to come and have fun while being creative! Please contact the staff at The Cube for more information regarding dates, times or location by calling 607-651-9120.

The Cube address: 208 State Street, Binghamton, NY 13901