

POSITIVE VOICES - JULY 2012

Your Newsletter by Positive People for Positive People

AIDS 2012 Lineup of Speakers is Stellar

Positively Aware online / Summer 2012.

Organizers of the XIX International AIDS Conference (AIDS 2012) announced on June 13 that President Bill Clinton, South African Health Minister Aaron Motsoaledi, philanthropist Bill Gates, and humanitarian Sir Elton John, will be among the high-level speakers who will join thousands of the world's top AIDS researchers, community leaders, and other stakeholders in Washington, D.C. this summer.

An estimated 25,000 attendees are expected to attend AIDS 2012, which will take place from July 22 to 27 under the theme Turning the Tide Together. This biennial event is the world's largest meeting on AIDS, where leading scientists report on the latest AIDS research, and together with implementers, community leaders and policymakers, help to identify next steps in the global response to AIDS.

President Clinton will deliver keynote remarks at the closing session on Friday, 27 July. Sir Elton John will deliver a keynote address on Monday, 23 July.

"We are delighted to welcome the world's leading AIDS scientists to AIDS 2012, and to have secured these high-level keynote speakers at this crucial time in the global response to HIV," said Elly Katabira, International Chair of AIDS 2012 and President of the International AIDS Society (IAS).

The theme of AIDS 2012, Turning the Tide Together, has been selected to emphasize how a global and decisive commitment is crucial to change the course of the epidemic now that science is presenting promising results in HIV treatment and biomedical prevention.

"AIDS 2012 represents a unique occasion to mobilize policy makers, governments, NGOs, scientists, people living with HIV and civil society to join forces," said Dr. Diane Havlir, U.S. Co-Chair of AIDS 2012 and Professor of Medicine at the University of California.

"Despite the global turbulent economic climate we cannot miss this historic moment, and it is vital to continue to attract funding to invest in AIDS research and promote programs based on effectiveness and efficiency in order to optimize the use of resources," concluded Havlir.

The full AIDS 2012 programme is now available through the conference [website](#) and significant parts of the program, including webcasts of key sessions, speeches, slide presentations, abstracts, digital posters, session-specific and daily rapporteur reports, as well as workshop handouts and audio recordings, will also be online during the conference.

Positively Aware Editor Jeff Berry, Associate Editor Enid Vázquez, and Art Director Rick Guasco will be reporting, posting, and tweeting from the conference.

Get conference updates and share your thoughts and ideas by tweeting @aids2012 or using #AIDS2012. Become a fan of AIDS 2012 on [Facebook](#). If your group or organization is participating in AIDS 2012, post photos and videos of your work on this page.

TROUBLED WATERS

Our arsenal of HIV prevention and treatment tools is good enough to end the epidemic in the U.S. Anthony Fauci, Mr. HIV/AIDS of the federal government, has said as much. Secretary of State Hillary Clinton has said an “AIDS free generation” is not only possible, it is a priority. President Obama agrees: “We can end this epidemic,” he said last World AIDS Day.

There’s a doozy of a rub, though. Only 28% of HIV-positive people in the U.S. have met one of the requirements to end AIDS by anyone’s calculation—total viral suppression. Only 41% stay in care, let alone start treatment and stay there. Oh, and federal HIV/AIDS funding is going in the wrong direction to right this boat. President Obama gave us some long-awaited goals in the first-ever national HIV/AIDS strategy, but he neglected to put any money where his mouth was.

Empty rhetoric couldn’t get this far without apathy and indifference. Where I live is an example, from state AIDS directors who seem almost content with more than a decade

of static infection rates, down to local clinics devoid of community outreach or involvement, and an AIDS service organization that exploits the most archaic notions of people with HIV rather than stamping out fear and judgment.

No wonder 34% of Americans still think HIV is transmitted via toilet seats, drinking glasses, and swimming pools, or that only 28% feel very comfortable eating food prepared by someone living with HIV/AIDS. Thirty years in, we're still stuck in the mud of ignorance, fear, and judgment.

If it's true that counting one's blessings is an antidote to depression, the pages of Positively Aware magazine are just the thing. It's hard not to feel inspired by the triumphant stories of the peer navigators featured here, for example, and how they've chosen to invest their hard-won success in bringing others into care and treatment.

There's also Rob Vassilarakis. He traveled a very different road to his HIV diagnosis than I did, yet my heart somehow recognizes the story he tells in his spoken word poetry, as if deep down we share a language of grief and shame, and survival and self-acceptance. Such is the power of honesty and art.

These personal stories highlight some critical, insidious challenges that have been blindly stepped over by policy leaders rather than looked at with full gaze. Structural barriers like poverty, discrimination, and violence lay down a path that, as research shows, can be a shortcut to addiction and HIV infection. Michael Mugavero takes on one consistently under-appreciated and overlooked element of the stories here and everywhere: trauma.

Over and over, the experiences of people living with HIV/AIDS—the original HIV experts, I dare say—show the way. A few who became outspoken activists share with us, alongside some equally passionate front-line providers and advocates, their reactions to the state of HIV/AIDS in the U.S. and ideas about the way forward. If they were steering our boat to the end of AIDS, we'd surely be heading double-time in the right direction.

Three clinicians, including the indefatigable pioneer of HIV specialists, Paul

Volberding, have a conversation of sorts in these pages about their experience and perspective as care providers, from San Francisco to Minneapolis to Santa Fe. Theirs is an interesting story about geographical, historical, and resource differences that carries an echo of what the peer navigators and activists say about stigma, fear, and silence.

The antiquated notion that HIV/AIDS equals a horrible life of pills by the fistful followed by an inevitably painful death keeps people from even getting tested, let alone starting treatment and staying on it. This is at odds with what we know: early treatment preserves health; fully suppressive treatment can render the virus essentially uninfectious; and today's medications are more like an occasionally bothersome houseguest than the ruthless intruder that is HIV. Somewhere along the way, Americans fell back into the sea of HIV ignorance, if they ever climbed out of it at all.

If I may quote the late, great Dorothy Parker, what fresh hell can this be? It is as preposterous today that people would die on wait lists for HIV medications (possible in 10 states) as it is that they would die of ignorance and shame, yet both threats are disturbingly real. How far we've come, how very far we have to go.

HEIDI NASS is an HIV-positive lawyer, treatment advocate, educator, and writer from Madison, Wisconsin. She serves on the U.S. Panel on Antiretroviral Guidelines for Adults and Adolescents and is a founding member of the AIDS Treatment Activists Coalition. She advocates nationally and internationally for the rights of people with HIV/AIDS.

*** Hopefully you would be inspired to read more & be AWARE of our HIV/AIDS Community outside of just upstate New York.....

SKY LAKE - 2012

Wow, another visit to Sky Lake (“camp” as I fondly call it) is in the books. This was my 4th year and “that place” always finds a way to impress or have an impact on the lives of those who attend. For many who attend they find it to be very powerful - Healing takes place for many. This year also allowed us to gather to remember those who have gone before us; especially our dear friend Wayne. Coming together with “our kind” assists in the healing - these tears are making things better. Friendships are strengthened; New friendships are born.

Now you would think something that has such a positive effect on so many would continue forever..... Reality Check - budget cuts. It is sad to say that Sky Lake Retreat “as we know it” has had it’s final day. From this point on WE will have to see that it is able to continue; simple just find a way to pay for the thing. During camp names & numbers were taken for those interested in a “planning committee” to work on this project....don’t worry “You Will Be Contacted”.

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.

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; 2nd 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 for further information.

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

Free EDUCATIONAL Lunch/Dinner: August/September 2012

Good News: We now have 2 Drug Companies willing to come to our area to continue to teach/inform us about new and upcoming advancements in the treatment of HIV. (* 2 events in June, therefore no event in July)

Gilead will have a lunch on August 13th at Grande's on Vestal Ave @ 12 noon (* this is the old address again)

Bristol Myers will have a lunch on September 24th at Number 5 on Washington Street @ 12 noon.

* 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 # 607-238-8350.*

These are "learning events" - please respect everyone's right to learn.

Ask The Medical Advocates:

This area of the newsletter is set aside to allow one of our Medical Advocates to answer “YOUR” questions about “OUR” shared battle against this virus. So I have to assume that everybody out there has T-cells in the 1000’s and all are undetectable viral loads, nobody has any side effects from their meds and their personal life is just peachy keen..... Yeah - right!

You can send questions / comments / stories to STAP to be added to the newsletter - especially if you would prefer to remain unknown.

If you have an announcement that you would like to inform all of, send it to me direct at: wzytka@live.com / monthly deadline is 3rd Friday of the month.

** 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 *(new time) - just before the Friends Dinner come join us for our monthly C.H.O.I.C.E.S. module (open to everyone). 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 July 17th at 4:30 pm *(new time) with Autumn Cook, Medical Advocate, 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”.