

POSITIVE VOICES - APRIL 2012

Your Newsletter by Positive People for Positive People

WHAT LIES AHEAD - Trends in HIV treatment and care

Positively Aware, March/April 2012

2012 promises a number of changes and advances in the way we treat and prevent HIV infection. There is growing enthusiasm for widespread use of antiretroviral therapy (ART), regardless of CD4 count, both for treatment and prevention. New drugs and co-formulations are coming this year that will expand treatment options and simplify drug regimens, especially for initial therapy. At the same time, political and economic realities may prevent us from being able to implement broad-scale treatment and prevention efforts, and the coming of generic drugs, while cost-saving, may put limits on our choices of antiretroviral drugs.

When to start

San Francisco and New York City now recommend ART for everyone with HIV, regardless of CD4 count and viral load. Current U.S. treatment guidelines already come close to that aggressive standard. They recommend ART for anyone with a CD4 count below 500, and say that everyone else should consider treatment. Treatment is also recommended at any CD4 count for people with additional conditions, including pregnancy, HIV-associated nephropathy (HIVAN), hepatitis B or C, older age, high viral load, rapid CD4 decline, and high risk for heart disease.

In the minds of many HIV experts, ART is now the “default”—recommended unless there’s a good reason not to treat. Reasons why not to treat? People who aren’t ready or willing to start should wait until they are. Some people have no way to pay for treatment, an increasingly common scenario even in the United States. We don’t know what to do with “elite controllers”—people whose viral loads are already undetectable without therapy. Assuming normal and stable CD4 counts, it would be hard to show a benefit to starting ART in those individuals.

How did we get to this point, where ART is recommended for virtually everyone else? First, we’re recognizing that HIV isn’t just a disease of immunosuppression due to CD4 decline. Untreated HIV has consequences even for people with high CD4 counts, due to the inflammation and immune activation caused by ongoing replication of the virus. Shutting off viral replication may help to reduce the long-term risk of conditions such as heart disease, cognitive decline, loss of bone density, and malignancies by reducing HIV-associated inflammation.

We also know that treating people with HIV lowers their risk of infecting others. In fact, the HPTN 052 study demonstrated that ART was 96% effective at preventing transmission to negative partners, a far greater efficacy than we've seen with any other form of prevention so far, including condoms, circumcision, microbicides, vaccines—probably even “abstinence.” Put simply, if everyone with HIV were on treatment with an undetectable viral load, we would see virtually no new cases.

Evidence of the benefit of early ART is clear, but the decision to treat early must also consider the cost of therapy, in order to weigh the costs against the benefits. Once-daily regimens are now the norm; a growing number of single-tablet regimens (STRs) are becoming available; tolerability and safety are high. Weighing the financial cost against the benefits is more complicated, since it involves economics and politics rather than science. This is where the prevention benefits of ART become so important. Some people may be unwilling to pay for universal ART for individuals, but if universal treatment can slow or even stop the epidemic, perhaps they'll see it as money well spent. (At least, that's what they should be thinking!)

The initial regimen

Things are good with respect to initial ART, and there's promise for continued improvement. We now have two single-tablet regimens available, Atripla and Complera, with the “Quad” pill coming soon, and additional co-formulated products and STRs in development. Before long, there may be an STR for almost everyone starting therapy, regardless of which nucleoside analog backbone they're using and whether they're starting ART using a non-nucleoside reverse transcriptase inhibitor, protease inhibitor, or integrase inhibitor. The co-formulations are likely to benefit treatment-experienced people too, either by allowing use of an STR or by reducing pill burden. For example, taking Norvir as a separate “booster” won't be necessary when the new booster, cobicistat, is approved and combined with Reyataz and Prezista. There's also the possibility that we'll begin to see use of Selzentry or other CCR5 antagonists as part of first-line regimens. People with high CD4 counts who haven't started ART are more likely to have R5-tropic virus, the kind that's required for use of this class of agents. The availability of less expensive tropism assays and once-daily CCR5 antagonists may make this an appealing strategy in the future.

The coming of generics is the wild card. The generic versions of Zerit, Videx, Retrovir, and Combivir have had little impact because they're not preferred drugs, but when Sustiva goes generic, everything could change. With a preferred agent potentially costing a fraction of the cost of its brand name equivalent, it may be hard to justify paying more for the shiny new STRs. Will people have to go back to taking 3-pill regimens to save money, while the STRs languish on pharmacy shelves? Only time will tell. The coming of generic ART is clearly a mixed blessing: On the one hand, who can complain about cheaper HIV drugs at a time when thousands of Americans are on waiting lists for treatment? On the other hand, a move from an STR to a 3-pill mixture of generic and brand name drugs will feel like a step in the wrong direction.

Beyond First-Line Therapy

The pipeline for new antiretroviral agents is focused on first-line treatment for one obvious reason: that's where the money is. The efficacy and tolerability of current therapy means that most people do well on their initial regimens and stay on them for a long period of time. Drug companies are far more interested in developing drugs for the large first-line therapy market than for the small number of people with highly resistant virus who are waiting for new drugs.

But there are still people with highly resistant virus, and who's to say we won't see the emergence of resistance to integrase inhibitors and other new agents in the future? Fortunately, there are a few drugs still being developed for treatment-experienced patients, including drugs with novel mechanisms of action, such as the elusive attachment inhibitors (drugs that block the first stage of viral entry).

Beyond ART

In the past, I rarely talked about anything "beyond ART," because there was so little to say. That has changed in recent years. While no one should volunteer for a bone marrow transplant to be cured of HIV, the experience of "the Berlin patient" tells us that cure is conceivable, and the topic of cure has been a much bigger focus of scientific conferences and research spending than in years past. We've even seen some corporate interest in this area: for example, Sangamo BioSciences is attempting to modify human CD4 cells to make them uninfected using zinc finger nuclease technology. We're still a long way from a cure, but it's moved from the realms of science fiction to science.

I should also mention what I'll call "ARP" (for "antiretroviral prevention"). There's now strong evidence that antiretroviral agents can be taken by HIV-negative people, either orally (as pills) or topically (as microbicides) to prevent infection. While many argue that condoms do the job for far less money, our 50,000 new cases per year tell us that our current approaches aren't working. If people who won't wear condoms would take pills or use microbical lubes to stay negative, that's money well spent. The unanswered questions have to do with finances and implementation: Who will pay for biomedical forms of prevention, and who will provide it?

The future of HIV care

We may be approaching an important turning point in the way HIV care is delivered, and the uncertainty is both promising and scary. If fully implemented, the Affordable Care Act may improve health care for a large number of uninsured Americans. However, it could also threaten the quality of HIV care if it leads to weakening of the Ryan White CARE Act, the source of a network of HIV centers providing high quality, multidisciplinary medical and social services to people with HIV throughout the country. Even privately insured people benefit from Ryan White, since they may get their care at HIV centers of expertise that wouldn't exist without the program. Ideally, the Ryan White program should serve as a model for what medical care could be like for all Americans. But policymakers could ignore that, instead transitioning HIV care to Medicaid-funded clinics with little or no HIV expertise, at a time when the already under funded Medicaid program is targeted by budget cutters in Washington.

Conclusions

It's an exciting time in the history of the HIV epidemic, with outstanding treatment options that keep getting better, and prevention breakthroughs that could have a major impact on the future of the epidemic. However, we're also in the middle of a global financial crisis, and more importantly, a political crisis, in which a large proportion of citizens reject virtually any form of government spending and believe that every dollar they earn is their own to keep. Of course it's not about the money; it's about having the right priorities and political will. Though costly, ART is a highly cost-effective way to treat HIV infection and prevent its spread. I wish I could conclude by saying that the future of the HIV epidemic will be guided purely by science and sound, evidence-based health care policy, but that may not be the case. Much depends on economics and politics, which we'll be hearing about in 2012.

My Story (part 2) continued from March 2012

After breaking the “news” to my family I started the HIV meds in the hopes that it would spare my unborn child the fate I had received. Gratefully she was born healthy and free of the virus, she too took HIV meds for the first year of her life as per doctors orders. My family was supportive and I returned to live in New Jersey to be close to them. At that time I tried to live my life as normal as possible. I continued to work, took my meds and went to my doctors appointments as scheduled and mostly did my best not to think about it.

Ten years later, 2006, I came to live in Binghamton for my girls to attend better schools than I could find for them in N.J. - my oldest daughter has special needs and she was accepted in a program here in Binghamton. I needed to find new doctors in the area and found Binghamton Family Care, they got me in touch with STAP. At that time I continued to deal with my HIV on my own and with my doctors. Needless to say it was very stressful emotionally and mentally trying to balance a job, raising kids and dealing with my diagnosis on my own. My doctors and STAP advised me to seek out a local HIV support group and the Friends Dinner, that was around 2008. That was a really big step for me and I had no idea how important it was going to be in the days to come.

Over time I developed special relationships with my fellow support group members which helped me to continue to work and live a “normal” life, even though the meds were adding to my depression and fatigue. Little did I know at the time my health was taking a beating from all my stress and my fast paced lifestyle. During a doctor visit we were talking about “how I feel” and she was explaining how some of my side effects were normal for someone with AIDS. “AIDS !” - that was the first time I heard that word being used to describe my diagnosis, as far as I knew I was just HIV+. It turns out that before I left N.J. my t-cell count had fallen below the 200 mark and my doctor here thought I was already aware of that. It was a huge blow to me to find out like that, my doctor back home in N.J. never mentioned it to me. Here I was working my butt off, raising my kids and thinking I’m taking good care of myself only to find out (after the fact) that my health was getting worse. There came a point where I had to stop working for health reasons and I was feeling that this was one of the lowest points in my life.

The strong support “network” that was now in place came to the rescue and helped me thru all the ups and downs that were to come. I was encouraged to get a lawyer to assist me in fighting for my Social Security Disability, which did finally get approved after several months of jumping thru the hoops. I have to admit, there were many times that I wanted to just give up and move back home - especially with my Mom who has her own health issues. But my new family here stood by my side and helped me put my feet back on the ground. The help they gave me and in turn the help I was able to give others has become such a source of strength for me. I have even been to Albany with STAP to speak to our Representatives to keep funding HIV/AIDS programs. (something I would have never done in the past) I am so grateful to be in a better place than I had been in the past, and some of that credit goes to my support network (my other family). They helped me see how strong a person I really was and that my own self doubt stopped me from being. With education, knowledge and support I took back my life from this disease and I’m happy to say “My health has improved” (mentally and physically). I am not the same person I was before, I have faced my demons head on and came out a winner. If I can do it, then so can you - take the first step on the journey to live a full and happy life with this disease.....never give up! Get involved in our community, give something back and you will be amazed how good it makes you feel.

Thanks for listening,
-Mo

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.

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 @ 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 : April 2012

Our next “EDUCATIONAL LUNCH” Monday, April 23rd 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.**

“JOURNEYS” IS BACK! - STAP’S CLIENT - ONLY SPIRITUAL RETREAT

JUNE 12 - 14, 2012

STAP will be holding this year’s client-only spiritual retreat from Tuesday, June 12 through Thursday, June 14, 2012 at the Sky Lake Retreat Center in Windsor, NY. The mission of this very special retreat is to assist individuals in finding their inner strength by awakening spiritual awareness as a means to deal with the difficulties of living with HIV and AIDS. This unique experience offers 3 days/2 nights of education, spiritual growth and an opportunity to meet others impacted by HIV/AIDS. Come, make new friends, learn about your own spiritual journey, and draw strength from a refreshed perspective on life.

To register, please find the inserted flyer in this newsletter, complete all the information and return the last page to Carrie Juraska c/o STAP, 122 Baldwin Street, Johnson City, NY 13790. You will then be mailed the registration paperwork which needs to be completed and returned to reserve your spot. We will only be able to bring the first 40 registered clients this year. Don't delay, or you could miss out on a really great experience!

Did you attend last year's retreat? Then we want to hear from you! A retreat planning committee meeting will be held on Thursday, April 12, 2012 at 1:00 pm at the STAP Johnson City office. Bring you great ideas and opinions to help make the retreat even better than last year. Even if you loved it and don't want to change a thing, we want to hear that too! Your input truly matters. If you cannot attend the meeting but have some ideas, please contact Carrie Juraska as soon as possible.

If you have any questions or concerns about this year’s retreat, feel free to contact the Retreat Coordinator, Carrie Juraska on her cell phone: (607) 725-2027 (texts OK) or via email: cjuraska@stapinc.org or leave a message at the STAP office: (607) 798-1706, extension 203. I look forward to seeing lots of new and returning faces this year!

Ask The Medical Advocates:

** Do YOU know what C.H.O.I.C.E.S. 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...

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
- 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

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

Medical Advocate: Autumn #426-9445

* Every 3rd Tuesday of the month at 5 pm - just before the Friends Dinner come join us for our monthly CHOICES 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 April 17th at 5 pm 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”.

Congratulations !!! to all those who have completed all the modules required to earn their certificate of completion of the CHOICES program. We will be having our Grad. Picnic during the month of May (date TBD).



A Call for Speakers:

The Southern Tier AIDS Program is having a meeting!

When: May 24, 2012

6:00pm to 7:30pm

Where: 122 Baldwin Street (the Johnson City Office)

Johnson City, NY 13790

800-333-0892

What: This is an informational meeting to discuss the new changes to the Speakers Bureau.

There is such a big need for speakers & speaker panels throughout the year, as well as during World AIDS Day events, in all of our service counties that we have not been able to meet every request!

We would like to have all current speakers and those of you that may be considering being a speaker in attendance for this meeting.

For more information and to make your reservation...

Please call Candace at (607) 798-1706 ext. 225 or 1-800-333-0892 ext. 225

All reservations must be in by May 18th at 5:00pm

We look forward to seeing you there!