

Positively Aware

The Journal of Test Positive Aware Network

Positive Parenting

- Birth Options For Positive Mothers •
- Sperm Washing • Adoption •



International AIDS Society Updates

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Paris Photo by Enid Vázquez

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LIFE BEYOND HIV

Life is funny, you know? You zip along on cruise control for a good long while. Living it. Loving it. Life is good. Life is fine. Taking it all for granted. Then just when you least expect it... it all comes crashing down on you. That's when you realize that life is too damn short.

From a personal standpoint, the past six months have probably been the most difficult months I've had to endure in quite some time. This past February a very dear friend, someone I have grown to love as much as my own mother, was diagnosed with cancer. This was not Althea's first date with cancer. She had been dancing with it and around it for 15 years. At first the doctors thought it was ovarian cancer, but during surgery the doctors discovered she actually had inoperable colon cancer. We lost her four months later.

My friend Althea was a brilliant woman. At seventy-five years young she was full of life. She embarked on more adventures after the age of seventy than most people take on in a lifetime, reminding me to enjoy life to its fullest, regardless of what others might think. Her willingness to give and to volunteer for others was so refreshing. I am so blessed to have shared the past eight years of my life with this wonderful, caring individual.

I've also had my own health problems these past six months. Much to my surprise, I was diagnosed with coronary heart disease in April. For the most part I take good care of myself. I eat right and exercise regularly. So while I was relieved to finally find out what exactly was causing the problems I was experiencing, the diagnosis came as a complete shock.

My physician tells me that I'm *lucky* because the disease was diagnosed early on. Most people aren't as lucky... heart disease... the silent killer. Currently I'm on a two pills once-a-day regimen. The side effects are minimal. However, I have to take these meds for the rest of my life. I've convinced myself that I can deal with that, because that's what you do. Does any of this sound familiar?

But then out of nowhere the other shoe dropped. By the time you read this I will have *hopefully* recovered from surgery. I was diagnosed with thyroid cancer in July and my surgery is scheduled for mid-August. Once again the doctor says that I am *lucky* and he expects me to make a full recovery. Lucky or not, I'm thankful that I have health insurance to cover my mounting medical expenses. I'm thankful that I've been able to educate myself on both of these diseases enough to ask questions of my healthcare providers. Others aren't so lucky.

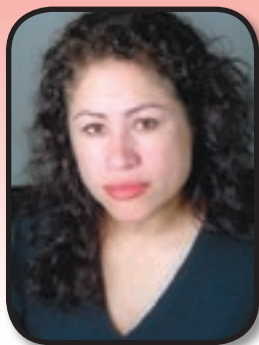
These last six months have ever so unkindly reminded me that tomorrow is not guaranteed. I've always known this, but for the first time in my life I actually feel like I'm living it. I've out-danced HIV (so far). I dodged an early date with colon cancer a couple of years ago. But for the last month or so, something else has crept into my consciousness. Fear. Fear of the unknown. I'm fighting a constant battle not to let myself become paralyzed with fear.

I've re-learned a great deal these past few months. I've re-learned that you can't make your work your life, because life is too short. I've re-learned that I must advocate for my own healthcare, because I count too. Most importantly, my experience with Althea has helped me re-learn to not only love life, but to cherish those once-in-a-lifetime moments—like watching the stretch run of the Belmont Stakes on a rainy Saturday afternoon in June or walking along the Seine River in Paris on a beautiful moonlit summer night in July. It's moments like these, and being a part of the TPAN family, that I will savor because they truly are once-in-a-lifetime moments.

Be Strong. Stay Safe.

Charles E. Clifton
Executive Director / Editor

Send comments and reactions to ed@tpan.com



by Enid Vázquez

ILLINOIS RESIDENTS TO GET NEEDLES FROM THE PHARMACY

Fulfilling a campaign promise, Illinois governor Rod Blagojevich in July signed into law legislation allowing adults to buy and possess syringes without a prescription. The AIDS Foundation of Chicago (AFC) worked long and hard with legislators for the change. State Senators Donne Trotter (D-Chicago) and Steven Rauschenberger (R-Elgin) and State Representative Sara Feigenholtz (D-Chicago) sponsored the bill. AFC reported that, “The governor’s action culminates a four-year campaign to expand access to sterile syringes and represents one of the most significant victories for AIDS advocates in Illinois.” New syringes will still be available for free through needle exchange programs, including the one here at Test Positive Aware Network, run in collaboration with the Chicago Recovery Alliance. Illinois was one of the few states left that did not allow syringe purchase without a prescription.

THE FIRST YEAR—HIV

The “essential guide for the newly diagnosed,” in which “a patient-expert walks you through everything you need to know and do,” is just that. Fresh on the bookshelves, *HIV: An Essential Guide for the Newly Diagnosed* (Marlowe & Company) is from the series of books *The First Year* (following diagnosis). The writing is easy-to-read, with a tone that’s friendly and down-to-earth. It’s like a good support group in a book, with quotes from the author’s personal experiences and that of other people living with HIV. Chapters are only three to five pages in length. Technical matters, such as resistance testing, are put in easy-to-understand terms. Even people way past the first year will find it useful.

Author Brett Grodeck is a former editor of *Positively Aware* who did much to professionalize the magazine and make it more reader-friendly. Brett was all about people having knowledge, dare I say it?—being aware. Dr. Dan Berger, a columnist for *Positively Aware* (see “The Buzz”), contributed greatly to the book and wrote the foreword. In addition to medical issues, the book covers topics such as disclosure, depression and where to go if you’ve been discriminated against.

ADAP RELIEF

In August, Bristol-Myers Squibb (BMS) announced it had reached an agreement with the state-administered AIDS Drug Assistance Programs (ADAPs) to provide interim emergency relief in order to help address the funding crisis facing the programs. The new agreement is estimated to provide up to \$35 million in relief to ADAPs over the next 20 months by making the company’s complete line of HIV medications, including the new protease inhibitor Reyataz (atazanavir) and the non-nucleoside reverse transcriptase inhibitor Sustiva (efavirenz), available at a reduced cost. Under this agreement BMS has agreed to provide its entire portfolio of HIV medications at a reduced cost to ADAPs through March 31, 2005, when the Ryan White CARE Act will be up for reauthorization by Congress.—Charles E. Clifton

IAS: DRUG NEWS FROM PARIS

The International AIDS Society (IAS) held its second Conference on HIV Pathogenesis and Treatment in Paris in July. IAS also organizes the International AIDS Conference. Earlier in the epidemic, when advancements were slow in coming, IAS

changed the international conference to every other year instead of annually. More recently, with so many advancements such as potent drug combinations and monitoring tests, IAS added the Pathogenesis conference during the “off” years of the international conference. The first one took place two years ago in Buenos Aires. Following are some highlights from this year’s IAS conference. (Look also for more IAS reports and ICAAC, the Interscience Conference on Antimicrobial Agents and Chemotherapy in the Nov./Dec. issue of *Positively Aware*.)

VIREAD AND ZIAGEN—WATCH OUT

New drugs tend to be stronger and have improvements over older drugs. Because HIV drugs must be taken in combination, it’s hoped that taking newer ones together would make for a better combination.

So it was disappointing to see that Viread and Ziagen (in combination with Epivir), two of the newest nucleoside analogs on the market, don’t work so well together. They’re not toxic when taken in combination. They’re just not as effective as you would expect. However, Ziagen was taken in an experimental dose of once-a-day (the standard dose is one pill twice a day).

“The reasons for failure are not clear and are probably not related to the once-daily [Ziagen], but rather a unique resistance issue when these drugs are used together, or a previously unrecognized drug-drug interaction. No one knows which yet,” said Dr. Stephen L. Becker of the University of California, San Francisco and Pacific Horizon Medical Group.

An unsuccessful small pilot study was reported at IAS. But there were also negative early results from a large pharma-

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ceutical company trial that did not make it onto the agenda of IAS. One staff member of GlaxoSmithKline, the maker of Ziagen, said the company has “lots of data” that the drug taken once-a-day is as potent as the standard dose. At least one HIV researcher scoffed at the claim.

Fortunately, *Positively Aware* columnist and medical advisory board member Dr. Daniel Berger was one of the doctors conducting that study. For his insider’s tale on this tangled web, see “The Buzz” on page 51.

TRIZIVIR MAINTENANCE

ESS400013 looked at Trizivir and Sustiva in what’s called induction/maintenance. Participants took Trizivir/Sustiva for a year, then half of them dropped the Sustiva for the second year. (Only people with less than 50 viral load at the end of the year could have their regimen simplified to Trizivir alone.) Results from only the first year were reported.

The year went well—61% of the participants were under 50 viral load when using a strict intent-to-treat (ITT) analysis. Missing data was counted as failure. When looking at only those people who actually stayed on the drugs, 90% had less than 50. T-cells went up by 305. Participants were treatment naïve.

Seven percent of participants had a hypersensitivity (allergic) reaction to the Ziagen in Trizivir. That’s higher than the 3 to 5 percent listed in registration trials that brought the drug to market.

Eleven percent of the 448 people in this large trial dropped out due to side effects. Six percent dropped out for virologic failure. (For 22 of the 28 participants with failing therapy, 46% had the Epivir mutation of M184V and 41% had the Sustiva signature mutation of K103N. The most common reason for developing mutations, that in turn lead to treatment failure, is taking the medicine incorrectly.)

Previous studies have shown that the higher a person’s viral load is, the longer it takes them to get to undetectable. Sure enough, it took a median of 35 weeks for people who started with more than 750,000 viral load to get to undetectable. This compared to less than half of that, 16 weeks, for the people who began the study with less than 100,000. Time to undetectable was only 17 weeks for the people in between.

Presenter Dr. Martin Markovitz, of Aaron Diamond AIDS Research Center in New York City, was asked if he had concerns about the use of Trizivir by itself, given the results from the ACTG (AIDS Clinical Trials Group) 5095 study (see page 25). Dr. Markovitz said the question was difficult to answer. Was Trizivir failing because of chronic infection? Higher viral load to start with? Low T-cell counts? Complex quasispecies in their virus?

He pointed out that the long induction phase of a year allowed people to achieve virological success. Otherwise, those people who started out with the highest viral load would not have been able to move into the maintenance part of the trial. Dr. Markovitz said he felt that 24 weeks is too early to begin simplifying a regimen into a maintenance phase.

IS SOMETHING BROKEN WITH THE TRIPLE NUKES?

The question arises with both ACTG 5095 (see page 25) and the Viread/Ziagen combination—is there something broken with the use of three nukes? If so, what is it and can it be fixed? The race is on to find the answer.

Researchers are looking at two main areas. First, is there some kind of pharmacokinetic effect among the nukes that cripples them when used together? That is, what are the drug interactions—primarily, how are they affecting each other’s blood levels. Secondly, are they influencing each other’s mutation patterns for the worse?

Drugs exert a so-called “selective pressure” on HIV which makes the virus mutate. Most HIV mutations make it stronger in the face of the drug therapy being used.

“We have signals here that three nukes don’t work for many people, despite their potency,” said Dr. Becker.

This is disappointing because people on a successful nucleoside-only regimen could save the three other classes of HIV drugs for later, if necessary. Expanding the available regimens is simply necessary in HIV.

The protease inhibitors, for example, are generally inconvenient to take and can increase blood lipid levels. Kaletra in specific is a popular protease inhibitor to use, but can greatly increase levels of triglycerides. “We’re scared of 1,500 triglycerides,” says Dr. Becker. “It’s rare, but it happens. Will we trade potency for simplicity? Who will three nukes work for? Not work for?” Once again, HIV research gets a curve ball.

“It is important to point out that the Trizivir regimen studied in 5095 did not do as well as the Sustiva-based regimen. If the goal of treatment is full viral suppression [viral load below 50 or 400], than a triple [nucleoside] regimen is not as good as one with Sustiva,” Dr. Becker explained. “That said, for many patients who have co-morbid conditions [other illnesses] or financial, social or psychological constraints, the simplicity of Trizivir is important and may make it an acceptable regimen. Seventy-four percent of patients on Trizivir in 5095 achieved viral suppression.”

KALETRA/SUSTIVA

Just as ACTG 5095 looked at sparing the protease inhibitors, the BIKS study looked at sparing the nukes. “BIKS” stands for “bi-therapy initiation with Kaletra/Sustiva,” even though in Europe Sustiva is called Stocrin.

French researchers reported that, “[Nukes] are associated with significant

long-term toxicities and cross-resistance. [Nuke]-sparing regimens need to be assessed as alternative HAART regimens.” (HAART stands for Highly Active Antiretroviral Therapy.) Early 24 weeks results were reported.

Using a strict intent-to-treat (ITT) analysis, 78% of participants achieved less than 400 viral load. For under 50 viral load, the number was 65% (75 people). The average increase in T-cells was 162. These results were especially good considering that 42% of participants started out with more than 100,000 viral load, although that’s to be expected since both Kaletra and Sustiva regimens have great success in this group. Most of the participants (65) were treatment-naïve and the other 21 were treatment experienced.

There were significant (Grade 3 or 4) side effects in 34 people (40%). These included the central nervous system (CNS) problems associated with Sustiva (17 people), diarrhea (11) and rash (4). The lipid problems seen with Kaletra were also found in Grade 3 or 4 lab abnormalities. Thirteen people had high triglycerides and 29 had high cholesterol. However, Sustiva is also known to raise cholesterol levels.

There were 14 discontinuations (16%); three for CNS side effects, three for rash, one for hyperlipidemia and three were lost to follow-up. Most of these discontinuations occurred early in the trial. Of four people with virologic failure (insufficient control of viral load), two had a blip above 400 before regaining virologic control, one did not take the medications correctly (was non-adherent) and only one had confirmed failure.

The French researchers concluded that a Kaletra/Sustiva regimen is as safe as a nucleoside-based regimen with similar effectiveness. Final results from 48 weeks are to come.

KALETRA/FORTOVASE

How about a two-class sparing regimen that consists solely of two protease inhibitors? Doctors at IAS were still talking about a study presented in February that looked at a combination of Kaletra and Fortovase (soft-gel saquinavir). Results weren’t so great. However, the doctors believed this was due to an incorrect dose of Fortovase, 1,200 mg. They said 1,600 mg should have been used. In fact, Dr. Dan Berger said his patients have great success with the standard dose of Kaletra and 2,000 mg of Fortovase (1,000 mg twice a day).

For those patients not tolerating Fortovase, primarily due to diarrhea, he switches to Invirase, at the same dose of 1,000 mg twice daily in combination with standard Kaletra dosing. Additionally, Dr. Berger invokes the study presented in Barcelona at the 2002 International AIDS Conference, presented by Dr. Staszewski from Germany, of patients failing other regimens, many with protease inhibitor resistance and many with nucleoside-related toxicity or side effects (neuropathy, lipodystrophy, etc). After a strategic treatment interruption (mean duration was 12 weeks), patients were placed on the combination of Kaletra plus saquinavir at the same dose Dr. Berger discussed (or uses). Dr. Staszewski observed HIV viral load drops of 3.5 logs and CD4+ T-cell gains of 159 cells. After 29 weeks, 73% of his patients were still on therapy.

Dr. Becker noted that Abbott, the manufacturer of Kaletra, has launched a study comparing Kaletra with Invirase (a form of Fortovase) against Kaletra with Combivir in people taking HIV drugs for the first time. “It’s a pilot study with lots of PK (pharmacokinetic analysis) to help determine the best dosage.”

EMTRIVA, SUSTIVA AND VIDEX

Emtriva is the newest anti-HIV drug on the market. It’s a once-a-day nucleoside that is a lot like Epivir. Here, French

researchers looked to see if Emtriva, Sustiva and Videx, all once-a-day drugs, could maintain viral load control after people switched from protease inhibitors. They could, out to 48 weeks.

The study enrolled 355 participants, most of whom were taking either Crixivan or Viracept. They all had less than 400 viral load, and none had taken a non-nucleoside analog before (the class of medication to which Sustiva belongs).

At the end of the year, the people who were switched to the once-a-day regimen had the same viral load suppression under 400 as did the people who stayed on their protease inhibitor—about 90% using ITT, or 96% looking at people actually on treatment.

However, for the ultra-sensitive viral load test of under 50, people on the once-daily drugs actually did statistically better. The numbers were 95% (once-a-day regimen) vs. 87% (protease inhibitor regimen), for the people still on treatment.

The average T-cell increase was only 13 for the control group and 21 for the once-a-day group. However, participants started out with an average of 540 T-cells. Treatment discontinuation was 12% and 10% respectively, not statistically different. Study participants had an average of 35 months on protease inhibitor therapy, and half of them had nucleoside-only therapy before then. Therefore, this was a highly treatment-experienced group, making the results extra good news. ☛

Special thanks to Dr. Stephen Becker of the University of California, San Francisco and Pacific Horizon Medical Group, for his review of this material. Thanks also to the Breakfast Study Group of Rush-Presbyterian St. Luke in Chicago, hosted by Dr. Harold Kessler, and sponsored by GlaxoSmithKline at IAS.

THE POWER OF BROTHERLY LOVE

by Keith Green

Throughout my nine-year journey of living with HIV, I have had several life-changing experiences, experiences that encourage, inspire, and empower me to keep fighting, to keep moving ahead. The most recent of those came in the form of the 8th Annual Brothers United in Support (BUS) retreat that took place on the weekend of June 12-15, 2003 at Camp Renora in Watervliet, Michigan. (The BUS support group meets at Test Positive Aware Network and is for HIV positive gay and bisexual men of African descent.)

The BUS retreat came at a time when life for me seemed to have lost its purpose and I was just about ready to give up on everything. Through the power of brotherhood, however, I came to realize that giving up was never an option for me. I realized that not only does life have so much more to offer me, but that I have so much more to offer the world.

Camp Renora, located just about two hours outside of Chicago, is one of the most serene places that I have ever been. With the exception of a couple of motor vehicles here and there, there are very few signs of city life. Featuring several cabins with interesting themes (Grandma's House, for example, really does remind me of being

in my Granny's home: warm, cozy and full of love), Renora sets the mood for a walk down the trail or a swim in the lake or a warm late-night campfire. A deep breath of the fresh country air reveals traces of pine and honeysuckle, elements that make the country *the country*. Stumbling upon a frog or a rabbit, or even a snake for that matter, is not uncommon at Camp Renora. It is an experience of nature, undisturbed,

and...What's Your Plan?" The workshops were centered on developing a plan for the future, both individually and as an HIV positive African American community. We started out with issues concerning health and treatment options, and ventured into relationships, spirituality and other issues concerning love and care of self.

Our main facilitator, Omari Martin, did an excellent job of soliciting group

We were all challenged to assume the responsibility of educating and empowering not only ourselves, but our partners, families and friends as well.

that instantly calms, soothes and heals the mind, frees the soul and mends the broken heart.

Our weekend was strategically planned with workshops and plenty of free time to enjoy the scenery. The theme for the retreat was "Brotherly Love Must Con-

participation and helping us realize where we actually are in our individual journeys, versus where we would like to be. We were made to take a deeper look at what it really means to be African American, gay and HIV positive, all characteristics considered to be strikes against you in the



society in which we live. Unfortunately, there was just not enough time in one weekend to draw any solid conclusions concerning any of these issues. However, seeds were planted that will remain in the minds and hearts of all who attended the retreat, that through much watering and nurturing will most definitely bring forth the sweetest of fruit.

The highlights of the retreat came during group discussions. There is nothing like getting a group of Black gay men to completely let their guards down in a safe space, and openly address their issues. On Friday evening we gathered around the fireplace at Trilogy House (the largest of the cabins at Camp Renora) to discuss the "Black Gay Men's Call to Action"—a challenge put out to the Black community by a group of professional Black gay men to join in the fight to rid our community of HIV/AIDS (see "Editor's Note," July/August). It was during that discussion that we were all challenged to assume the responsibility of educating and empowering not only ourselves, but our partners, families and friends as well. Mainly due to homophobia and pure ignorance has this epidemic been allowed to

devastate our community to the extent that it has. For whatever reasons we have remained in the shadows and been silent

about who we are for way too long. That deadly silence has cost us many precious lives, and will claim many more if we do not open our eyes to change, and fast.

Sharing and fellowship with my brothers inspired me in ways I never thought possible. I was encouraged by the many testimonies of victory over battles with HIV/AIDS related illness. I was moved by the tales told by brothers who had overcome severe rejection and even verbal and physical abuse because of both their sexuality and their HIV status. And I was humbled at the strength, courage and wisdom that were flowing from my brothers as we bonded together in support of one another.

We concluded our weekend on Saturday evening with a talent showcase, hosted by me, and an anniversary party in the main dining hall (which, by the way, served some of the best fried chicken and fresh fruits you ever want to taste). I had not prepared anything special for the talent showcase. In fact, I had kicked myself several times over the weekend for volunteering to host it.

It wasn't until about an hour before show time that I took a real deep look within myself and realized that this was exactly what I was supposed to be doing. I had gotten so much from my brothers over the past 72 hours or so that I had to give something back. I had to let them know that they had touched me, deeply. So deep that I was no longer looking for a way out, but was planning to fight my way through.

We shared our talents that evening. We laughed and cried and prayed together, as brothers. We sat by the campfire until the wee hours of the morning until there was nothing left to be said. The silence in the country air spoke to our hearts until we truly understood that *Brotherly Love Must Continue*.

What's your plan? ☒

Keith Green, 28, currently serves as Distribution Coordinator for Positively Aware. He is a poet and organizer of spoken word events throughout the Chicagoland area as well as Charlotte, North Carolina. He is currently working on his Bachelors Degree in Elementary Education and is in the process of publishing a collection of poetry and essays.

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To Break or Not to Break, That is Still the Question

by Charles E. Clifton

Ever since Dr. Anthony Fauci presented data on the seven-day-on, seven-day-off structured treatment interruption study in Durban in 2000, a debate has raged over whether or not a Structured Treatment Interruption (STI) provides more benefit than harm to individuals living with HIV. Clinicians, physicians and treatment advocates go back and forth over the long-term and short-term consequences of interrupting HAART (Highly Active Antiretroviral Therapy) in any situation, whether in clinical trials or clinical practice.

If this strategy is a real possibility it would be an important cost savings for developing countries struggling to address and treat the AIDS epidemic.

At the International AIDS Society Conference (IAS) this July, in Paris, the debate was renewed. Gregg Gonsalves of the Gay Men's Health Crisis, New York City, moderated a panel entitled, "There is More Risk Than Value in Treatment Interruption." The premise of the debate, as outlined by Gonsalves, was to determine if, based on evidence rather than theory, individuals could stop therapy for a considerable amount of time and retain the efficacy of anti-HIV drugs when therapy is re-started. As stated, if this strategy is a real possibility it would be an important cost savings not only for developing countries struggling to address and treat the AIDS epidemic, but domestically, as states struggle to keep ADAP (AIDS Drug Assistance Programs) and Medicaid programs afloat.

The panel included Dr. Diane Havlir (Professor of Medicine at the University of California, San Francisco and Chief of the AIDS division at San Francisco General Hospital) and Dr. Bernard Hirschel (Chief of the HIV/AIDS division of the Geneva University Hospital). Dr. Havlir took the "pro" stance in the debate, arguing that there is indeed more risk than value, and Dr. Hirschel took the "con" position, arguing that there is more value than risk in treatment interruption.

Dr. Havlir presented several interesting theories and data supporting her position against structured treatment interruptions. As the data collected over the last 10 years has proven, therapy works; therapy improves the immune system; CD4 T-cells increase, viral



Photos by Enid Vázquez

load and opportunistic infections decrease. As a result we have observed dramatic reductions in morbidity and mortality in the era of HAART. A series of studies have shown that anti-HIV therapy has also reduced the rates of perinatal transmission (see “Perinatal Transmission and Birth Options” on page 45).

Dr. Havlir also put forth a theory that there is an increased risk of developing drug resistance during treatment interruptions. However, as she indicated, many ongoing and completed studies are not conducted long enough to get answers or do not look at this occurrence at all. Drugs are often selected because of the pressure they can put on the virus. However, because of different half-lives, many drugs are also vulnerable to a single mutation. When therapy is stopped the immune system is exposed to high levels of viral replication. Unwittingly, the individual can expose himself or herself to dual or mono-therapy as drugs are cleared from the body. As a result, sometimes a single mutation can eliminate the availability

The best treatment plan is an individualized treatment plan carefully monitored by a HIV physician or other knowledgeable healthcare provider.

of drugs from an entire class, as in the case of NNRTIs. At least six studies listed at IAS this year looked at the development of drug resistance and treatment failure with STIs. At this point, as Dr. Havlir stated, we still cannot determine who is going to develop resistance if they stop therapy, but it is an area in need of further research.

Another interesting theory put forth by Dr. Havlir is what she described as a “reticence to resume therapy” or the “I feel fine, I don’t need to resume therapy” syndrome, observed in clinical trial settings and in clinical practice. Who can blame someone for delaying the re-initiation of therapy as long as possible, when what waits are the toxicities associated with antiretroviral therapy? The drawback is that while being off therapy might feel wonderful, it affords the virus to silently go about its dirty work. The bottom line is that individuals on therapy like treatment interruptions and once they’ve had one they want to do it again. The dilemma physicians and HIV positive individuals face once the STI is introduced is where to draw the line, when to re-start therapy?

Following some anecdotal observations, Dr. Bernard Hirschel made the following statement: “No clinical benefit has ever been shown for early, as opposed to late start of HAART.” He continued, “the same is true for patients starting treatment during primary HIV infection and for those patients, there is more value than risk in treatment interruption.” Evidence, you might ask?

Dr. Hirschel presented interesting perspectives on alternatives to not stopping therapy; what to expect in stopping treatment; and lessons learned from the SSITT (Swiss-Spanish Intermittent Treatment Trial) study and the Swiss HIV Cohort Study. In SSITT, the protocol for restarting therapy was a rebound of viral load above 5,000 copies, but according to Dr. Hirschel, neither participants nor physicians accepted these levels and the decision to restart therapy following the STI was actually based on a viral load somewhere between 50,000–100,000. The second criterion was based on a drop



in CD4 T-cell count. The median T-cell count for participants was about 700. It was expected that a fall of about 200 cells during the first four to 12 weeks would level off to about 50 to 100 per year. Participants who had less than 350 T-cells when treatment was interrupted had a greater chance of having to restart treatment sooner than individuals with more T-cells. However, Hirschel stressed that the variations between individuals were enormous and that interruptions require proper monitoring.

The Swiss HIV Cohort Study follows more than 4,000 HIV positive individuals not enrolled in clinical trials, so this study is a good marker for what is going on in clinical practice. The study monitors whether individuals are on HAART, are treatment naïve, or have been treated and have interrupted treatment. The interesting observations from this study are that in general clinical practice approximately 16% of HIV positive individuals have interrupted their treatment at some point and the median duration of a STI is 13 months.

One alternative to not interrupting treatment is to continue treatment. With the average age of HIV positive individuals being 39, and average life expectancy around 80, that means an additional 40-odd years of continuous therapy. And realistically as Hirschel stated, “prolonged courses of continuous HAART are not an option for most HIV-infected individuals, because of the short and long term problems associated with a variety of regimens.”

What about the risks of resistance? Hirschel clarified that while SSITT had more than 600 total treatment interruptions, it was not geared to properly measure the development of resistance. The participants in that trial were all treatment naïve and had no virologic (viral load) failure while on HAART. Hirschel went on to say that while the risk of developing resistance is real during any STI, we need to keep resistance in the proper context. Back in 1992 there was no

real chance of constructing useful treatment options. In 1996, an individual basically had one shot and if resistance developed that shot was gone. Today, however, he emphasized, that with appropriate care, improved drugs, new targets to attack the virus and careful monitoring, we now have several chances. “Resistance,” Hirschel concluded, “is not what it used to be.”

So what do we know? Treatment interruptions place the individual at a higher risk for drug resistance, increase the risk for transmission of the virus, and place the individual at risk for disease progression and opportunistic infections, particularly for individuals with low T-cells. As Dr. Havlir pointed out, this group has the greatest risk of returning to the lowest T-cell count they’ve had after therapy is discontinued.

However, as Dr. Hirschel clearly pointed out, the likelihood of an individual remaining on therapy for 40, 50 years plus is not conceivable with the therapeutic options currently available. There is mounting evidence demonstrating the benefits of structured treatment interruptions in general clinical practice.

Which takes us nearly full circle to when to start therapy. Hit Hard, Hit Early? Hit Later, Hit Lighter? What’s the best procedure in treating chronic and acute infection, treatment experienced and treatment naïve patients? The best answer at this point appears to be what many treatment advocates and physicians have been saying all along—the best treatment plan is an individualized one carefully monitored by an HIV physician or other knowledgeable

healthcare provider. If we can ever figure out a way to eradicate the toxic part of the drugs we may finally begin to see the most benefits of antiretroviral therapy and treatment interruptions. ☒

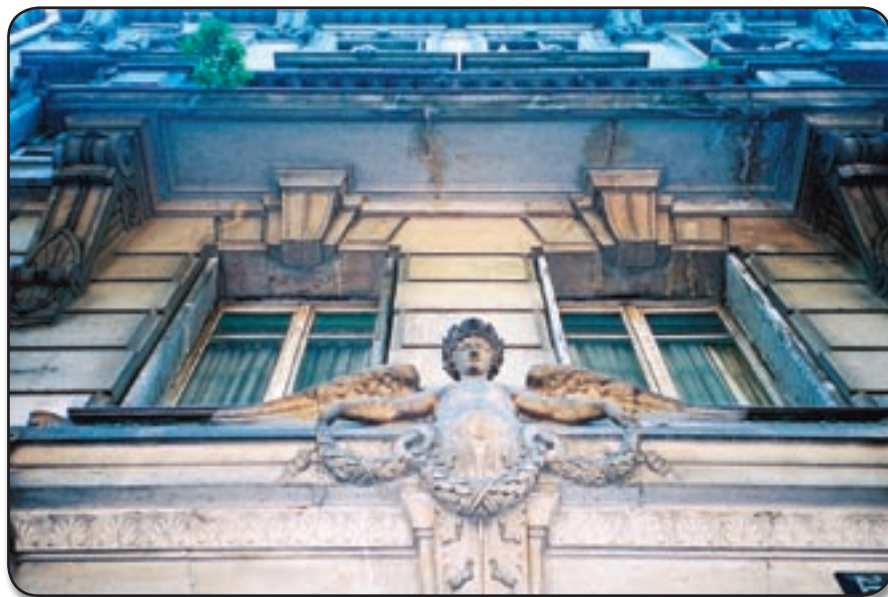
Additional reports from IAS and the upcoming ICAAC will be included in the November/December issue of Positively Aware.



Photos by Enid Vázquez

New Formulations, New Drugs... Not Always Better

by Matt Sharp



This summer, two new drugs were added to the growing list of AIDS drugs, increasing options for people with HIV. In addition, several new formulations and combinations of existing, older anti-HIV drugs are also now available. As a result, there are now a grand total of 22 different antiviral “formulations” and 19 separate drugs from *four* different classes.

The speed at which the FDA granted approval of all these drugs for treating HIV is remarkable in medical history, but all these options also present more and more confusion among physicians, care providers and people living with HIV/AIDS. As more drugs are added we must try to figure out what drug to use when, and consider all of the toxicities and drug interactions, which creates a growing complexity to HIV management. Also, the costs of AIDS drugs present new dilemmas regarding reimbursement from HMO’s, Medicaid and the cash-strapped AIDS Drug Assistance Program (ADAP). Further clouding the issue is whether all these new drugs sped to the AIDS community were scrutinized enough by the FDA. We certainly needed the therapies when they arrived, but the question must be asked, are we now somehow paying a price in terms of long-term effects?

REYATAZ

One new drug, Reyataz (atazanavir), which shows some benefits as a second gen-

eration, once-daily protease inhibitor, was recently granted full approval by the FDA. Currently, 24 weeks of clinical trial data are sufficient for FDA approval, but there are so many issues left unanswered with the data submitted. Providers and people with HIV should consider all the different variables such as the individual’s drug resistance and the drug’s toxicity profile and not jump to a decision to switch just because it’s a shiny new drug.

Bristol-Myers Squibb (BMS), the manufacturer, has shown that Reyataz has a lower lipid elevation profile (cholesterol and triglycerides) than the other protease inhibitors—which didn’t apparently translate to whether the drug improved body fat changes. Still, this should be a positive thing since lipid abnormalities are so common today with HIV therapy. While data indicates otherwise, the early spin put forth by the company was that Reyataz was a *remedy* for lipodystrophy, and physicians and patients alike may confuse the issue. Doctors may rush to prescribe the drug for their patients with lipodystrophy even though their resistance pattern would prohibit them from benefiting from a switch in therapies.

The resistance question is fairly complex with Reyataz and depending upon if you’ve been treated before determines how effective it will be. BMS did discover a unique resistance mutation with Reyataz in

the laboratory, but with scant information from clinical trials they want to promote it as a first choice and then also as a second or third protease inhibitor. Results from clinical trials do not give us complete information on where this drug fits in sequential therapy.

One other concern with Reyataz is liver-related side effects such as elevated bilirubin levels (you may develop jaundice or turn yellow) and elevated LFT levels, which are a protease-class side effect. The FDA didn't seem concerned about jaundice since it is only an effect of elevated bilirubin levels, and cosmetic in nature. We've heard that before with lipodystrophy, but any liver side effect is still a concern for people with a history of elevated bilirubin levels, and those with chronic liver toxicity.

The best promise for a stronger treatment effect is by boosting levels of Reyataz with Norvir (ritonavir). Initially, there was concern that by doing so levels of lipids would increase as well, as has been seen with other boosted therapies, thus diminishing the potential benefits of Reyataz. But at the International AIDS Society (IAS) meeting this July in Paris, a study was presented with boosted Reyataz versus Kaletra in combination with two nucleoside analogs in treatment-experienced individuals. Interestingly, Reyataz had a more favorable lipid outcome, but ended up showing less of an antiviral effect than did Kaletra. This type of information is perplexing as people may consider the positive lipid effect before the antiviral effect.

Who will best benefit from Reyataz is still unclear based on information obtained thus far. Selecting this drug because of its ease of use, its good lipid profile and its unique resistance profile should be weighed against each individual's need for a change in therapy and their distinct metabolic, resistance and liver panel profile.

EMTRIVA

Emtriva (FTC/emtricitabine) is the new nucleoside analog on the block

approved this July based on 48 weeks of data. This drug is almost identical to Epivir (3TC), with a similar resistance and toxicity profile, so it doesn't offer much for people who have developed Epivir resistance. In pre-clinical studies its activity against HIV was 4–10 fold greater than Epivir. But two clinical trials comparing it to Zerit and Epivir showed it to be “non-inferior,” which is a safe way to say it is no better and no worse. Another one-pill, once-daily drug, it has a long half-life and stays in cells up to 39 hours. But because there is less safety information about Emtriva due to the company's decision to not have an expanded access program, we will undoubtedly learn more about side effects as time goes by. People considering Emtriva as a new drug should first be tested for resistance to Epivir.

The drug is a combination of three drugs from the same class—AZT, Epivir and Ziagen, all nucleoside analogs. The standard of care had been to use three drugs from two different classes, known as HAART (Highly Active Antiretroviral Therapy), so it was surprising when GSK came up with Trizivir, only targeting the reverse transcriptase phase of HIV.

At the IAS meeting a large study from the AIDS Clinical Trials Group here in the U.S. showed this “single class” drug to not be as effective compared to two other treatment arms used in the study (Combivir + Sustiva and Trizivir + Sustiva). The Trizivir-only arm was considered “demonstrably inferior” and was discontinued. Concern over the results were so significant that on March 10th, the National Institutes of

As more drugs are added we must try and figure out what drug to use when, and consider all of the toxicities and drug interactions, which creates a growing complexity to HIV management.

Plans are underway to study Emtriva as a combination pill with Viread (tenofovir), the fastest selling new AIDS drug. When you take the two drugs together levels of Emtriva are increased by about 20%. Gilead Sciences, the manufacturer of both drugs, may have a safe, potent and useful once-a-day therapy with this combination—but not until 2005.

TRIZIVIR

Trizivir is an approved anti-HIV drug not showing to be the breakthrough its maker, GlaxoSmithKline (GSK) had hoped.

Health issued a clinical warning because of the study's early results (see “We Want Our Trizivir” on page 25).

Another study of 500 people who had never been on AZT, Epivir or Ziagen compared Trizivir to Crixivan plus AZT and Epivir for one year. There was no difference between the two arms in reducing viral load to undetectable levels. However, those with higher viral loads did better in the Crixivan arm. GSK had hopes that Trizivir was a better drug, in fact it was approved based on effectiveness. There were high hopes in this drug as a simple 3-in-1 drug, but it



turns out it probably should only be used with a protease inhibitor or non-nucleoside analog.

ZIAGEN

Another surprise stirring up the HIV treatment world is the poor showing of once-daily Ziagen, now approved as a twice-daily nucleoside analog. In two separate studies, once-daily Ziagen or “fixed dose” in combination with Viread and Epivir is proving to be a disaster in terms of controlling HIV. The studies showed a high rate of virologic failure in those who were using the experimental once daily Ziagen in combination with Viread and Epivir. GSK, the maker of Ziagen, issued an Important Health Warning to doctors because of the results of the studies. The letter warns not to use the three-drug combination by itself for those who may be considering it; that anyone currently being controlled on the regimen should be closely monitored and consider other options; and that those using the triple-drug regimen with other anti-HIV drugs should be closely monitored. So far there have been no clinical setbacks because of once-daily Ziagen. But once again, as more information is gained we are learning that new and simpler is not always what its cracked up to be. (see “The Buzz” on page 51)

FUZEON

Probably the one new drug that is showing the most promise is Fuzeon, a new drug that was approved in March of this year from an entirely new class of anti-retrovirals, fusion inhibitors. Fuzeon may extend the lives of those who have fewer treatment options. It is the most welcomed new drug because it is from an entirely new

drug class and is needed for those who have failed other drug classes.

One study from the IAS meeting showed longer-term durability and a sustained effect from 48 weeks of Fuzeon use. However, one important distinction is that the drug was most effective in conjunction with an “optimized background regimen” (a combination of drugs that work best according to prior usage and resistance testing) for those who have less than 100,000 viral load and greater than 100 CD4 cells. Until now people had thought Fuzeon was a drug of last resort.

Fuzeon is the most expensive AIDS drug ever, and has magnified the crisis with ADAP and Medicaid programs, already strapped for cash. Also, since it is given by twice-daily injections, causing painful injection site reactions, it is not at all an easy drug to take. So, the favorable treatment aspects are clouded with access, pricing and side effect issues. And now we have longer-term data that tells us an even more select group of people will benefit from the drug. Bottom line is that few people with AIDS will probably end up using and benefiting from Fuzeon.

BUYER BEWARE

Often in HIV, follow-up studies and real world usage will provide more information on the benefits of a therapy in different treatment strategies and over longer periods of time. However, people with HIV need to be aware that sometimes in these follow-up studies an old drug can prove to be ineffective, or less than it appeared to be when it was approved. We have to remember that these new anti-HIV drugs are not like new designer jeans to try just because they are new. As with drugs used for other

illnesses and conditions, fancy pharmaceutical ad campaigns and the marketing spin of just “being new” get a lot of attention and sometimes cause drugs to be misused. Health care providers and people with HIV must weigh all the intrinsic characteristics of each drug carefully before using them, and remember that individualized care must take precedence.

It is impressive that so many drugs are available today to treat HIV. The good news is that there are many options. The bad news is cross-resistance. According to the newly published U.S. Guidelines for the Use of Antiretroviral Agents, virologic failure is seen in 63% of patients in population-based studies. This most certainly has to do with adherence, but it also has to do with the biology of HIV resistance and the fact that most of the drugs we have today are cross-resistant.

As a result, treating HIV has proven to be extremely complex and confusing and will become more so as time goes by. Many of the new formulations and new drugs are mere copies of older ones with similar mutation patterns. Others are proving to not work in simpler doses. So, although there are lots of options, there are a limited number of effective regimens and there are lots of variables that throw a wrench in this positive treatment era. There must be easier ways to take these drugs, but they must also work! The drug companies should work to study new ways to fight HIV with new drug classes and work less on making “me too” drugs. There are several new drugs from new classes being studied, but it will be some time before we know how well they work. Stay tuned... ☛

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We Want Our Trizivir!

by Enid Vázquez

I've never seen so many doctors so reluctant to accept the results of a clinical trial. Everyone wanted so badly for Trizivir to show stellar results.

As three medications in one tablet taken twice a day, Trizivir's easy-to-take, easy-to-tolerate profile makes it an attractive option (if you're not allergic to it). This is in spite of the fact that the three medications in Trizivir (made by GlaxoSmithKline)—Retrovir (AZT), Epivir (3TC) and Ziagen (abacavir)—are all in the same drug class, nucleoside analogue, or nuke for short. Usually, combination therapy consists of at least two of the four drug classes on the market.

Here, when Trizivir was compared to Trizivir plus Sustiva or Combivir plus Sustiva, people on Trizivir alone had more virologic failure. As a result, the Data and Safety Monitoring Board (DSMB) overseeing this clinical trial, ACTG 5095, stopped the Trizivir arm of the study early. (Combivir is made up of two of the three drugs in Trizivir—Retrovir and Epivir.) But this clinical trial was a little more complicated than it would seem, as Dr. Daniel Berger explained in the May/June issue of *Positively Aware* (see "The Buzz").

ACTG 5095

Dr. Roy M. Gulick of Cornell University faced an onslaught of questions when he presented the results of this study in Paris during the International AIDS Society conference in July. ACTG 5095 was a large trial of 1,200 people, 19% of them women, more than half of all participants people of color (60%). (ACTG stands for AIDS Clinical Trials Group.) All participants were treatment naïve—that is, they were taking anti-HIV therapy for the first time. The treatment naïve have the best results in clinical trials, as do most people taking therapy for the first time.

Trizivir did worse at lowering viral load whether or not people started with more or less than 100,000. Twice as many people had virologic failure, defined as going above 200 viral load twice at 16 weeks or later, as compared to the Sustiva arms of the study (21% vs. 11%).



Moreover, the time to virologic failure was shorter with Trizivir. For most of the Trizivir failures, that was within four weeks. Looking at whether people started out with more than 200 T-cells or less, the results were the same. The simple conclusion of the study, not surprisingly, was that, "In treatment-naïve patients, [Trizivir] was inferior to [Sustiva]-containing treatment in terms of rates and time to virologic failure."

QUESTIONS

One audience member pointed out Trizivir's advantages in simplicity, plus lack of drug interactions and co-pays for other drugs. Another asked about the clinical disadvantages of Trizivir for the 20% of failures who didn't have enough viral load to run a resistance test (1,000). In other words, they still have relatively low viral load and wouldn't be expected to get sick.

Gulick said that, "A strict definition of virologic failure is needed in this study to power the results [make them statistically relevant]. But in the clinic you can use your judgment and look at what patients want to do with the information."

Another audience member raised the question of drug resistance. If most people had the Epivir signature mutation (M184V)

at the time of first failure (before the routine confirmation viral load test), doesn't this raise the issue of inadherence or of inaccurate reporting of good adherence? Gulick said that 22% of failures had wild type virus—indicating that those people took little or no medicine. (Nevertheless, this would point to another glitch in the Trizivir glamour—it's supposed to lead to better adherence, not worse, because it's more convenient to take.)

Another audience member asked, "Are we to give up Trizivir forever?" Gulick replied, "Trizivir did have efficacy. If you look at other studies, that can help you."

Yet another member of the audience pointed out that because Sustiva was in two of the three arms of the study, that the Sustiva arms actually had half of the failures. "That's worse, because you fail two classes [of drugs]. Half the failure with double the resistance is not so great." Another doctor made the same point after the presentation: when you have resistance to Sustiva, you have resistance to the entire non-nucleoside analog class of drugs. He called that "an expensive failure."

A Florida researcher said that when clinical trial participants don't have early strong results in viral load drop, the clinic brings in those participants and focuses on adherence, and "nine out of 10 times, that's the problem. The pill count is off."

One doctor pointed out that because the study was placebo-controlled—so that everyone took the same amount of pills in the

same way—Trizivir's simplicity of only two pills a day was compromised. He said Trizivir was studied "with one arm tied behind its back."

Doctors also lamented the loss of another advantage if they have to cut back on Trizivir use—one co-pay for three drugs.

Perhaps the biggest question raised: Is a three-nuke regimen really inferior? Gulick pointed out that the remaining Sustiva arms of the trial have not been unblinded. (Participants are still taking medicine in a blinded fashion—neither they nor the clinic staff know which regimen they're on.) In other words, maybe Trizivir with Sustiva will have better results than Combivir with Sustiva. Nevertheless, Trizivir didn't make it on its own.

QUESTIONS UNSOLVED

There's no question that people are doing well on Trizivir. They can continue their regimen with the same careful monitoring anyone else should be getting while on HIV therapy. (They can also choose to switch or intensify with another drug if they want.)

The question is, should anyone be started on Trizivir as their first regimen? The answer remains to be seen. So far, it may be that only people with low viral loads should be started on it. In this trial, it was recommended that even the people who were undetectable with Trizivir add Sustiva, or that they switch out Trizivir for Combivir and add Sustiva. ☞



And They Said This Was a Gay, White Male Disease

by Deneen Robinson

The South is known for many things. Some good, some bad. Among them, the assassination of John F. Kennedy, Juneteenth, good manners, big hair, and the Bible belt. In addition, the South is now known as having the highest incidence of



HIV positive women. In a book entitled *You're the First One I've Told—New Faces of HIV in the South* coauthored by Kathryn Whetten-Goldstein and Trang Quyen Nguyen, the authors state people newly diagnosed with HIV/AIDS today are more likely to be female, young, heterosexual, a racial minority and living in rural areas than in the past. They write, “we have more females infected, and we look like less-wealthy countries in Africa. HIV is much more prevalent among very poor and African-American Southerners.” I can't imagine the South wants this distinction.

According to the CDC (Centers for Disease Control and Prevention), the Southeast has had the highest increase of

new HIV/AIDS cases among all regions in the country since 1993. Pandora Singleton, Founder and Executive Director of Project Azuka in Savannah, Georgia established her organization nearly 10 years ago. She says, “I never thought I would see this. When I first opened Project Azuka, it was sad to see five new clients a week. Now I may have five new clients a day. It's difficult. It's generational.” Charles Seabrook of the *Atlanta Journal-Constitution* wrote in a recent article, “While the South represents a little more than one-third of the U.S. population, it accounts for 40% of people who have AIDS and 46% of new cases.”

Southern cities, including Atlanta, represent 18 of the top 25 U.S. metropolitan areas hardest hit by the AIDS epidemic. These states also have large numbers of African Americans who are poor. Seven of the 10 states with the highest AIDS rates are in the South. Georgia's AIDS rate—20.8 cases per 100,000—is the sixth highest in the nation. The statistics clearly show that in many parts of the United States, HIV has become a disease of people of color, women, and the poor.

There are several opinions as to why the rate of infections is increasing in African Americans. In Arkansas, officials

say, “the rising infection rate in the black community is an information problem. Blacks who thought HIV was a gay, white male issue are showing up in hospitals with AIDS.” Others say that stigma and denial are not the reasons for the rise of HIV/AIDS cases in the black community. With nearly one in four blacks living in poverty, according to the CDC, black people have limited access to health care. According to a report issued by the Southern AIDS Coalition, the South is more severely plagued by HIV/AIDS because of racial and economic differences and a conservative cultural attitude that interferes with attempts to halt the disease.

The reasons are numerous as to why HIV has reached epidemic proportions in the African American community. In the end, there is such stigma attached to HIV that many do not want to talk about it. It's too scary. "We must demystify HIV among women of color," says Kim Anderson of AID Atlanta. "In order to normalize HIV among women of color, we have to create

horrors of HIV. Many people have died and continue to die because far too many African Americans have difficulty accepting that they are at risk for HIV. The reality is that HIV has always been a disease that impacts everyone.

Government and private sources often follow trends of HIV infection when it comes to funding prevention and educa-

medical community to discuss HIV when a woman has her yearly gynecological exam. Often women think they are being tested for HIV and they are not. The healthcare provider should explain the test and offer testing to the woman at the time of her exam. This way, any woman can regularly be tested for HIV. This epidemic will never end as long as there are people who do not

The fear of losing your community, friends, and relationships keeps many African American women in the dark about their HIV status.

campaigns that communicate to women of color that HIV is an issue for them. We have to represent HIV in a way that breaks [down] the barriers around people knowing their HIV status. HIV must become a topic that people are able to discuss in the same way they discuss hairstyles and makeup. We are a long way from this level of comfort."

tional programs. The drawback is that in following trends, inevitably some group will be eliminated. While one group is off the radar, they may continue to participate in behaviors that put them at risk for HIV infection. Without realizing it, we say to people that they are no longer at risk. It sounds crazy, but we live in a society where people are constantly looking for ways to

know their status. There has to be a way to focus on the education and prevention needs of a community while ensuring that everyone is aware they are at risk for HIV. The message needs to be clear: your color, gender or sexual orientation will not protect you from HIV.

Traditionally in African American communities, especially in the South, sex

One of the most difficult misnomers to correct is the idea that HIV is a gay, white male disease. Anderson says, "White, gay disease is old school thought." Yet consistently African Americans seem to be surprised upon learning they are HIV positive. Singleton states, "Women consistently come in to care with an AIDS diagnosis." The puzzling statement, "I'm not gay. I'm not white. How did I get this?" These questions are often followed by distrust of the test results. Many people will be tested over and over again, because they cannot believe they are infected with HIV.

There are communities of people that have made erroneous decisions because they believed they were exempt from the

escape. The consequences are too grave to continue doing this.

What is happening to women in the South is an example of the dire consequences of focusing on one group over another. HIV has to be marketed with specific populations in mind. Even though we presently have large numbers of women who are becoming infected, we cannot ignore the fact that anyone can become infected. The prevention messages should indicate that no one is exempt from the risks of exposure to HIV. If you choose to have unprotected sex or share needles, you are at risk for HIV infection. Anderson says, "we must provide access for women to be tested." One way, she says is to get the

is often not discussed. The message that is communicated in relation to sex is one of shame; shame for wanting to share yourself with someone you love. The cultural issues around how we respond in relationships keeps us from talking about sex. Parents often talk to their daughters about how they should be submissive to their mates. Early on many women learn that they are to please their mates, not question; simply follow. Because women are normally not taught how to take care of themselves within a relationship, they are often unprepared to discuss condom use or someone's sexual past.

Another message traditionally directed at women is that sex outside of marriage is

a sin. Irrespective of your personal belief, everyone should be provided with the skills to make appropriate and healthy choices. The attitude that sex is a sin only increases the need for secrecy. In silence HIV is spreading throughout the South. HIV in the rural South is growing faster than any place in the nation. The entire Southeast has the highest number of people infected with HIV. In six Southern states—South Carolina, North Carolina, Georgia, Alabama, Mississippi and Louisiana—25 percent of those infected are African American women, a Duke University study found. This figure is significantly higher than the national average.

IN SPITE OF THE STAGGERING NUMBERS, SILENCE STILL PERMEATES THE SOUTH.

In the deafening silence, lack of access to medical services, poverty and fear continue to contribute to the alarming numbers of African Americans with HIV. The fear of losing your community, friends, and relationships keeps many African American women in the dark about their HIV status. For many the risk is too great. The African American community's ignorance and lack of education surrounding HIV causes individuals to be kicked out of their

have yet to get a response ...[but] there is something to consistency." When asked what her message to Oprah is, she replied, "You have made a lot of money and have helped some people get on their feet. Now it is time to take some chances. It's time to help a sister live." Anderson echoes this need for Oprah to discuss HIV and its impact on women in the South. "We have to begin to discuss HIV as a health issue. Until the greater community embraces this, African Americans will continue to become infected and die. Just as they are doing in Africa," she asserts.

The epidemic in the rural South has similarities to that of the epidemic in Africa. According to the CDC (Centers for Disease Control and Prevention) 75% of women in the U.S. were infected through heterosexual sex. Of newly infected women, approximately 64% are Black; in Africa, as much as 80 percent of the transmission is through heterosexual sex. In Africa, people travel to different villages or cities to be tested and receive medical care because they do not want to risk anyone in their communities finding out they have HIV. Many in the South will travel hundreds of miles to see a physician. They travel because they do not want to risk anyone in

administration and the waiting list for AIDS Drug Assistance Programs (ADAP) around the United States will cause already resource poor areas to suffer even more. For many in resource poor communities, ADAP is the only means of getting medications and Ryan White programs are their only means of accessing medical care. If someone does find out they are HIV positive, there may not be resources to provide direct or support services. We must get involved. We need to stand up and represent ourselves just as gay men did early on in this epidemic. If we do not, we will lose out and that is very scary.

Anderson made a future projection. "In Africa, we are concerned about the loss of an entire race of people from HIV, if we do not do something soon, in 300 years, we (African Americans) will not be here." In protecting the secret, we infect others and still do not tell. The thought of a race of people disappearing is not acceptable. HIV is preventable. It is an illness that people can be educated as to how to reduce their risk of infection. The prevention messages to people living with HIV as well as those who are HIV negative must represent the different communities in the United States. The messages must include issues unique to



homes, treated cruelly and lose the love and support of people they have known their whole lives. In Savannah, Project Azuka has a number of programs to deal with the fear of HIV. Executive Director Pandora Singleton states, "we need to keep saying it over and over—there is such a fear about having HIV and that fear cripples people. Having HIV is so crippling for women that they can't talk about it."

In addition, we must get African American leaders to discuss HIV. It is not about who you have sex with or what kind of sex you have. Singleton has been writing letters to Oprah Winfrey regularly for a number of years concerning HIV among women in the South. However, she says, "I

their community knowing they have HIV. The similarities between Africa and the rural South go deeper than these two issues. There's a great stigma here attached to the disease, a sense of fatalism that it doesn't matter what they do.

In spite of the wealth of our nation, the people in the rural South are less likely to have access to medical care. Recently the CDC issued a new initiative that would allow women who were pregnant and women who were having gynecological exams to opt out of testing for HIV. The goal of the new initiative is to find the people who do not know their HIV status. Testing for HIV does not equal access to care. The flat funding by our current

the targeted community. If you are trying to reach women in the rural South, then your campaign must include women who look like women in the area, and dealing with issues the women are dealing with.

Talking about HIV in our everyday lives is one way of demystifying this epidemic. Everyone has the responsibility of educating themselves about HIV and then educating someone else. No one should have to hide the fact that they have HIV because they are afraid their community will not embrace them. As long as we encourage people to keep secrets, we will continue to die. That, my friend, is unacceptable. ☘

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Positive Women Speak Out About HIV and Pregnancy

by Cathleen E. Williams, RN, Esq.



Originally published in the Spring/Summer 2003 issue of Juice, the newsletter of S.M.A.R.T. (Sisterhood Mobilized for AIDS/HIV Research & Treatment)

A couple of Saturdays ago I had the opportunity to lead a roundtable discussion about HIV and pregnancy with women from S.M.A.R.T. University, Inc. The discussion lasted only an hour, but the issues covered during that hour spanned generations. As a trainer in HIV/AIDS, I have conducted numerous trainings on HIV and pregnancy, but never have I been as inspired as I was that Saturday morning.

As anyone who follows HIV/AIDS or issues facing HIV positive women knows, **HIV can be transferred to the unborn child of an HIV positive mother during pregnancy, labor or childbirth.** The rate of mother-to-child transmission of HIV is approximately 25% without treatment. AIDS Clinical Trial Group (ACTG) 076, taught us that administering zidovudine (AZT) to the mother during pregnancy, labor and delivery, and administering it to the child for the first six weeks of life, reduced the risk of perinatal transmission to 8% or lower. ACTG 076 resulted in significant changes in the management of pregnant women and newborns, particularly in New York where state law mandated testing all newborns for HIV. As recently as a few weeks ago, **federal officials proposed testing all pregnant women for HIV as a routine part of obstetric care.** Without minimizing the importance of the reduction of perinatal transmission, and acknowledging it as a critical step in the prevention of HIV, our discussion extended beyond a mother passing the virus to her child to examine the numerous psychological and physical aspects of HIV in pregnancy.

An HIV positive woman in the United States is very likely to be in her childbearing years. According to the *HIV/AIDS Surveillance Report*, (December 2001), 115,324 women or 80% of all women infected in the United States are between the ages of 13 and 44. The reduction in perinatal transmission is very exciting. Excitement alone, however, is not enough to support an HIV positive woman's decision to have children. She needs the support of family and friends, a broad knowledge of HIV/AIDS, and the cooperative care of a knowledgeable, HIV savvy obstetrician-gynecologist (OB-GYN).

The women in our discussion recalled the days when physicians recommended abortion as the best option for an HIV positive pregnant woman. Twenty-plus years into the epidemic, not all obstetricians are equipped to provide quality care to HIV positive

women. As a result, women must be prepared to seek out a physician who :

- is committed to the care of HIV positive pregnant women,
- is trained in high-risk HIV obstetric care, and
- believes in encouraging patients to participate in their own care.

Women must have a working knowledge of HIV and be willing to participate in their own care. This is very important for a woman managing HIV and pregnancy. For example, something as common in pregnancy as morning sickness, or loss of appetite can be severely complicated by HIV. Understanding adherence to Highly Active Antiretroviral Therapy (HAART), drug resistance and other problems is necessary to minimize the possibility of drug resistance in the mother, in the newborn if infected, or both.

HIV/hepatitis C co-infection in pregnancy was of particular interest to our group. The risk of transmission of hepatitis C to an infant increases if the mother is HIV positive. In a woman with HIV/hepatitis C co-infection, liver function tests should be followed on a regular basis. Interferon therapy, the treatment for hepatitis C should be discontinued during pregnancy because the affect on the fetus is unknown, and interferon and Ribavirin combination therapy has been associated with birth defects and, therefore, should not be used during pregnancy or breastfeeding.

Other topics of concern were domestic violence, bloodless C-sections (an elective C-section during which the mother's blood vessels are cauterized to prevent the baby from being exposed to the mother's blood), HAART, the long-term effect of HAART on children, substance use/abuse, the right of a mother to refuse HIV medications for her newborn, hyperglycemia and diabetes. The exacerbation of existing diabetes *mellitus* has been associated with the administration of protease inhibitors. As pregnancy itself is a risk factor for hyperglycemia, it is unclear if protease inhibitors lead to pregnancy-associated hyperglycemia in HIV positive women.

Discussing these topics reaffirmed our beliefs that an obstetrician with detailed and current experience



treating women with HIV, or a team of doctors, one of whom is an HIV specialist is the best choice for a woman managing pregnancy and HIV. The women of SMART recognize that advocacy, empowering women to negotiate quality, culturally-sensitive health care for themselves and their children, and education are the best ways to assist women in their search for locating this kind of care. Poor women of color in their childbearing years, who account for 80% of the infected women in the United States, are not likely to be prepared to negotiate for themselves, hence the need for advocacy and legal organizations that will assist a woman in negotiating her benefits and her care.

Taking a look at adolescents, we discussed the importance of older women living with the virus to mentor and encourage younger positive women as they come face-to-face with their own sexuality. A wonderful connection was made when one member of the group, who focuses her volunteer efforts and mentoring solely on her peers—women over fifty with HIV, decided that she wanted to seek opportunities to nurture younger women living with the virus.

While the number of individuals infected with HIV from birth is quite low, our group had quite a bit of experience working with children infected at birth. Other issues that developed out of our conversation about children infected at birth (not exclusively) were:

- **Disclosing HIV status to children infected at birth**

This was a very sensitive topic. We all knew of cases where the children were approaching adolescence but were not told their HIV status or that of their mothers. There were no absolute answers to when a child should be told they are HIV positive. We concluded that the time should depend on the developmental level of the child, the parent's comfort level, communication skills, support and a host of other factors. Disclosure to the child was a difficult issue, and uncovered the underlying guilt that many mothers felt for having infected their own child with a deadly virus. The guilt, if not dealt with, we felt, would in turn affect when disclosure takes place, and how the child receives the message.

- **Disclosure to partners**

Disclosing one's HIV status to their partner was another area of concern. This is a hefty task for a person of any sex and any age. A young woman faced with this challenge without support may not be able to handle it. The fear of abuse, violence or loss of her partner may be so overwhelming that she may avoid disclosing to her partner at all.

- **Women in prison**

The treatment and care of HIV positive pregnant women in prison really pulled at our heartstrings. Pregnancy in prison is convoluted enough. HIV presents another tremendous burden on a woman concerned about the safety and

health of her unborn child. The treatment and care of HIV positive pregnant women as discussed earlier requires highly skilled high-risk OB-GYN care. Advocating for this type of care in prison is problematic at best.

- **Women over fifty**

While this is not a group that we usually think about when considering HIV and pregnancy, it cannot be overlooked that grandmothers are often involved with the care of the infants born to HIV positive women, and whether infected or not, the child's mother will need support. We should not overlook the fact that there are 14,117 women over fifty infected with HIV, or 9% of all women infected with the virus.

- **Legal Issues**

Advances in HIV treatment has resulted in longer life spans and improved quality of life for persons with HIV/AIDS. Notwithstanding this success, estate planning and establishing guardians or standby guardians for the children of HIV positive parents will always be important. Legal services can be invaluable in the event that assistance is needed in obtaining entitlements, life insurance, housing, credit, treatment of substance use, refusing treatment for children, etc.

There is a critical need for a focus on pregnant women with HIV. Women need support at every stage of life, from birth to their golden years, and when considering HIV and pregnancy, no stone can be left unturned. It wasn't that long ago that a woman diagnosed with HIV looked forward only to permanent planning, guardianship issues, and preparation for prolonged illness and death.

With the support and advocacy of other women, organizations, and dedicated physicians, a woman can plan for a healthy life filled with many options and hope.

This was one Saturday morning that I will not soon forget. I am grateful for the opportunity to have been involved in this discussion. During roundtable sessions like these, ideas are born, organizations are made, networking occurs, and support systems that are so desperately needed are created. Hopefully more of my Saturday mornings will be as dynamic and prosperous. ☕

Ms. Cathleen Williams is a senior trainer with Cicatelli Associates Inc. in New York City. She is a licensed attorney in the state of New York, and is also a Registered Nurse with an extensive background in clinical nursing in HIV/AIDS, critical care, quality improvement case management of special disease populations, and administrative nursing.

Ms. Williams is a member of the New York Chapter of the Association for Nurses in AIDS Care, and still volunteers as a speaker for community, youth and women's organizations.



FULL CIRCLE—ONE WOMAN'S STORY



by Wendy Williams

Not having a baby ourselves was a huge hole in our lives. It was as if HIV had taken everything away from us.

Years went by and many of our HIV positive friends had found ways of having children. One couple adopted, another used a surrogate mother, another used sperm washing (father was positive and mother was negative) and one couple had a child themselves. In all cases the babies were fine. Not having a baby ourselves was a huge hole in our lives. It was as if HIV had taken everything away from us.

By this time the results of the study showing that AZT reduced the risk of transmission were released, but I had already

developed resistance to AZT. The protease inhibitors were coming out and I thought that I might be able to go on a combo containing one of them, bring my viral load down to undetectable and feel okay about getting pregnant.

I planned all this very carefully, got on a regimen that worked and started interviewing obstetricians. I was worried that they would all be judgmental. But I found a doctor who was wonderful. I remember walking out of my first appointment and saying to my husband, "She treated me like a normal woman." That's all I wanted. Just the fact that she was willing to accept me as a patient would have been enough, but she also was obviously a great doctor with a lot of experience with HIV positive pregnancies.

With all systems go, my husband and I got underway using artificial inseminations so as not to put him at risk. Believe me, the whole process with the turkey baster was not particularly romantic! After about three months I went for a viral load test and found out that my protease inhibitor regimen was not working. My viral load had gone up and I no longer felt safe trying to have a baby.

It seemed that every time we made some plans, they turned out to be built on a house of cards that came crashing down around us. I was very distraught. I didn't know what HIV drugs to take. I didn't know what drugs would still work for me. I remember lying in bed one night when my husband was away and thinking: I am completely alone—no one can help me, no one can tell me what to do, no one knows the answers.

I eventually went on a double PI combo that brought my viral load down to

For me, deciding to have a baby will always be wrapped up in finding out my HIV status. When my husband and I decided we were ready to start a family, he suggested I get an HIV test. (He had already had one before we got married and was negative.) I was annoyed at the suggestion, as I thought I was never at risk and didn't need to take the test.

After thinking about it some more, I went ahead and on December 17, 1992 we got the news that I was positive. (My husband was still negative, thankfully.) My diagnosis was the end of life as we knew it. Everything changed and we thought our luck had run out. We both expected that I would get sick within a few years and die. We concentrated on dealing with the news and put aside the idea of having a child.

But the desire to have a child would not go away. I went to a workshop on women and HIV and the speaker (who was a nurse) said that just because a woman was HIV positive, she did not give up the right to have a baby. This was a revelation to me. I couldn't believe that someone was saying that it was okay to think about having kids in my condition.

My husband and I started talking about it again. I remember thinking that if I could just give him a baby, it would be a piece of me he could have forever, even if I was no longer around.

My husband felt we should go ahead, but after agonizing over the decision, I felt I couldn't go through with it. This was before AZT was used to reduce transmission and the risk of my passing the virus to the baby was one in four. I felt it was wrong for me to take that chance. When I told my husband my decision, it was very difficult for him to accept.

undetectable and kept it there. After about six months on the new combination, we decided to try again. But when I started working with my obstetrician again, she told me I needed to see a fertility specialist. This was too much—on top of everything else I found out I had a fertility problem.

The fertility specialist was also non-judgmental and she had no problems treating me even though I was HIV positive. Nonetheless, it was a real blow when I had to start on fertility drugs. It's a very expensive process that insurance did not cover. If it weren't for my parents, we would not have been able to afford it.

After several months I hadn't gotten pregnant and the doctor started me on stronger and more expensive fertility drugs. It was about \$100 a day to buy those. We did it for a few months and felt we had to make a decision about what to do. I was 36 by then and time and money seemed to be running out.

I just couldn't face giving up, but my husband was starting to feel that it would never happen. I started accepting that we might never have a child and had just about convinced myself that it was all over. We gave ourselves one, or maybe two more cycles to try.

Then in March 2000, when the doctor inseminated me, I felt different right from the start. My husband and I both had a feel-

ing that it was going to work this time. Sure enough, a few weeks later I went for the pregnancy test and it came back positive!

I have to say that because this decision was so difficult and such a long time in coming that once I actually got pregnant, I was not as worried as I thought I would be. After getting over the initial shock, I started to enjoy the pregnancy. Then we started seeing movement when I would go for sonograms. We saw the baby's heartbeat at week 10. That was amazing.

We started telling people after that and it was such a joy. Seven years earlier we had told everyone I was HIV positive and brought such devastating news to our family and friends. Now, we were able to go back and tell all those people who had stood by us and helped us that I was pregnant. It was as if we had come full circle in so many ways. My husband felt we were blessed for all we had been through. As I got larger, I started to enjoy the pregnancy even more. It was one of the happiest and most joyful times of my life. I felt it was very healing for us.

On December 3, 2000, our son arrived. We couldn't get over how tiny and perfect and precious he was. He was a winter baby. The first few months after he was born it was snowy and cold outside. All I wanted was to stay snug and warm in our little house with my little family. I had every-

thing I had always wanted right here at home.

After a few months, we got the final HIV test results and found out our baby was negative! Although I hadn't really expected him to be infected, it was still a huge relief that we could stop worrying about it.

He got more beautiful as he got older. It has been truly amazing to watch him grow and develop physically and mentally. Time seems to stop and race ahead all at once. Each moment can be so intense and yet all the moments blur together and before we knew it, 2½ years had passed!

We still find great pleasure in holding and kissing our son's warm, soft, sweet-smelling little body. But he is no longer our little baby. He has grown into a toddler with endless curiosity, energy, and desire to push the boundaries of his abilities and his world. Even though it is not always easy, I feel so lucky that I am a mom at last.

I hope I am here to watch my son grow up, graduate school, and go on to have a life and family of his own. But even if I am not, I will never regret what we went through to have him and will always be grateful that we have had the privilege of being parents to such a remarkable child. ✚

Wendy Williams is a pseudonym.

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"The Happiest Day of Our Life"

A Gay Couple Living With HIV Adopts

by Enid Vázquez

At 26, Greg was all set to get married when Frank walked through the door of his workplace. It was love at first sight. Greg put aside all thought of blending into the straight world. The two men have been together ever since.

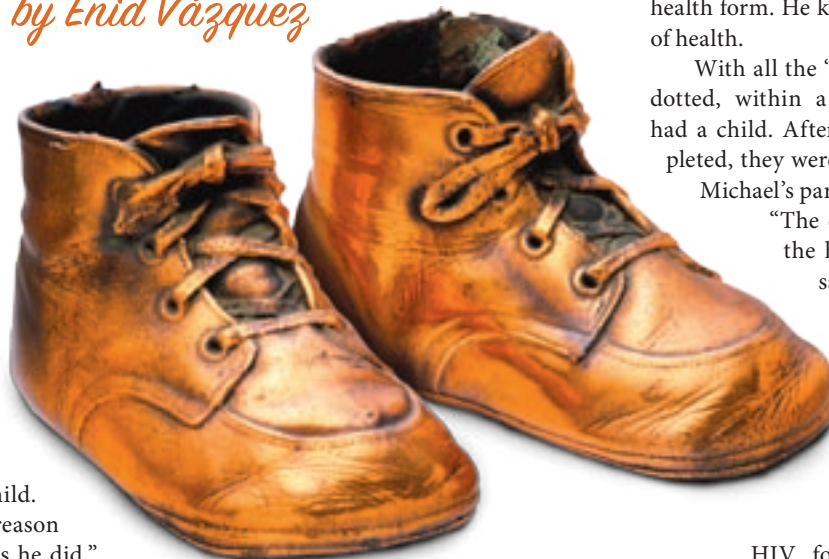
One thing, however, didn't change for Greg: his intense desire to have a child. "I think that's the main reason why he came out as late as he did," says Frank.

Frank was "the one," but he was also living with HIV. For a while, his health was too shaky for him to consider parenting. Then, just around the time of the new HAART (Highly Active Antiretroviral Therapy) era in 1995, when his health greatly improved, the couple read a story about a program for orphaned children near their home. "It really struck me. We're highly educated and have many resources to share with a child. It started us talking about being parents."

Those conversations continued over a long period of time. Frank continued to enjoy good health. Greg's family began to have children. "The more I spent time with my nieces and nephews, the more I felt I wanted to be a parent."

The two men joined a gay parenting support group. "Within a year, most people were adopting. Every time you turned around, there was a new baby. I started thinking about things that were missing in my life. My health was stable—a great gift that I never expected. I wasn't thinking in terms of one year or five years anymore. I could see into the future."

Finally, Greg and Frank were ready. They had already spent years talking with other couples and weighing several options, including a surrogate mother and international adoption.



The couple, however, did not understand the passion many people have for a "biological" child. "I always want to say, what does it matter? People probably feel they can't love an adopted child as much without that biological relationship. We never saw parenthood that way. Greg and I are strong supporters of adoption." Moreover, they wanted to adopt a child who may otherwise not be adopted.

They began the paperwork with an adoption agency that helps gay couples. Greg, especially, felt very comfortable with this agency. Because gay couples face special problems in adopting, Greg, who is HIV-negative, was adopting as a single parent. The process often involves separate agencies, each with its own philosophy, rules and sometimes, even legislative jurisdictions.

First there was a home study. Why do you want to be a parent? What do you think your parenting style will be? What was your childhood like?

Then there was a health form, which differs from region to region. All "roommates" had to complete the health questionnaire. "This was a big let-down to me emotionally," Frank says.

They consulted two different lawyers. One suggested Frank go to a "doc in a box" clinic to get his paperwork done. But they

wanted to run an HIV test. Frank walked away. Feeling hopeless, he talked to his own doctor about the situation. Having been Frank's physician for a long time, that doctor felt comfortable signing off on health form. He knew Frank is the picture of health.

With all the "T"s crossed and the "I"s dotted, within a year, Greg and Frank had a child. After the adoption was completed, they were able to both register as Michael's parent in their city.

"The day we got Michael was the happiest day of our life," says Frank.

Greg and Frank now have a beautiful, playful child who's full of charm. He's also a very smart kid who keeps them on their toes.

Frank has survived HIV for 20 years. He's completely healthy. "I'm more worried about my heart than I am about HIV!" he says. He's getting older, and though he's slim and trim and works out regularly, his older brother, a non-smoker, recently survived a heart attack, giving Frank "family history" to consider in terms of his own risk. During the adoption process, Frank—like many expectant parents—was afraid for his health. He says that, "Having lived through so much suffering and death, I was afraid of dying and leaving Greg alone to raise this child." He's not anymore. All is well.

"I feel that already six or seven years later, everyone has forgotten what it was like from 1986 to 1996. I don't want to re-live it, but there seems to be a deliberate move to forget, even by people who lived through it. The losing of so many friends. It will always be a part of my life. But it makes me a better parent.

"[Adopting Michael] is the best decision I've ever made in my life, no doubt. I'm glad I did it when I did it. HIV was no longer central to my life. I'm old enough to be able to offer a lot to parenthood, and I'm enjoying it."

"I've always tried to not let this virus and this disease take away anything that I really wanted. I always said, 'You're not going to have the upper hand.'" ✚

Dr. Deborah Cohan directs the Bay Area Perinatal AIDS Center (BAPAC), part of the University of California - San Francisco's Positive Health Program at San Francisco General Hospital. It was here that women participated in the landmark ACTG 076 study which found that AZT lowers the risk of transmitting HIV from mother to child by 66%.

But despite all the power science offers to people living with HIV, when it comes to conceiving babies Dr. Cohan finds her medical judgment overruled by another force—the law. In California, as in a few other states, it is illegal for any tissue to be donated from an HIV positive person. This includes sperm from a HIV positive husband to a HIV negative wife. (Most of the issues discussed here are the same for a gay male donor.)

There's no law stopping an HIV positive woman from becoming pregnant, but for couples where the male is HIV positive and the woman is HIV negative, the law in these few states stops them from taking advantage of reproductive technology that can bring their risk of HIV transmission down to practically zero.

"It's crazy. I'm in a position to see a lot of these couples, and even though we have the science to help them, our hands are tied," says Dr. Cohan.

In most states, people with HIV can—in concept—access reproductive services. Researchers have shown the safety of reproductive assistance in those with HIV. Altogether, they have documented hundreds of couples around the world who have succeeded in bearing children without transmitting HIV to the mother or the child while using reproductive services.

One case of transmission to a woman through sperm washing occurred in 1990, before PCR testing was available to test the sperm sample; the couple claimed to use condoms consistently, so it is thought the sperm washing sample led to the infection. The woman did not get pregnant. There have also been a few cases of HIV transmission to the woman when sperm washing and Intrauterine Insemination (IUI) were used, but it's believed that the couple's self-reported inconsistent condom use led to the infections.

Whatever society at large might think about positive people having babies, HIV specialists note that couples are at much greater risk of transmission without the expert guidance of medical providers. Trying to conceive on their own is not the only option they want couples to have. Specialists advocate for harm reduction—reducing the harm associated with certain behaviors that people will engage in anyway.

POLICY SHIFT

Last year, the American Society for Reproductive Medicine reversed its previous policy of almost a decade of not helping

Having Children When He's Positive and She's Negative

by Enid Vázquez



couples with HIV. The Society stated that, “according to the Ethics Committee, doctors practicing reproductive medicine ought not to deny treatment to individuals infected with HIV. Ethically as well as legally, they have the same obligation to treat HIV positive patients as patients suffering from any other chronic disease.”

But policy alone didn’t move many reproductive service providers to help these couples. Some clinics are not readily accepting of couples living with HIV. Some simply don’t have the technology required.

NEW CLINIC FOR HIV POSITIVE PEOPLE ONLY

At the urging of Chicago HIV specialists determined to help their patients conceive a child as safely as possible, andrology specialist R. S. Jeyendran, Ph.D., in January opened a clinic and laboratory specifically for couples living with HIV, Reproductive Lab Service. “Andrology” refers to male diseases, especially those of the reproductive tract. Jeyendran already had an established fertility clinic, Andrology Laboratory Services.

Dr. Jeyendran emphasizes that reproductive specialists need to be clear about the difference between the prohibition against HIV positive sperm donors and the use of sperm specifically for a committed couple willing to accept the risk of HIV transmission. Women using sperm banks of anonymous donors—samples that are basically bought and sold—are protected against diseases, while couples wishing to conceive are only lowering the risk of disease, whether it’s HIV or anything else. He says the word “donor” is misleading because a husband is not a donor. Instead, he would be a “depositor,” someone who stores his semen for later insemination of a sexual partner.

“Right now it’s a misdemeanor for a physician to transfer a contaminated sample,” says Jeyendran. “But if you’re transferring sperm from the woman’s sexual partner, there’s no issue. She’s already at

risk of infection.” Jeyendran said the U.S. Food and Drug Administration (FDA) is planning to begin regulating the transfer of sperm from an HIV positive man with the consent of his partner. With such a legal waiver, he says, “at least the federal government is doing the right thing.”

He says most reproductive services labs have two main problems dealing with HIV: they don’t have the right equipment to keep a separate lab within a lab for samples from HIV positive men, and they don’t want to risk negative publicity should an infection occur. “That’s why we started this lab, so these concerns don’t exist,” he explains.

There’s another big problem. Few labs can test for HIV, and there’s no FDA-approved testing of sperm. For couples living with the virus, it’s important that the semen sample be tested for HIV after it’s been washed.

AN ESTABLISHED CLINIC

When one Florida couple living with hemophilia and HIV tried to access sperm washing six years ago, no one would help

them. But they got a tip: try Dr. Mark Sauer of Columbia University Medical Center in New York City. Dr. Sauer had a reputation for challenging conventional wisdom. When he received a letter of appeal from the couple, he agreed to help, and a program for people with HIV was born.

“Basically what we do at Columbia is not discriminate,” Dr. Sauer says. “In some states, insemination—with HIV involved—would be seen as a felony. For that reason we put our work through an institutional review board, so that we do this procedure as a study.”

Today, the Women’s Reproductive Center at Columbia University has treated between 150 and 200 couples, and sees one to two new couples a week. He reports that, “The couples I see are very devoted. Many people, when HIV enters their lives, they walk out. These are also very well-informed individuals. It’s insulting to think that they don’t understand the risk. They live with HIV every day.”

The Center uses a strict standard: ICSI with IVF (see “Step-by-step”). “We’re

THE SUPREME COURT

“Clinicians faced with requests for reproductive assistance from persons who are HIV positive should be aware of the 1998 United States Supreme Court decision in *Bragdon vs. Abbott*. The court ruled that a person with HIV is considered ‘disabled’ and therefore protected under the Americans with Disabilities Act. According to that decision, persons who are HIV positive are entitled to medical services unless a physician can demonstrate ‘by objective scientific evidence’ that treatment would pose ‘a significant risk’ of infection. The Court determined that having HIV was a disability because it interfered with the ‘major life activity’ of reproduction due to the risk of transmitting HIV to offspring. Unless health care workers can show that they lack the skill and facilities to treat HIV positive patients safely or that the patient refused reasonable testing and treatment, they may be legally as well as ethically obligated to provide requested reproductive assistance.”

*From “Human Immunodeficiency Virus and Infertility Treatment,” an Ethics Committee report in *Fertility and Sterility*, a journal of the American Society for Reproductive Medicine, February 2002, Vol. 77, No. 2, pages 218–222.*

trying to change attitudes on a national level, so we're very careful," said Dr. Sauer. "I hope to educate my peers that this is safe and make this more open in my field." In addition to publishing reports on their work to get the word out to other fertility specialists, the center recently sent out a mass mailing to HIV doctors around the country to create awareness about their services.

"As an academic, I know that you can't tell which process is better and safer without thousands of people studied," Dr. Sauer said. "We do ICSI—one sperm per egg. So you limit the exposure to the sperm. Insemination with semen from an HIV-positive individual is outlawed in approximately half of the states, so we get around that with ICSI." Men must be healthy, with less than 30,000 viral load and stable T-cells, and under the care of an HIV specialist. A third of the men also have hepatitis C.

"As an advocate of women's rights and children's rights, we should advocate for doing this as safely as possible," Dr. Sauer noted. "I would not advocate at-home insemination. Seroconversion with insemination at home over time is pretty high, about 20%.

PROHIBITIVE COSTS

Even if people with HIV have specialists on their side, they'll find the cost of reproductive assistance shockingly high. Rarely will insurance cover these costs where HIV is involved. This is not so surprising, given that HIV is a relatively new disease, which in turn makes practically all of the science surrounding it new or outright experimental. Insurance providers are adverse to covering experimental therapies



even in matters of life-and-death.

Not only are reproductive techniques expensive, some of the services must be used more than once. Sperm washing—separating diseases from sperm—is an established technology that costs a few hundred dollars. The cost of testing for HIV after the washing is done will cost a few hundred more. Prices are available at clinic websites.

However, using *in vitro* fertilization with artificial insemination to get the sperm into the woman runs approximately \$8,000 to \$12,000, or even as high as \$20,000. Couples should understand that the *in vitro* procedure may not take. Using IVF, however, gives—per cycle—a higher pregnancy success rate, so there are advantages despite the cost.

COMPASSIONATE CARE

Dr. Cohan says, "It's absolutely essential that women and couples with HIV have the right to live as couples who don't have HIV. They should demand the same services available to anyone else. That's their right."

As with all of HIV care, expert medical advice is vital to family planning. Only a compassionate medical provider will help couples navigate their options. Dr. Cohan believes a doctor's sensitivity comes through experience. The more HIV positive patients doctors have had, the more open-minded they will be. She suggests that people check with the clinics currently helping couples with HIV to get referrals to medical providers near them.

She also recommends that individuals seek out other couples who've had children and talk with HIV service organizations such as WORLD—Women Organized in Response to Life-threatening Diseases—in Oakland, California. "That's a great place to start," she says. ☩

Special thanks to Dr. Deborah Cohan of the Bay Area Perinatal AIDS Center, San Francisco General Hospital for her suggestions and review of the above information.



STEP-BY-STEP: SPERM WASHING

compiled by Enid Vázquez

1. FIND A SENSITIVE MEDICAL PROVIDER

- See resources at the end. Ask members of your support system, such as other people living with HIV and your medical providers.
- Be aware that your doctor may have to sign a statement verifying that you're in good health. The wording of these statements varies among the fertility clinics (example: "Does this individual have a life-threatening disease?"). Many doctors will feel able to say "no" in good conscience.

2. GET MONEY

- Reproductive services are expensive. If your insurance won't cover the costs or you don't have insurance, you will need to pay out-of-pocket at the time of the service.

3. CHECK FOR FERTILITY PROBLEMS IN BOTH PARTNERS BEFORE PROCEEDING

4. LOWER VIRAL LOAD

- The lower the man's viral load, the lower the risk of infection.
- Research has found that plasma viral load differs from viral load in seminal fluid. Someone who has an undetectable viral load in their blood may have detectable viral load in their genital fluids, and vice versa (this is true for the female genital tract as well). Please note that "undetectable" means not able to be detected with the test used. HIV is still there.
- At least one study has found protease inhibitors to have different effectiveness in the genital tract.

5. LOOK FOR OTHER STDs

- The presence of other sexually transmitted diseases should be looked for and treated. They increase the risk of both HIV transmission and infertility. They may also increase seminal viral load even if there is no change in the plasma viral load.
- If the male also has hepatitis A or B, the woman should be vaccinated against those viruses.
- If the male has hepatitis C, for which there is no vaccine, it should be eliminated during sperm washing at the same time as the HIV and the sample tested for its presence afterwards (just as with HIV). It is currently unclear whether hepatitis C is transmitted easily during sex.

6. USE SPERM WASHING

- Sperm washing is a procedure long used to help couples trying to conceive without passing on diseases or genes for disease. Sperm are separated from the surrounding seminal fluid by a centrifuge, a device that separates components of a liquid as it spins at high speed. The sperm are then washed twice in a solution, in an effort to remove the undesirable materials.
- Not all reproductive service laboratories can conduct sperm washing for HIV.

7. TEST THE SPERM SAMPLE

- Not all reproductive service laboratories can test sperm samples for HIV after it's been washed—a step considered key to safer conception.
- PCR (polymerase chain reaction), the same technology behind viral load testing, is used to test the sperm sample. There are different PCR tests that can be used. The best test to use is not established.

8. STORE THE SPERM SAMPLE

- The sample is frozen and stored until the HIV test results come back. It may also be stored for use during the woman's next fertility cycle if she is past ovulation when the results come back.
- There is a cost for storage.

9. FERTILIZATION

- *In vitro* fertilization (IVF) represents the "test tube" baby. Eggs are removed from the woman's ovary and fertilized with sperm in a petri dish, resulting in zygotes (or "pre-embryos") that are placed in the woman's uterus or stored for later use. IVF is considered the safest method for conceiving with HIV.
- Intracytoplasmic sperm injection (ICSI—pronounced "icksy") is another type of IVF. ICSI is when a single sperm cell is used to fertilize the egg. It is an additional step that can be taken, so it's more expensive. However, it also increases the level of safety. It is especially useful with a low sperm count when the fertilization otherwise would not occur.

10. INSEMINATION

- Intra-Uterine Insemination (IUI)
- Washed sperm is placed directly into the cervix or the uterus itself.
- Sperm washing with IUI may be just as safe and less expensive than other insemination methods.

- Cervical cup. The Duncan Holly Clinic offers an oligospermic cup, inserted over the cervix by a doctor. The washed sperm then travels into the uterus. Anti-HIV medication is given at the time of insertion. The safety in preventing transmission of HIV is not well-established. For example, there might be the potential for microscopic tears of the vagina.

LOW-TECH METHODS AT HOME

- PEP stands for “post-exposure prophylaxis.” It’s HIV medicine that can be taken to prevent transmission following exposure. In this case, it can also stand for “pre-exposure prophylaxis” (or “PREP”) meaning that the woman takes medicine to prevent transmission before exposure to HIV. This is where knowledge of HIV medicine comes in handy (see past issues of *Positively Aware*). Many HIV specialists are willing to prescribe PREP to serodiscordant couples (where one partner is HIV positive and the other is not) who are trying to conceive. Cost will likely be out-of-pocket, and you may want to avoid using your insurance because it could raise red flags on your coverage that may haunt you later. Some organizations may clandestinely have limited quantities of pills for HIV therapy available for free. It is illegal to give prescription medicine to someone other than the person for whom it was prescribed. These services make use of leftover pills for situations such as a gap in refills or for out-of-towners who forgot their medicines at home. There are also programs that send medications abroad. You can check with them.
- The effects of PEP or PREP on fetuses and children born to women who used either PEP or PREP, if any, are currently unknown.
- Ovulation kits can help a woman determine when she is most likely to conceive, thereby limiting sexual exposure to this time. Kits are available at most drugstores at an affordable price.
- Do-it-yourself insemination (the “turkey baster” method) can be done with a syringe (without the needle) and washed sperm or unwashed semen. According to WORLD, “It’s best if the woman is on her hands and knees, shoulders down and hips in the air, and stays there as long as possible [after insemination].”

Even after sperm washing, there’s no 100% guarantee that HIV will not be transmitted. Ironically, sperm doesn’t seem to be infected by HIV; however, HIV may be present in the seminal fluid surrounding the sperm. In addition, while sperm washing and testing may be relatively simple and inexpensive, the processes and procedures involved with *in vitro* fertilization, zygote implantation, and clinical insemination are complex and expensive. These are, however, the safest ways to conceive. Please note that the clinics listed have differences of opinion in which procedure is best to use. The websites or a consultation will clarify those differences.

Using a turkey baster or syringe (without the needle) at home is more risky. Here, too, is another irony: the risk of infection with one act of vaginal intercourse is relatively low. The risk of infection increases with the presence of other sexually transmitted diseases or lesions, repeated unprotected intercourse, higher HIV viral load and biological factors in the man and the woman that are still largely not understood and which cannot be detected at home. Doctors cannot publicly advocate for these procedures—another good reason why you need a compassionate physician to guide you in private.

RESOURCES

American Society for Reproductive Medicine. Visit www.asrm.org.

Center for Women’s Reproductive Care, at Columbia University in New York City. Conducts IVF for serodiscordant couples. Call (646) 756-8282.

Duncan Holly Biomedical. Operates the Special Program of Assisted Reproduction (SPAR), started in 1994 as a support group for couples living with incurable sexually transmitted virus diseases such as HIV. Developed a mail-in product for shipping sperm-washed samples to fertility clinics around the country, as well as an HIV testing kit for sperm that can be mailed to you at home. Complete details and in-depth articles available on its website, including the story of Baby Ryan, the first baby conceived through SPAR. Call (781) 665-0750 or (617) 623-7447, or visit www.duncanholly.com/idi/spar/spar_main.html.

Reproductive Lab Service, 233 East Erie St. Suite 309, Chicago, IL 60611. Call toll-free: (877) REPROLAB (737-7652). Visit www.reprolab.org.

SMART (Sisterhood Mobilized for AIDS/HIV Research & Treatment), New York City. Call (917) 593-8797, write smartuniv@aol.com or visit www.smartuniversity.org.

“Sperm Washing: Reducing the Risk of Father to Mother Transmission.” Comprehensive article, although written in 2001. Visit www.hivinsite.ucsf.edu.

Women Organized in Response to Life-threatening Diseases (WORLD), 414 13th Street, 2nd floor, Oakland, CA 94612. Call (510) 986-0340. Visit www.womenhiv.org. Unfortunately, not all copies of their excellent newsletter and articles are available on-line. However, an abbreviated version of their article “Reducing the Risks of Conception: Getting Pregnant When One or Both Partners is HIV positive,” is available at www.PositiveWords.com. The article is very easy to understand and extremely detailed. ☩

Perinatal HIV Transmission and Birth Options for HIV positive Mothers

by Laura Jones

Many people are misinformed about the risks of perinatal HIV transmission, including many healthcare providers. Some people mistakenly believe that all babies born to HIV positive women will be infected, or that HIV positive women are too sick to have healthy pregnancies and give birth to healthy children. Many people also don't know that there are ways to greatly reduce the risk of mother-to-child HIV transmission. About 25% of children born to HIV positive women who receive no treatment or interventions against perinatal HIV transmission become infected with HIV—that means an average of 25 out of 100 babies, or 1 in 4, can pick up HIV from their mothers during pregnancy, birth, or afterward from breastfeeding. But perinatal HIV infection rates can drop to as low as 1% or 2% for babies whose mothers are able to use combination antiretroviral therapy during pregnancy, AZT or nevirapine prophylaxis during labor and after birth, and choose the birth option that's safest, according to maternal viral load levels, for both mother and baby.

You are a good place for your baby to grow, and you deserve respectful care. If your HIV care specialist or prenatal care provider tries to dissuade you from becoming pregnant or recommends you terminate a wanted pregnancy, get another provider! With good care and support, your risk of transmitting HIV to your fetus or baby is very low. Don't let that worry stop you if you want to be a mother.

HOW PERINATAL HIV TRANSMISSION HAPPENS

A fetus (your baby from 8 weeks gestation until birth) or newborn can become infected with HIV through contact with virus in their mother's blood, cervical and vaginal secretions, and breast milk. It's the mom's HIV status that matters, not the father's—HIV transmission to babies is all about the virus in their mom's fluids, not in their father's semen. If the mom stays HIV negative throughout her pregnancy, there's no risk to the baby even if the father is HIV positive.

No one knows the exact mechanisms involved in perinatal transmission, but it's believed to occur three different ways:

Prenatally (*in utero*): Some babies acquire HIV because the virus crossed the placenta during pregnancy—this doesn't happen very often, but it can. During pregnancy, the mother's blood supply is connected to the fetal blood supply via the umbilical cord and placenta. The mother and the baby do not share the same blood supply, but sometimes HIV in the mother's blood is able to cross the placenta and infect



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the baby. The following conditions can increase the risk of transmission during gestation:

- **Becoming infected with HIV during pregnancy.** A person's viral load is very high right after they acquire the virus, and a high viral load increases the transmission risk to the fetus.
- **Infections of the chorion, amniotic membranes, or reproductive tract.** Sexually-transmitted vaginal infections like chlamydia, gonorrhea, and trichomoniasis can cause a spike in the pregnant woman's viral load, which can in turn increase the risk of transmission to her fetus.
- **Placenta Previa.** This is when the placenta grows over part or all of the cervix—a condition that can lead to heavy bleeding before or during labor. Placenta previa often corrects itself as the uterus expands during pregnancy.

At birth: During labor and delivery, the baby comes into contact with her/his mother's blood and cervical/vaginal secretions while passing through the cervix and vagina. Research indicates that the majority of babies who pick up HIV infection from their mothers probably acquire the virus during the birth process.

During breastfeeding: There have been several documented cases in which HIV has been transmitted through breastfeeding. HIV has been isolated in breast milk, and the documented cases of transmission through breastfeeding indicate that the virus was passed through the milk rather than during gestation or the birth process. Blood from cracked nipples or breast infection (mastitis) may also be present during breastfeeding, and may contribute to the risk of infection.

The risk of perinatal transmission risk at any stage can be greatly reduced by:

1. Taking combination therapy during pregnancy to reduce maternal viral load.
2. Taking AZT during labor and birth to help protect the baby while it's exposed to HIV in blood and cervical secretions.
3. Choosing the birth option that poses the least risk to both mother and baby—a normal vaginal birth, or an elective cesarean section (surgical birth).
4. Administering AZT to the newborn for up to six weeks after birth.
5. Bottle-feeding formula or breast milk from a milk bank instead of breastfeeding or bottle-feeding your baby your own breast milk.

PRENATAL CARE

You'll receive the same prenatal care as an HIV negative woman, except for a few instances. You'll be working either with a prenatal healthcare provider who is also an HIV specialist, or with an obstetrician in addition to your regular HIV specialist.

During prenatal care, your OB should avoid the following tests and procedures unless they are considered medically neces-

sary, because they are invasive and may increase the risk of HIV transmission to your fetus during pregnancy:

Amniocentesis: a diagnostic test for chromosomal abnormalities like neural tube defects and Down's syndrome. It involves inserting a long, very thin needle through your abdomen and into your uterus to obtain a sample of amniotic fluid. Another screening method that checks for alfa fetal protein (AFP) levels in a blood sample can be done instead.

Chorionic villi sampling (CVS): taking a sample of the chorionic villi, tissue which will form the placenta. This is another way to check for chromosomal abnormalities, but because it disturbs the placental site and causes some bleeding, it's not as safe for your fetus as AFP testing.

Your provider may also want to perform more ultrasounds (visualizing the fetus in the uterus) than they would for a woman without HIV, especially if there is a question about your fetus's gestational age due to irregular menstruation. If this bothers you, talk with your provider about how to keep ultrasound use at a minimum while still getting information that will help you both decide when an elective cesarean section can be done safely if you decide to give birth via C-section.

USE OF COMBINATION THERAPY FOR CONTROLLING MATERNAL HIV INFECTION

Combination antiretroviral therapy (also called Highly Active Antiretroviral Therapy, or HAART) is recommended for use during pregnancy regardless of a woman's CD4 count or viral load. Using combination therapy between 14 and 34 weeks in pregnancy can be helpful in reducing your viral load, which in turn helps reduce the risk of transmission to the fetus during gestation and also during labor and birth. You can work with your HIV specialist to choose a regimen from among the drugs recommended for non-pregnant adults. Your HIV specialist may suggest a regimen that includes AZT. If you are resistant to AZT or have experienced toxicity with past use, be sure to tell your provider.

Avoid Sustiva! It's not recommended for use at any time during pregnancy due to risk of birth defects. If you find out you're pregnant while using Sustiva, don't panic! Just consult your HIV specialist and change your regimen for the remainder of your pregnancy. If Sustiva is working well for you, you should be able to go back to it again after your baby is born.

For your own safety, you should also avoid using the following meds in combination with each other during pregnancy:

- **d4T (Zerit) + ddI (Videx)** Can cause serious and potentially fatal lactic acidosis.

- **AZT (zidovudine) + d4t (Zerit)** These don't react well together pharmacologically. If you're taking Zerit as part of your regular HAART regimen, talk with your provider about substituting it altogether for the duration of your pregnancy, or stopping it during labor and delivery so you can safely use AZT prophylaxis.

If you're already on combination therapy when you become pregnant, most healthcare providers will recommend that you stay on your regimen during the first trimester of pregnancy unless you're too nauseous to keep your meds down. Pregnancy-related nausea and vomiting ("morning sickness") tends to be worst during the first trimester for women who experience it—puking up your pills isn't helpful, so for some women it's safer to stop meds until morning sickness subsides. If you decide to take a break from your meds, all drugs should be stopped at the same time and then re-started at the same time in order to reduce the risk of developing resistance (consult your physician).

If you've never used combination therapy before, many providers will recommend waiting until after 12–14 weeks of pregnancy, unless your viral load is very high or your health would benefit from starting combination therapy right away. There are two reasons for this recommendation: 1) to avoid potential side effects such as nausea/vomiting and diarrhea at the same time you may be struggling with morning sickness, and 2) because the risk of medication-related birth defects (for any medication, not just antiretrovirals) is considered highest in the first trimester, when the fetal organ and skeletal systems are forming. However, a woman cannot be denied therapy at any time during a pregnancy—if you want it, you should be given it.

AZT FOR FETAL PROTECTION AND INFANT PROPHYLAXIS

Even if you don't use any combination therapy during pregnancy, taking AZT during the birth process and administering it to the baby after birth will help to greatly reduce the risk of transmission. Remember, the studies that showed AZT to be effective in reducing perinatal transmission focused on the use of drugs during labor and given to the baby after birth—that's where they found the reduction from 25% to 8%. Use of AZT and other meds during pregnancy can help reduce the risk even more (down to as low as 1%), but it's almost never too late to do something until 24 to 48 hours after the baby is born.

AZT is currently the standard prophylactic treatment against perinatal transmission used in the United States. If you use AZT during labor and birth, it will be administered to you through an IV regardless of whether you give birth vaginally or by elective C-section. After birth, your baby will be given AZT syrup within 8 to 12 hours, and you'll be shown how to give the syrup yourself at home for the next six weeks.

HAART AND CHILD SAFETY

It's totally understandable if you're worried about what effect these powerful antiretrovirals may have on your fetus or baby. Fortunately, studies conducted by research entities such as the Antiretroviral Pregnancy Registry are indicating that children born to mothers who have used antiretroviral medications during pregnancy do not appear to be statistically at higher risk for birth defects than babies born to mothers who didn't use HAART. The preliminary results for the study following the children who were born to women who participated in ACTG 076 (the study that demonstrated AZT's effectiveness in reducing perinatal transmis-

sion) show that, after 6 years, these children do not appear to be experiencing a greater degree of health problems than are noted in the general population of children. However, we can't yet know the long-term outcomes for children born to women who used combination therapy during pregnancy and/or AZT prophylaxis. Research is being conducted continuously, though, so we're getting more and more information as time goes on.

No one can force you to take meds while pregnant. If you don't want to or can't take meds during your pregnancy, you cannot legally be made to take any medication on behalf of yourself or your fetus. Right now, the use of AZT and other antiretroviral medications in pregnancy is recommended because the known risks of pediatric AIDS are thought to outweigh the unknown possible long-term risks of their use during pregnancy for both mother and child. If you have concerns about the effect AZT or other meds may have on your child, now or in the future, discuss them with your healthcare provider, HIV/OB specialist, or a local agency that advocates for HIV positive people. The information in these links may also be useful to you:

- **Antiretroviral Pregnancy Registry**
<http://www.apregistry.com/>
- **Information About the Safety of Combination Antiretroviral Treatment for Human Immunodeficiency Virus Infection During Pregnancy**
<http://www.thebody.com/cdc/pregnancy.html>
- **HIV/AIDS Treatment Information Service (800) 448-0440**
<http://www.hivatis.org>
- **AIDSinfo website**
<http://aidsinfo.nih.gov>

OPTIONS FOR BIRTH

If your viral load is less than 1000 copies/ml, there is currently no evidence showing that elective cesarean section will reduce the risk of perinatal HIV transmission. C-section is major abdominal surgery—you want to avoid it unless it's considered beneficial to you or your baby, because of the increased risk of post-operative complications in mothers who give birth by C-section. Women with viral loads under 1000 can consider a normal vaginal birth to be the safest option for both them and their baby, unless there are other factors (baby in difficult position for birth, obstetric emergency, etc.) that necessitate C-section.

To reduce tissue damage, extra bleeding, and infection risk during vaginal birth, your care provider will avoid the following invasive procedures and use of instruments unless medically indicated:

- **Artificial Rupture of Membranes** (AROM—"breaking your water" with a small instrument that looks like a crochet hook). When your bag is intact, your baby remains protected by the amniotic fluid and membranes that form a barrier between it and virus in your blood and cervical secretions. Maintaining that protection for as long as possible reduces the risk of HIV transmission to your baby.

- **Multiple vaginal exams after membranes have ruptured.** Vaginal exams are generally done to check for progress in labor. Because there's an increased risk of bacterial infection each time an exam is done, these exams will be kept to a minimum after your water breaks.
- **Internal fetal monitors and fetal scalp tests.** These cause small cuts in the baby's scalp, which would then be exposed to HIV in the mom's fluids.
- **Episiotomy** (a surgical incision to enlarge the vaginal opening). Episiotomies always cause bleeding, increasing the amount of blood your baby is exposed to as it's being born.
- **Instruments like forceps or vacuum extractors** that necessitate episiotomies and/or can cause vaginal tears and bleeding.

If your viral load is over 1000 copies/ml, research shows that elective cesarean section done prior to rupture of membranes can reduce the risk of HIV transmission by preventing contact between the fetus and the blood and cervical secretions that are present during the birth process ("elective" means you choose to do it, rather than have it done for emergency reasons). C-section after the membranes have been ruptured for at least four hours has not shown to be statistically helpful in reducing HIV transmission, so elective C-sections done to reduce HIV transmission are usually performed at 38 weeks gestation (well before most women's water breaks on its own). Because of the increased risk of post-operative infections in women who give birth by C-section, your care provider may give you antibiotics to take after the surgery.

The choice of how to give birth is ultimately yours. Your healthcare provider should discuss your options with you and provide their professional opinion based on your lab tests and overall health of both you and your fetus, but you are still the person who makes the final decision.

WHAT ABOUT BREASTFEEDING?

Because there are documented cases showing that HIV can be transmitted from mother to infant through breastfeeding, HIV positive women are counseled to avoid breastfeeding if safe alternatives to breastfeeding exist. If you don't want to feed your baby formula, you can try to find a milk bank (an organization that collects donated breastmilk and ships it out) in your area and use that instead. For more information on this option, call Human Milk Banking Association of North America, Inc. at (919) 861-4530 or on the Internet at <http://www.hmbana.com>.

HIV positive women living in places where clean water and consistent supplies of safe formulas are not available need to weigh the risks and benefits of breastfeeding their babies. If their children are at high risk for starvation, dehydration, and diarrhea associated with unsafe formula-feeding, breastfeeding may be the safer alternative even though it increases the risk of HIV transmission to the baby. In the U.S. and Canada, HIV positive women are largely

able to safely formula-feed, and are therefore encouraged to do so. If you live in the United States and are considered "low income", please know that you should also qualify for Medicaid and WIC supplements that provide free infant formula (regardless of your immigration status, if that's a concern). In many places, services may be prioritized for HIV positive mothers, so ask your healthcare provider or case manager for more information.

REMEMBER!

Preventing transmission of HIV to your baby is one very important aspect of your care, but it shouldn't be the only focus. Your physical and emotional health are important for your own sake, too—and taking care of yourself is taking care of your baby! Aside from HIV infection, you're just like any other pregnant woman. Your provider should respect your decision to become pregnant and have a baby, and should assist you in having the healthiest and happiest pregnancy you can have. You and your baby deserve nothing less. Congrats, and good luck! 🍀

Note: This article was written with assistance from the Pediatric AIDS Chicago Prevention Initiative (PACPI). For more information on PACPI's Chicago-area services and classes for HIV positive pregnant women, call (773) 327-0509. Clinicians and social service providers can call the 24-hour hotline at (312) 926-7380. Thanks to Anne and Brenda!

SOURCES:

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Viracept

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Here

A NEW PARANOIA

by Tom Setto

"Hey, Ken, is that guy still following you?" I was kind of hoping no one would bring it up, but Jerome couldn't resist. You see, Ken has been mentioning this mystery man since he read *The New York Times* article about how insurance companies are hiring private investigators to follow people living with AIDS who are receiving long-term disability benefits. I was looking forward to our weekly breakfast and not having to hear about his conspiracy theory.

"You guys think I'm going crazy, but I see him sitting in his car outside my building almost every day. It can't be a coincidence. I really worry that they are trying to take away my benefits, that they're trying to find some evidence to force me back to work. The forms they have me fill out every year and the ones my doctor has to fill out are unbelievable."

"Really? What do they want to know? And would it be so bad to go back to work?" Joey asked.

"Well, they want to know how much I can lift and for how long I can carry it, whether I can still bend and kneel and crawl, stuff like that."

"I hear you have no problem bending, kneeling, and crawling," Miguel interrupted, "at least that's what your date last week said."

"I'm not too old for that, but I think I'm too old to have to start over. I'd love to be able to go back to work. Who would hire a guy with who hasn't worked for six years? How do I explain the time off? 'Oh, by the way, I have AIDS and I got so sick I couldn't work, but I'm feeling better now so how about a job?' That would get my foot in the door."

"You sell yourself short," Jerome answered. "You make yourself out to be an old fart who can't do anything anymore."

"Sure, I feel great now but what if I go back to work and I get sick eight months later and have to quit? What if I can't get back into ADAP? My Social Security would drop because my base income would be less and I'd have already given up the long-term disability. I think I have the right to be paranoid."

"Calm down," Gary said, "you're preaching to the choir here, but you have to stop being so Oliver Stone. I doubt very much if that guy is watching you, maybe he's working for that show *Cheaters* and trying to catch some cheating boyfriend. How well did you know that guy you went out with last week?"

"Why all the abuse about my date, guys? I may be an old fart, Jerome, but I ain't dead."

"I used to worry constantly about dying," I jumped in. "Now I worry that I might get sick enough that I need to take a pill for it. It's tough not having prescription drug coverage. You take that for granted when you're working and have health insurance. With all the financial problems I hear that ADAP's are having, I'd be afraid to get into the HMO that Medicare offers. I agree with Ken, I worry that I might not be able to get back into the program."

"You know what I worry about?" Gary said. "I worry about how my body is changing. I was never the best looking guy in the bars, but I didn't scare children either. I don't think my legs can get bonier or my ass get any flatter. I worry about growing a buffalo hump and how my belly is getting bigger even though I keep doing more crunches. I worry about watching my cheeks sink into my face. I never thought in a million years that I'd ever think about plastic surgery but I am. This disease is

making me paranoid in ways I never was before."

Miguel added his fears. "I worry about getting KS again. I look at my body everyday. Each time I see a new mark I get obsessed with it. I watch it constantly to see if it gets any bigger or darker. I don't know if I could go through the chemo again. What is worse, though, is the embarrassment of having those marks all over you and having people stare at you. I couldn't stand to see people whispering around me. I was so paranoid that they were talking about me. I hated leaving the house, hated looking in a mirror. I don't think I could go through that again."

"My fears are a little different from you all," Jerome said. "I moved from the neighborhood I grew up in and left the church I'd gone to all my life because I was worried that folks would find out my secret. I'm sure you know how the ladies can talk. Not only am I Black and gay, but I am Black and gay and HIV positive."

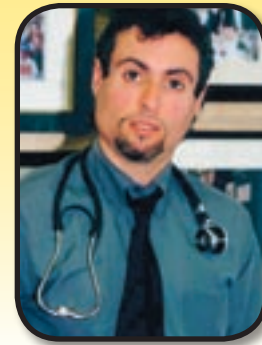
"I thought you moved in with me because you love me," Miguel asked. "And you can always come to church with me."

"First of all, you're Catholic. Enough said there. And I did move in with you because I love you. I never really talk about how Black people look at AIDS. I just don't think you guys would really relate. Maybe some day if you all want we'll really get into it. When you're ready and when I'm ready."

"I think I speak for us all when I say that we'd love to talk about it with you and that we're all here for you," Ken said. "It's amazing that after over 20 years we still have to worry about how others think about us, our condition, and how they treat us. We should have to worry about our health and staying alive, not how we are going to survive the system and get beyond people's negative attitudes." ✚

VIREAD, EPIVIR AND ZIAGEN COMBINATION: FAILURE IN NAÏVE PATIENTS WITH A ONCE-DAILY REGIMEN

by Daniel S. Berger, MD



Since the first release of the drugs, abacavir (Ziagen) and tenofovir DF (Viread), scientists and researchers were caught in a quandary. What seemed at the outset like a no-brainer, administering two very potent and promising agents in combination once-daily, should have resulted in satisfactory results. This was not the case.

What happened? The FDA approved abacavir to be administered twice daily. Later, some pharmacokinetic studies suggested that one could potentially take this drug once-a-day. A clinical study, though preliminary, presented last year in Buenos Aires, added to the fuel. Thus a GlaxoSmithKline (GSK) sponsored study, ESS30009, was designed to look at a “fixed dose tablet” or “Easy Tablet”, that is, a new formulation of 3TC (Epivir) and abacavir in one pill and to be administered once daily. The study compared Epivir + Ziagen + Viread against another regimen of Epivir + Ziagen fixed tablet + efavirenz (Sustiva) with all regimens dosed once daily. As a principle investigator in this study, I found the protocol to be of interest, especially in light of data showing both Ziagen and Viread as being quite potent. In another study, the potency of Viread was compared with the protease inhibitor, ritonavir (Norvir); preliminary work with Ziagen monotherapy also showed it to be a strong and potent agent.

In study ESS30009, investigators knowing full well what regimen their patients were randomly assigned to (being open-label) soon observed obvious differences between the regimens. Our clinic, Northstar Healthcare in Chicago, enrolled 14 patients in this study, six of whom were on the Viread regimen and eight patients on the Sustiva based regimen; nine of whom have reached between 8 and 16 weeks. In the global study 345 patients were randomized and only 125 individuals had reached 12 weeks. At this early point differences in the study arms were already being observed, which forced an early interim analysis.

Thus, in mid July, principle investigators received urgent communications from GSK. So, as soon as the early indications emerged, GSK sought to notify the unexpected results to their investigators, however disconcerting. Their letters described that a substantial number of patients on the Epivir + Ziagen + Viread regimen were failing and recommended that our clinical judgment

and practice should take steps to ensure the best possible care of our individual patients. This meant that if our judgment dictated withdrawing certain individuals from the study, then this should be done. Additionally, talking with scientists at Gilead Sciences, makers of Viread, it was obvious they were also working diligently in investigating the cause for these outcomes.

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ANALYSIS OF THE DATA

Of 102 individuals randomized, 50 subjects or 49% who were on the fixed dose of Ziagen/Epivir in combination with Viread with at least 8 weeks of viral load data (HIV-RNA) demonstrated “non-response.” Non-response means those individuals failed to achieve viral load drops greater than 2 logs or were already showing increases in viral load from their previous visit values. This compared with only 5/92 patients or 5.4% randomized to the Ziagen/Epivir + Sustiva combination. Looking at the data in fewer patients but at 12 weeks, again the results were similar. 30/63 patients or 47.6% on the Ziagen/Epivir + Viread arm were non-responders vs. 3/62 or 4.8% on the Ziagen/Epivir + Sustiva arm.

Although this analysis was carried out at an early juncture of the study, the results were of much concern. Under normal circumstances with *effective* regimens, this phenomenon of high “non-responders” should not normally be observed.

This in concert with another study reported at the International AIDS Society meeting in Paris during July only confirmed and intensified the implications. Dr. Charles Farthing from Los Angeles studied 20 patients also naïve to antiviral treatment. The subjects were placed on a once-daily regimen of the same agents, Ziagen,

Epivir and Viread. Nine of 17 patients (52%) had viral load rebound. These patients were adherent to their regimen based on “pill count” during their follow-up visits.

POSSIBLE EXPLANATIONS AND HYPOTHESES

It is worthy to note that Gilead Sciences has conducted its own studies on the pharmacokinetic interactions of both drugs, finding that neither agent significantly compromised blood levels of the other.

Dr. Michael Miller, Director of Clinical Virology at Gilead Sciences, says two principle possibilities may explain the regimen’s poor potency. First, it is possible that an intracellular interaction between Ziagen and Viread may be occurring and lowering drug levels in cells. Second, resistance to the drugs themselves may be at fault. Whatever the reason, patients being administered these agents “once-daily” may only be exacerbating the manifestations of the problem. If, however, resistance was the start of the problem or primarily at fault, one would expect more complete resistance mutations in those failing patients. In Dr. Farthing’s cohort the Epivir-associated M184V mutation was observed in many failure patients, the K65R was seen in only half of the failures. Thus complete resistance occurred in relatively too few patients and does not explain the observation of high levels of failure; in general, I believe that the presence of K65R as the sole mutation is not as common, nor significant enough cause for individuals to completely fail their regimens clinically.

Moreover, resistance mutations can often be due to one of several causes including non-adherence, not enough antiviral penetration into body compartments, or not enough blood levels of drug. And it may be that once-daily doses of Ziagen and Epivir may not be enough throughout a 24-hour period to maintain enough suppression and pressure on HIV in some select patients. Recently in the ACTG 5095 study (see “The Buzz” May/June 2003) we saw another triple nucleoside regimen, Trizivir, also demonstrate lower potency compared to a Sustiva based regimen. Although this particular drug regimen of Trizivir was twice daily we may be receiving the same message: triple nucleoside regimens are not consistently effective as non-nuke or protease inhibitor based regimens—clinician beware.

It may be that once-daily doses of Ziagen and Epivir may not be enough throughout a 24-hour period to maintain enough suppression and pressure on HIV.

However, many argue that there is a place for triple nucleoside therapy, particularly for individuals without a heavily compromised immune function. Alternatively, one should remember that resistance occurs usually after having responded to treatment. The fact that many patients in ESS30009 did not respond leads one to consider possible drug interactions. Researchers at Gilead Sciences note that various other studies are ongoing in which Viread and Ziagen are being used successfully in combination. These studies are not once-daily, triple nucleoside regimens, however.

CONCLUSION

It may be premature to invoke a rule of not using these two drugs in combination in other clinical scenarios at this time. Physicians should use their clinical judgment in their individual patients. However for now, it would be prudent for clinicians not to use these two agents in a once-daily regimen, especially in naïve patients. Furthermore, physicians should not initiate patients on a once-daily regimen of Epivir, Ziagen and Viread. Both companies, GSK and Gilead are aggressively pursuing the challenge of identifying the direct cause of the problem with laboratory and intracellular research. Patient care is paramount. ☞

Daniel S. Berger, MD, is Medical Director of Chicago’s largest private HIV treatment and research center, NorthStar Healthcare, Clinical Assistant Professor of Medicine at the University of Illinois at Chicago and editor of AIDSInfoSource (www.aidsinfosource.com). He also serves as medical consultant and columnist for Positively Aware. He has contributed to the recently released The First Year—HIV, An Essential Guide for the Newly Diagnosed (2003; Marlowe & Company, New York). Dr. Berger can be reached at DSBergerMD@aol.com or (773) 296-2400.

DHIVA

by Jim Pickett



“YOUR NAME HAS BECOME SYNONYMOUS WITH AIDS.”

A friend of mine told me this yesterday. She has AIDS and is someone I have gotten to know working in the field. We have done several speaking engagements together, sharing our personal stories for high school students so they’d have a better understanding of the epidemic and maybe not make some of the choices we made.

Her comment took me totally by surprise, and for once in my life, I was rendered nearly speechless. I didn’t know what to say. And I didn’t know if I liked what I had just heard. As a matter of fact, I was kind of disgusted.

“I mean that in the best of ways,” she continued, trying to fill the pregnant pause, trying to let me know she was complimenting me, telling me she was proud of me and my work.

I knew that, I knew she was referring to my advocacy/activism and to the level of my involvement, all of which have increased substantially in the last couple of years. Almost out of control. It’s like, before I knew it, I was on a million committees and signing up for a zillion things and running a crazy fleckin’ listserv with thousands of subscribers. Before I knew it I was being honored as an activist and as an advocate, before I knew it I was being asked to speak, I was being asked for my opinion, I was being asked to share, I was being asked to participate, I was being sought, I was wanted, I was needed, I was hired, I was necessary, I was leading the struggle, I was crucial, I was essential.

I was prostituted.

I was AIDS.

Yuck.

Before I knew it, I had become synonymous with AIDS. I had become AIDS. People thought of me and AIDS in the same sentence. This is who I was... am... me... AIDS.

Eight years ago in August I tested positive. If you had told me then that my name would be so closely linked to this vile and disgusting disease, I would have said, “Uh, you got the wrong queen, missy.”

I’m still a wrong queen, but now I’m an HIV/AIDS diva too. As in, DHIVA, as in, you can’t spell DIVA without HIV. How fucking fabulous. How fucked up.

Is this what I really want? Do I want to be this disease-ridden poster child? How did I get here? What the hell was I thinking? No one to blame but myself—I walked in every door that opened for me on my own. Many times I skipped in, or sashayed in, or jumped in—but was I ever forced in? No.

I PROSTITUTED MYSELF FOR THIS LOUSY DISEASE.

I was talking to my boyfriend one day about work, going on and on and on about this and that activity I was involved in, such and such event, policy, legislation, the bullshit politics, the ideology, regime change, the fighting, the struggling, the squabbling, the backstabbing, community, the 60 million without health insurance, homophobia, racism, poverty, malnutrition, substance abuse, depression, disenfranchisement, disinformation, comprehensive

I had become
synonymous with AIDS.
I had become AIDS.

sex education, abstinence only, the CDC, HRSA, NIH, ignorance, cynicism, complacency and burnout. The responsibility, the pressure, the pressure, the pressure. The meetings, the summits, the conferences. The pressure. God bless him, he’s really interested, and he really likes to hear me go on and on and on about this stuff. Really he does. Go ahead, ask him.

Then there was a lull in the conversation—catching my breath to start another rant—and he asked me, in that moment of tranquility, “Are you ever tired? Do you ever feel overwhelmed?”

I burst into tears and sobbed, hard, for at least a couple minutes. “Yes I am tired. Yes I do feel overwhelmed.” I choked the words out. “I don’t think I can do this anymore. It’s too much.” I proceeded to tell him why it was too much, why I couldn’t do it anymore, why I was tired, so tired, why I was so sick of it all. I substantiated everything. And he listened. And he said, “I understand.” And he listened some more, until I was done.

The next day I woke up and got back on that horse. I’m mindful that I need balance in my life if I am going to continue ranting and raving about HIV/AIDS. And I am. I need to remember that I am not only those letters. Whatever others perceive, there is a lot more to me than simply what I bring to the cause. And I nurture those other things—like the love in my life, like my friends, my interests, my hobbies—so I can keep on fighting. Because, really, what else can I do? What else would I want to do?

You can’t spell DHIVA without HIV. ☘

TPAN Events Calendar

All events held at TPAN unless otherwise indicated.
For additional information on these events please contact TPAN at (773) 989-9400.

September 2003

DATE	TIME	EVENT
Wednesday 3rd	7:30 – 9:00 PM	Committed To Living - HIV Legal Issues – AIDS Legal Council of Chicago
Friday 5th	6:00 PM – 12:00 AM	Cold Gin Hot Jazz – Cabaret Chicago, the annual TPAN gala benefit, Hyatt Regency Chicago at the Riverwalk
Saturday 6th	12:15 PM game time	Out at the Ballgame - Chicago White Sox presented by Chicago Free Press and Until There's a Cure Foundation, benefiting TPAN, AIDS Foundation of Chicago, Project Vida & Howard Brown Health Center
Saturday 6th	5:00 – 11:00 PM	Dance for Life benefiting TPAN, AIDS Foundation of Chicago and The Dance for Life Fund. Skyline Stage at Navy Pier
Tuesday 16th	6:00 – 8:00 PM	Fuzeon Panel, Learn about Fuzeon with a panel of patients currently using Fuzeon (T-20)
Thursday 25th	6:00 – 10:00 PM	PULSE – The Social Event for Chicago's HIV Community, Berlin, 954 W. Belmont End of the Month Celebration

October 2003

DATE	TIME	EVENT
Wednesday 1st	7:30 – 9:00 PM	Committed to Living – HIV Related Cancers
Wednesday 15th	6:00 – 9:00 PM	T.E.A.M. Update - Prevention
Saturday 18th	9:00 AM – 4:00 PM	Man Alive – A one-day health summit for Gay Men featuring Dr. Stephen Fallon, Frank Oldham, Jr., and workshops on HIV Treatments, Substance Use in the Community, Body Image and Relationships at the Hyatt Regency Chicago
Monday 20th	6:00 – 9:00 PM	T.E.A.M. Training
Wednesday 22nd	6:00 – 9:00 PM	T.E.A.M. Training
Monday 27th	6:00 – 9:00 PM	T.E.A.M. Training
Wednesday 29th	6:00 – 9:00 PM	T.E.A.M. Training
Thursday 30th	6:00 – 10:00 PM	PULSE – The Social Event for Chicago's HIV Community, Berlin, 954 W. Belmont End of the Month Celebration

Man Alive
A one-day health summit
for Gay Men
Saturday, October 18th

featuring
Dr. Stephen Fallon, Frank Oldham, Jr.,
and
workshops on HIV Treatments,
Substance Use in the Community,
Body Image and Relationships
at the Hyatt Regency Chicago

Programs and Meetings

All meetings held at TPAN unless otherwise indicated:

5537 North Broadway, Chicago.

Office hours: Monday–Thursday, 9 am–8 pm. Friday, 9 am–6 pm

phone: (773) 989–9400 • fax: (773) 989–9494

e-mail: programs@tpan.com • www.tpan.com

Support groups sponsored by the
Chicago Department of Public Health

Peer Support and Buddy programs sponsored by the
AIDS Foundation of Chicago

Monday

MEDICAL CLINIC

HIV/STD screenings and full medical care for HIV positive clients is available. This program is offered by Access Community Health Network. Call for an appointment. Mondays 10:00 am–6:30 pm.

TPAN DAYTIMERS

A group for people with HIV who prefer to meet during the day. Mondays and Thursdays at 10:30 am.

SPIRIT ALIVE!

Through a collaborative effort of AIDS Pastoral Care Network (APCN) and TPAN, Spirit Alive! meets Monday evenings from 7:30–9 p.m. at TPAN. With a respect for people of all faiths, Joe Flint facilitates group discussions. Individual, one-on-one counseling by appointment, Mondays only.

Tuesday

YOGA

Tuesdays 10 am–11 am. Yoga for all levels.

LIVING POSITIVE

HIV positive gay men discuss how being positive affects life and relationships. Socials and speakers on occasion. Meets Tuesdays at 7:30 pm.

POSITIVE PROGRESS

A peer-led group for HIV positive individuals in recovery. Special emphasis is placed on living a clean and sober lifestyle as a priority to effectively living and dealing with HIV. Meets Tuesdays from 7–9 p.m.

Wednesday

MEDICAL CLINIC

See description on Monday. Call for an appointment. Wednesdays 10:00 am–6:30 pm.

Wednesday continued

NEEDLE EXCHANGE PROGRAM

Free, anonymous, legal syringe exchange and HIV/AIDS prevention. Wednesdays 5:00 pm–7:00 pm, or by appointment, at TPAN office. In association with Chicago Recovery Alliance.

SHE (STRONG, HEALTHY AND EMPOWERED)

A group for HIV positive women. Meets on Wednesday at 7:30 pm. Call Kathleen at (773) 989–9400 for more information.

POZ LEATHERMEN

A new support and social group for HIV positive leathermen and friends. Wednesdays 7–9 pm.

Thursday

TPAN DAYTIMERS

A group for people with HIV who prefer to meet during the day. Mondays and Thursdays at 10:30 am.

NEEDLE EXCHANGE PROGRAM

Free, anonymous, legal syringe exchange and HIV/AIDS prevention. Thursdays 2:00 pm–5:00 pm, or by appointment, at TPAN office. In association with Chicago Recovery Alliance.

BROTHERS UNITED IN SUPPORT (BUS)

A group for HIV positive gay and bisexual men of African descent. Thursdays at 7:00 pm.

POSITIVE NOW

Whether newly diagnosed or having been living with HIV, you're invited to join Positive Now. Providing support, education and the opportunity to share experiences in a relaxing, empowering environment. Socials on occasion. Meets Thursday evenings at 7:00 p.m.

PULSE AT BERLIN

Berlin, 954 W. Belmont, Chicago. Thursdays from 6:00–10:00 pm.

Friday

NEEDLE EXCHANGE PROGRAM

Free, anonymous, legal syringe exchange and HIV/AIDS prevention. Fridays 2:00 pm–5:00 pm, or by appointment, at TPAN office. In association with Chicago Recovery Alliance.

SAFE PASSAGE

A group for young adults (ages 18–24) who are HIV positive. Fridays at 7:00 pm.

Scheduled By Appointment

FAMILY AIDS SUPPORT NETWORK (FASN)

A group for family, friends, and caregivers. Call Betty Stern at (773) 989–9490.

SPEAKERS BUREAU

Individuals are available to community groups and organizations to educate on HIV, safer sex, harm reduction and experiences of living with HIV. Call Ida at (773) 989–9400.

PEER SUPPORT NETWORK / POSITIVE BUDDY

Trained volunteers provide individuals living with HIV/AIDS one-on-one peer, emotional support. Whether newly diagnosed or having been living with HIV, volunteers provide buddies with information, support and referrals. Call Ida to get a buddy or to volunteer!!!

Miscellaneous

CHICAGOPos18to24 AT AOL.COM

AOL chat room for young adults (ages 18–24) who are HIV positive. Hosted by TPAN's Young Adult Program. Go to AOL town square. Monday through Friday 3:00 pm–5:00 pm.

PSSST!
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THE DATE**



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with Hostess Miss Foozie

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Oriental Theatre

SPACE IS LIMITED, SO RESERVE YOUR SEATS NOW!

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Call Jeffrey Allen at
773-989-9400
to reserve your seats

